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VIEWING AND DOING IN ALZHEIMER’S DISEASE: MIND THE GAP!
“Dementia-ism”

• Attributing or explaining everything about people with a dementia diagnosis that is different from those without the diagnosis only to their diagnosis.
What is Alzheimer’s Disease?

• (That is the question)
• How you see it will shape what you do for people who have been diagnosed with it and are seen as......
• Leaving the “hypercognitive world” (Post)
What is AD?: Progression of memory loss

Kinds of memory
1. Semantic - words
2. Episodic – events
3. Procedural – how to do things

Four A’s
1. Aphasia – forgets words
2. Amnesia – forgets events that happened (recent→remote)
3. Agnosia – doesn’t recognize people or objects
4. Apraxia – forgets how to do things
Descartes’ Error

“I think, therefore I am.”

The self exists through cognitive competence.
Typical time course of normal brain aging and Alzheimer’s disease

<table>
<thead>
<tr>
<th>Clinical diagnosis</th>
<th>Normal adult</th>
<th>Age associated impairment</th>
<th>Mild cognitive impairment</th>
<th>Mild AD</th>
<th>Moderate AD</th>
<th>Moderately severe AD</th>
<th>Severe AD</th>
</tr>
</thead>
<tbody>
<tr>
<td>GDS and FAST stage*</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Years</td>
<td>Many decades</td>
<td>Approximately 15 years</td>
<td>0 (onset)</td>
<td>9</td>
<td>10.5</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>MMSE score</td>
<td>29</td>
<td>29</td>
<td>25</td>
<td>19</td>
<td>14</td>
<td>5</td>
<td>0</td>
</tr>
</tbody>
</table>

*Note: GDS and FAST stage values are approximate and may vary depending on the specific assessment tools used.
What is Alzheimer’s Disease?

“A disease is never a mere loss or excess-there is always a reaction of the affected organism or individual to restore, to replace, to compensate for and to preserve its identity, however strange the means might be”

Oliver Sacks in The Man Who Mistook His Wife for a Hat
What is Alzheimer’s Disease?

“I used to read, and discuss it with people. Now I read and I can’t remember what I read. That’s not the real me, the real Molly, so I go around looking for myself, but I’m nowhere to be found.”

Molly, age 82, explaining her “rummaging behavior”
“I feel, therefore I am”

Personhood = the self exists through feeling and relating (Post)
Person Centered Care for individuals with Alzheimer’s and Related Dementias
THREE NARRATIVES (BRUNER)

- **Personal**
  - Autobiography

- **Social**
  - Groups we identify with or are seen as part of

- **Illness**
  - The diagnosis and the story society tells about it
  - changes over time (ulcers, dementia)
  - *illness narratives in different cultures*
AN ILLNESS HAS A PERSON

The experience of an illness involves all three narratives:
- Personal
- Social
- Illness

These interact to affect how the person views himself/herself and how others view him/her.
People have strong preferences with regard to how they would like to behave, how they would like to see themselves, and how they would like to be seen by others.

This constellation of ideas is the Preferred View.
Preferred View has to do with...

The attributions people make about their behavior:

- I did that because I am caring, skillful.”
- I did that because I am independent.”

A person’s preferences, hopes and intentions for their behavior.
The Gap

Person’s Mindset

Preferred View
How I would like to see myself and be seen by others

View of self and behavior
How I see myself and my behavior

View of others’ view of self and behavior
How I think others see me and my behavior

The wider the gap,
The greater the person’s distress
Preferred View and Personal, Social and Illness Narratives may not align in person with AD:

I’m not who they say I am: AGNOSIA
Often called denial (not the case)
Meeting Unmet Needs

AD and other Dementias:
1. Compromises the person’s ability to satisfy needs in the “least restrictive” environments.
2. Increases dependence on others for satisfying needs.
3. Creates a pressure to migrate toward “resource rich” environment as dependency increases.
4. Increases likelihood that the illness narrative will replace the personal narrative as the frame for explaining behavior.
   A – Illness narrative dominates how the person is identified.
**BASICS** is built on a biopsychosocial model that provides a system to help staff plan care to support remaining abilities and care relationships (staff/family/significant others.)

<table>
<thead>
<tr>
<th>Need Satisfied</th>
<th>Fosters</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. BIOLOGICAL Basic needs for</td>
<td>Self-preservation</td>
</tr>
<tr>
<td>food, water, oxygen, safety</td>
<td>Resident physically cared for and safe.</td>
</tr>
<tr>
<td>rest, human stimulation.</td>
<td></td>
</tr>
<tr>
<td>2. ACTIVITIES OF DAILY LIVING</td>
<td>Self-dependence</td>
</tr>
<tr>
<td>Personal needs that support</td>
<td>Environment provides supplies and assistance to foster self</td>
</tr>
<tr>
<td>life style (eating, mobility,</td>
<td>performance.</td>
</tr>
<tr>
<td>dressing, toileting, personal</td>
<td></td>
</tr>
<tr>
<td>hygiene).</td>
<td></td>
</tr>
<tr>
<td>3. SOCIETAL Need for unique</td>
<td>Self-identity</td>
</tr>
<tr>
<td>personal identity, privacy</td>
<td>Environment provides for privacy, affiliation with groups, culture,</td>
</tr>
<tr>
<td>(Resident’s place in society).</td>
<td>family customs, education, resident selection of associations with</td>
</tr>
<tr>
<td></td>
<td>individuals and groups.</td>
</tr>
<tr>
<td>4. INTER-PERSONAL Need for</td>
<td>Self-esteem</td>
</tr>
<tr>
<td>connection with others (love</td>
<td>Environment fosters social role expression, supports interpersonal,</td>
</tr>
<tr>
<td>and belonging).</td>
<td>and social abilities, promotes social confidence and an atmosphere</td>
</tr>
<tr>
<td></td>
<td>of caring and being cared about.</td>
</tr>
<tr>
<td>5. CREATIVE Need for personal</td>
<td>Self-expression</td>
</tr>
<tr>
<td>expression, problem solving</td>
<td>Environment supports independent activity, humor, creativity, and</td>
</tr>
<tr>
<td>opportunities, and meaningful</td>
<td>encourages use of talents and skills. Environment identifies and</td>
</tr>
<tr>
<td>activity. Need for the</td>
<td>fosters the activity that brings that “spark of life” to the resident.</td>
</tr>
<tr>
<td>activity in the resident’s</td>
<td>It also, supports the resident to continue to problem-solve and make</td>
</tr>
<tr>
<td>life that brings joy (face</td>
<td>decisions in his/her everyday life.</td>
</tr>
<tr>
<td>lights up—“the spark of life”</td>
<td></td>
</tr>
<tr>
<td>is there, if even for a fleeting moment).</td>
<td></td>
</tr>
<tr>
<td>6. Symbolic Need for</td>
<td>Self-actualization</td>
</tr>
<tr>
<td>expression of: beliefs, hopes,</td>
<td>Environment encourages hopefulness and self-fulfillment: (*Being all</td>
</tr>
<tr>
<td>dreams, values and autonomy</td>
<td>you can be*) Environment respects and encourages expression of</td>
</tr>
<tr>
<td>(ability to control important</td>
<td>the spiritual dimension of the resident and supports spiritual</td>
</tr>
<tr>
<td>aspects of life). Sense of</td>
<td>ministry as requested by the resident or family.</td>
</tr>
<tr>
<td>peace in the universe</td>
<td></td>
</tr>
<tr>
<td>according to the individual</td>
<td></td>
</tr>
<tr>
<td>resident’s belief of the</td>
<td></td>
</tr>
<tr>
<td>meaning of life.</td>
<td></td>
</tr>
</tbody>
</table>
Origins of Behavior in Dementia

System of dynamic eqilibria

- Lifelong habits and personality
- Current condition physical and mental
- Environment: physical, psychological, social
- Unmet needs and direct effects of dementia (BASICS)

Behavior
All behavior has meaning.....

But may not mean the same to everybody

Meaning is in the eye (and mind) of the beholder
PROBLEM BEHAVIOR: viewing and doing

PROBLEM CREATING?

PROBLEM SOLVING?
What is the question?

• Why are they doing that?
• What are they thinking?
• How can I be a detective and get to the “facts”?
• How can I change failure to success?
DECODING BEHAVIOR

- Cognitive
- Psychiatric
- Medical
- Environmental
- Caregiver

- Where is there poor P/E fit?
- Where is there too much or too little environmental press?
Meet George and Wilbur

- **George:** “wandering”
- **Wilbur:** “eloping”

- How can their behaviors be reframed to promote successful adaptation?
- Which narratives can we see in action by reframing their behaviors?
- How does this change caregiver behavior?
Family and paid caregivers

• Have Preferred Views too
• Gap widens for them when they are unsuccessful in providing the care they aspire to give
• Care based on “Alzheimerism alone can be unsuccessful
• That widens the gap for them too
Dueling Disjunctions (not an action adventure movie title)

• Results when a caregiver’s response to “problem” (whose problem is it?) behavior makes the problem worse

• *Problem maintaining solution*

• Vicious cycle of gap widening actions that promote unsettling emotions in both

• May prompt more discomfort and escalating problems
Behavior is a form of Communication

• Our job is to understand the verbal and non-verbal communication and meet the person’s needs
• How we view it will determine how we treat it
WHAT IS ALZHEIMER’S DISEASE?

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Molly, age 82, explaining her “rummaging behavior”
The Gap
What is the “gap” Molly is dealing with?
Behavior that communicates unmet needs

Physically Non-aggressive behaviors

Does the person seem upset?

Is the person looking for a home?

Try to make the place look and feel like home.

Are you concerned about the safety of the person?

Is the person restless? Does the person seem to be looking for something?

Try to find activities that are meaningful for the older person.

Is the person trespassing and bothering others?

Try to develop a more inviting environment where the person can wander; camouflage other entrances.
Behavior that communicates unmet needs

Verbal Agitation

- Is it physical pain or discomfort?  
  - Medical treatment: Reposition

- Is it loneliness or fear?  
  - Try social interaction real or taped

- Is it an hallucination?  
  - Try using familiar objects or people; medication

- Is it boredom?  
  - Try activities which may be meaningful based on history
Behavior that communicates unmet needs

Aggressive Behaviors

Is the person trying to communicate discomfort?
- Change the environment to make it more comfortable

Could the person feel that you invaded her/his personal space?
- Try new approaches to getting closer to the person

Is the person trying to refuse an ADL?
- Try to accommodate by performing the ADL at a different time or by a different method

Is the person bothered by another resident?
- Try to separate the people who may trigger negative responses in each other
BEING A DETECTIVE

• What does the research show?
• How does the research eliminate “dementia-ism” as the only explanation?
• How does it help reframe the behavior’s genesis from malevolent to benevolent; from problem creating to problem solving?
The person centered approach allow us to:

1. Understand the behavior as need-based
2. Empower staff and caregivers to observe, analyze, and help meet the need; go from being “observers of chronicity” to problem solvers who prevent “excess disability”
3. Educate staff, volunteer, visitors, family and residents without dementia – what the “communication” means.
4. Look at behavior through a new lens.
Any questions?

THANK YOU