Positive Approaches to Caring for Individuals with Dementia
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Dementia Overview

- What is dementia?
- What causes dementia?
- How is dementia different from normal memory loss?
- What does dementia look like?

What is Dementia?

- Dementia is an “umbrella term” for a group of symptoms that accompany certain diseases and conditions and cause lapses in:
  - Remembering
  - Thinking
  - Reasoning
  - Problem-solving
- These symptoms severely interfere with daily life and represent a significant decline from previous abilities
What Causes Dementia?

- Over 50 known causes
  - Reversible
    - Caused by infections, reactions to medications, hormone or vitamin imbalance, depression, heart and lung problems
  - Irreversible
    - Alzheimer’s disease, Parkinson’s disease, stroke, Huntington’s disease
- Alzheimer’s disease is the most prevalent type and accounts for approximately 70% of dementia followed by vascular dementia

Changes in the Brain

- Alzheimer’s disease: Caused by the destruction of brain cells in areas important for memory and problem-solving
  - Deposits of plaques and tangles may interrupt communication among nerve cells in the brain
- Persons with dementia try to do the best they can while suffering from changes in the brain

What Does Dementia Look Like?

- Memory loss is not dementia
  - Difficulties remembering may occur for many reasons.
- All adults experience over time:
  - Some problems hearing or seeing
  - Some decline in reaction time for complex tasks
  - Some decline in long-term memory
  - Some decline in word-finding
- These problems are not severe or persistent nor do they worsen over time
What Does Dementia Look Like?

- Memory loss
- Difficulty communicating
- Visuospatial deficits
- Inability to reason
- Reduced motor skills and coordination
- Impaired problem-solving skills
- Inability to learn new information
- Mood changes
- Challenging behaviors
- Paranoia

Behaviors differ from day to day and from person to person
- Each individual with dementia is different
- Past behavior affects current behavior

“If you’ve met one person with dementia… you’ve met one person with dementia.”

The behavior of an individual with dementia is still influenced by
- Other people
- Things going on around them

Quality of Life in Dementia

- Individuals with dementia can have a quality of life
  - Doing activities that he/she enjoys
    - Activities enjoyed may be different than what was enjoyed earlier in life
    - Based on what the individual is able to do
  - Living in an environment that meets their needs
    - Physical needs
    - Emotional needs
Quality of Life in Dementia

- An important way quality of life is maintained for the individual with dementia is through SAVING what behavior the individual is still able to engage in
  - Individuals with dementia are at a risk of losing their abilities at a faster rate than the dementia alone
    - Decreases the individuals quality of life pre-maturely
    - Increases the work load for the caregiver

Excess Disability

- What is excess disability?
- What are common causes of excess disability?
- What risks are associated with excess disability?

What is Excess Disability?

- Excess disability: When a resident becomes impaired due to something other than dementia
- Problem: The excess disability impairment is often mistaken as a behavioral symptom of dementia
Why is this important?

- Interventions for “behavioral symptoms” of dementia include psychotropic drugs
  - This often serves a sedating function
    - Reduces or eliminates the “symptom”
    - Reduce or eliminate non-problem behavior
  - There can be significant risks involved with psychotropic drug use in individuals with dementia

Common Causes of Excess Disability

- Pain
- Medication side effects
- Medication interactions
- Delirium
- Depression
- Problems hearing or seeing
- Untreated infections
- Malnutrition
- Dehydration
- Isolation

Example – Marilyn

- 91-years old, dementia diagnosis, chronic heart failure
- Severe memory impairment
- Enjoyed talking to people, smiling and making eye contact
- Suddenly stopped making eye-contact and began crying throughout the day, everyday
Example – Marilyn

• Outcome:
  – Marilyn was given an anti-anxiety medication several times
    • Marilyn’s speech was slurred, but the crying behavior continued
  – It was discovered that Marilyn had a severe UTI and the infection had spread to her blood
  – She was put on IV antibiotics for several days
    • Marilyn began making eye-contact again
    • Marilyn’s crying behavior was reduced

Example – Marilyn

• Staff members assumed that Marilyn’s crying behavior was due to her advanced dementia

• This wrong assumption led to:
  – Marilyn receiving drugs to reduce her crying that did not stop the crying or her discomfort, but made her more confused
  – A longer time period before Marilyn’s infection was discovered and treated
    • This meant that Marilyn was suffering with a UTI for longer than necessary
Problems with Undetected Excess Disability

- Lower quality of life for the individual
- Individual loses behavior
- Increased behavioral problems the caregiver has to manage
- Increased prescription of psychotropic drugs to manage the behavioral problems
  - Use of psychotropic drugs increases the risk of poor outcomes for the resident
- Increased risk that the caregiver will feel the individual needs to be moved to a facility

Risks Associated with Psychotropic Drugs

- Increased risk of falls
- Increased risk of stroke
- Increased risk of confusion
- Decreased ability to communicate
- Sedative effect reduces ability to engage in adaptive behavior
- Some types of dementia (Lewy bodies) cause individuals to be very sensitive to antipsychotic drugs
  - In this population it can increase aggression and other problem behavior

Your Role: Dementia Detective

- Due to the communication challenges in individuals with dementia you have a unique role
- Excess disability can impair an already diminished ability to communicate that something is wrong
- Your role is to look for clues in the residents
  - Behavior
  - History
  - Environment
Clues of Possible Excess Disability

- Changes in adaptive behavior
  - Adaptive behavior is unique to the resident
    - Sense of humor
    - Telling stories
    - Interest in a hobby
    - Making conversation
    - Answering questions
    - Walking/moving in a wheelchair
    - Feeding themselves
    - Making eye contact
    - Smiling

- Changes in problem behavior
  - Problem behavior is also unique to the resident
    - Physical aggression
      - Hitting
      - Pushing
      - Throwing an object
    - Verbal aggression
    - Wandering
    - Crying
    - Disruptive vocalizations
    - Refusing to complete a task

Adaptive Behavior and Problem Behavior

- When a resident is experiencing excess disability
  - Adaptive behavior is reduced or stopped completely
  - Problem behavior increases

- Two behavioral clues that excess disability may be occurring
Restraint Overview

- History of restraint use
- What is restraint?
- What are risks and outcomes of restraint?

How has Restraint been used in the Care of People with Dementia

- Restraint has been used for more than a century in attempts to:
  - Reduce falls
  - Control behavioral problems
  - Prevent treatment interference

- Common in nursing homes throughout the 20th century
  - In 1988 41% of nursing home residents were physically restrained

How has Restraint been used in the Care of People with Dementia

- 1987: The Omnibus Reconciliation Act (OBRA)
  - Skilled nursing facilities must
    - “Promote maintenance or enhancement of the quality of life of each resident”
    - “Provide services which enhance the physical, mental, and psychosocial well being of the individual”
  - Residents have the right to be free of
    - Abuse
    - Punishment
    - Seclusion
    - Physical or chemical restraint
What is “Restraint”?  

- Physical restraint:  
  - "devices places on or near the body of an individual, limiting freedom of voluntary movement and precluding independent functioning"  
  - Examples  
    • Lap belts  
    • Mittens  
    • Geri-chairs  
    • Bed rails  
    • Wrist straps

What is “Restraint”?  

- Chemical restraint:  
  - "a drug or medication when it is used as a restriction to manage the patient's behavior or restrict the patient's freedom of movement and is not a standard treatment or dosage for the patient's condition.”  
  - Examples:  
    • Anti-anxiety drugs  
    • Anti-psychotic drugs

Risks of Restraint

- Falls  
- Increased confusion  
- Depression  
- Decreased social engagement  
- Increased dependency in care  
- Increased chance of death  
- Increased behavioral challenges  
- Increased risk of urinary tract infections  
- Increased risk of pressure ulcers  
- Increased risk of illness  
- Increased risk of incontinence
Prevention of Restraint: Tools for Positive Dementia Care

- Communication Strategies
- Ruling out Excess Disability
- Positive Behavioral Management

Effective Communication Strategies

- Why communication is important
- Communication tools

Importance of Communicating

- Everybody needs to participate in social interaction
  - Social interaction prevents depression and anxiety
- Communication can reduce some of the biggest challenges of caregiving
Communicating May Be Difficult

- An individual with dementia may not be able to fully engage in a conversation anymore because of difficulties
  - Finding or using appropriate words
  - Following conversations
  - Understanding and following instructions
  - Remembering what to say in a given situation

Communicating is Valued

- While difficulties producing and understanding language are present, an individual with dementia may still enjoy participating in social interactions by
  - Asking or answering questions
  - Giving reasons or explanations
  - Making small-talk about past events
  - Telling stories
  - Finding out about and discussing present events

Key Strategies for Communicating

- Do not argue!
- Do not argue!
- Do not argue!
What Replaces Arguing?

- Tool #1: Caring detachment
- Tool #2: Being P.O.L.I.T.E.
- Tool #3: Distracting the person with dementia

Tool #1: Caring Detachment

- Step back from the situation:
  - The individual is struggling with his or her deficits
- Try not to get caught up in your feelings and responses, instead
  - Notice your feelings and thoughts
  - Remember what you are trying to accomplish
  - Then think about what the individual is trying to accomplish

Signs of Caring Detachment

- “Compassionate misinformation”
  - Appeal to authority (family member, physician, etc)
  - Do not remind the individual that the family member about whom they are asking has passed.
  - Do not remind the individual of memory loss or diagnosis.
- Responding to the individual’s feelings and to what he or she is trying to accomplish, rather than to the content of the words
Tool # 2: Being P.O.L.I.T.E.

- **P. = patience**
  - Don’t be in a hurry.
  - Ask or say one thing at a time.
  - Allow a moment of time before repeating instructions.
  - Speak slowly and clearly – not necessarily louder!

Tool # 2: Being P.O.L.I.T.E.

- **O. = organize and observe**
  - Eliminate distractions.
  - Break tasks into simple steps.
  - Use hand gestures to demonstrate what you are asking the person to do.
  - Written signs or notes may be helpful (early on).
  - Think of the individual’s behavior as a cue to how he or she is feeling right now.

Tool # 2: Being P.O.L.I.T.E.

- **L. = Laughter**
  - Smile!
  - Use a warm and respectful tone of voice.
  - Cheerfulness and gentle humor can help in difficult moments.
  - Give sincere praise for even a simple job done well.
Tool # 2: Being P.O.L.I.T.E.

- I. = Ignore what you can
  - “Pick your battles.”
  - Refrain from correcting the other person unless what he or she is saying or doing is unsafe or unhealthy.

- T. = Tone of voice
  - Avoid giving orders or acting “bossy.”
  - Provide few, simple choices.
  - Use pleasant, matter-of-fact statements instead of commands.
  - Ask yourself, “Would I want the other person to be talking to me this way?”
    - Persons with dementia become very sensitive to nonverbal cues such as tone of voice, facial expression, body gestures, and mood. If you are angry and upset, they are more likely to act the same.

- E. = Eye and body contact
  - Look directly at the individual when speaking or listening.
  - Stand or sit at eye level. This helps if the individual is hard of hearing, and keeps him or her from feeling as if you are talking down to them.
  - Gentle touch can help orient the individual to you, as well as provide comfort and reassurance.
Positive Behavioral Management

• Why do challenging behaviors occur?
• Tools for managing challenging behaviors

Why Do Challenging Behaviors Occur?

• Behaviors communicate what words cannot
• Behavior of individuals with dementia continues to be influenced by the environment
• The same behavior may occur for different reasons in different people
• Each individual is unique and has a unique history

Look For Environmental Cues

• Investigating environmental cues and consequences can reveal the purpose of behaviors
• Environmental assessment: What is the purpose of the problem behavior?
  – Escape a situation?
  – Avoid a situation?
  – Attain something that is needed or wanted?
Checking Environmental Causes

- **Check the A-B-C’s:**
  - **A = “Antecedent”**
    - Situation in which the behavior occurs most often
  - **B = “Behavior”**
    - The observable behavior
  - **C = “Consequence”**
    - What happens as a result of the behavior

### Antecedent Behavior Consequence

#### Your Dementia Detective Role

- **Antecedents**
  - What happened immediately before the behavior?
  - When did the behavior occur?
  - Who was around?
  - What activity was going on?
  - Where was the individual with dementia?

- **Behavior:**
  - What behavior did you observe?

- **Consequences**
  - What happened as a result of the behavior?
  - What did you or others do?

- **Remember to rule out medical or sensory issues that could be causing or contributing to the challenging behavior**

#### Examples: Behavior Increases If...

<table>
<thead>
<tr>
<th>Antecedents</th>
<th>Consequences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Over-stimulation</td>
<td>Less stimulation</td>
</tr>
<tr>
<td>Under-stimulation</td>
<td>More stimulation</td>
</tr>
<tr>
<td>Social isolation</td>
<td>Attention</td>
</tr>
<tr>
<td>Fear, embarrassment</td>
<td>Escape/avoid people</td>
</tr>
<tr>
<td>Difficult task</td>
<td>Escape/avoid task</td>
</tr>
<tr>
<td>Unmet need</td>
<td>Have need met</td>
</tr>
<tr>
<td>Frustration, discomfort</td>
<td>Reduction in these</td>
</tr>
</tbody>
</table>
Basic Principles for Changing Behavior

- Change the situation
- Reduce exposure to the situation
- Change the consequence
  - Minimize the effectiveness of challenging behavior in getting needs met
  - Help person to get needs met in more appropriate ways
- Change the situation and the consequence

Environmental Interventions

- The kindest way to change the behavior is to change the environmental cause of the behavior
- In some situations this can be difficult:
  - Hygiene
  - Eating
  - Taking medication

Environmental Interventions

- Distraction
  - Is a very useful strategy
  - Knowing the person very well is the key to successful distraction.
  - Can be a verbal or a non-verbal strategy.
  - Can be used for a variety of behavioral problems
Environmental Interventions

• Embedding
  – Some tasks may be very unpleasant.
    • Being undressed by someone you do not recognize
    • Taking a medication that is hard to swallow
    • Painful procedures
  – The environment where these tasks occur often is a cue for challenging behaviors.
    • Being in the bathroom with someone you do not recognize
  – Make the unpleasant environment more pleasant (e.g., smells, music, videos, people).

Environmental Interventions

• Prompting and Modeling
  – Individuals with dementia often cannot follow complex verbal instructions and do not initiate behavior.
  – Prompts = verbal or non-verbal “reminders”
    • Try simple verbal prompts first.
    • For more complex tasks, the person may need physical prompts.
    – Light touch
  – Modeling = showing the person how to do something by doing it yourself.

Environmental Interventions

• Simplifying tasks/slowing down
  – If a resident feels rushed or overwhelmed it may lead to problem behaviors
  – Some everyday tasks may lead to problem behaviors if tasks require
    • Dealing with and complex or overwhelming relations: Break larger tasks into several smaller ones.
    • Quick movement: Slow down.
    • The invasion of personal space: Approach slowly.
  – You can often get the job quicker and with less problems if you act like you have all the time in the world
Environmental Interventions

- **Establishing Routines**
  - The more predictable the environment, the better the chances of preventing agitation and challenging behaviors.
  - This can be helpful for bathing, dressing, taking medication, going to a day center or engaging in other activities, including eating.

Environmental Interventions

- **Making things more noticeable**
  - Sometimes challenging behaviors occur because the person is disoriented and does not know what to do in a given situation.
  - Putting large signs, clocks, calendars, post-it notes, or lists in familiar places may help individuals.
  - Increasing lighting, especially in the bathroom at night, may help prevent accidents.

Importance of Looking for Clues

- When you look for the purpose of the behavior you can apply interventions that meet or compete with that purpose
- This is more effective than applying interventions without looking for the purpose of the person’s behavior
  - Increases the chance of reducing the behavior
Each Person is Different

• Continued monitoring is important – your role as a dementia detective does not end
  – The same behavior can serve different purposes for different people
  – The same behavior by one person can serve different purposes at different times
• Attend to events in the person’s environment, notice the ABC’s, and make adjustments as needed
• Be flexible: Strategies that work one day may not work the next

Conclusions

• Environmental interventions can be effective, even for people with severe memory problems.
• You are the expert
  – Applying the strategies with the individual
  – Finding out which strategies work best in what situation.

Reference for Caregiving
Detachment and P.O.L.I.T.E.