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How to Cope with Behavioral and Emotional Changes



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Lecture Outline

- Key points
- Understanding the diagnosis and prognosis
- Recognizing and responding appropriately to behavior changes
- Effective communication
- Patient-centered care
- Common family dynamics and possible remedies
- Tips for caregivers to avoid isolation and depression
- Summary



8 Key Points

- 1) The individual who is living with dementia and anyone who is connected to the individual living with dementia may experience behavioral and emotional changes.
- 2) Knowledge is power. Although sometimes painful or uncomfortable to talk about, knowing as much as possible about dementia and about the affected family member's prognosis is essential.
- 3) Behavior change is a form of communication and may signal an underlying medical problem.
- 4) As much as possible, share the burden of caregiving.



8 Key Points

- 5) Make an inventory of who is willing and able to help and what special skills and talents they possess.
- 6) Encourage all care giving family members to learn and use effective communication techniques when interacting with the family member who is living with dementia.



8 Key Points

- 7) Become familiar with some of the common problematic family dynamics and their respective potential remedies: the out-of-town family member, the parent who refuses help from their adult child; the adult child with unrealistic expectations.
- 8) Watch out for isolation and depression.



How to Cope with Behavioral and Emotional Changes

Understanding the Diagnosis and Prognosis



Diagnosis and Prognosis

- **Prognosis:** The foretelling of the probable course of the disease.
- Obtaining a precise diagnosis of the dementia and the associated prognosis helps family members and friends cope more successfully with behavioral and emotional changes in the in person living with dementia and in themselves.
- Knowledge is power. Knowing as much as possible about the illness helps family members and friends prepare and plan for the future. For example, this information helps with allocating resources so that there are sufficient resources to last for the duration of the illness.



Diagnosis and Prognosis

- Dementia is a general term used to describe a condition involving the development of cognitive problems/losses/deficits that were not present earlier in a person's life and which are serious enough to cause impairment in function.
- Historically, most definitions of dementia have required that one of the cognitive problems/losses or deficits was a loss of memory. Newer definitions may not include this requirement.
- There are dozens of illnesses that may include dementia as a manifestation but four causes are responsible for 90% of dementia diagnoses.



Diagnosis and Prognosis

- The four most common causes of dementia and their frequencies are:
 - Alzheimer's approximately 55-60%
 - Lewy body dementia approximately 15-20%
 - Frontotemporal approximately 10%
 - Vascular approximately 5%



Other Causes of Dementia

- Alcoholism
- Amyotrophic lateral sclerosis (ALS)
- Carbon monoxide poisoning
- Creutzfeldt-Jakob disease
- Heavy metal poisoning
- HIV/AIDS
- Huntington's disease
- Hypothyroidism
- Irradiation
- Major depression
- Multiple sclerosis
- Neurosyphilis
- Normal Pressure Hydrocephalus (NPH)
- Parkinson's disease
- Thiamine deficiency
- Trauma (e.g. dementia pugilistica and CTE)
- Vitamin B12 deficiency



Diagnosis and Prognosis

- Dementia illnesses have different clinical characteristics:
 - Usual age of onset
 - Most common initial changes in cognition and behavior
 - Most common changes in cognition and behavior that occur later in the course of illness
 - Rate of progression
 - Life expectancy
 - Response to various medications and treatments
 - Other factors
- Knowing the cause of dementia helps in a variety of ways including how to cope with cognitive and behavioral changes



Prognosis:

The Foretelling of the Probable Course of the Disease

- Although Alzheimer's is now recognized as a terminal illness, individual's with Alzheimer's may live for years.
- It is important for caregiving family members to have the best information possible about life expectancy.
- Family caregivers need to plan ahead in order to ensure that their resources (personal, psychological, social and financial) will last until the individual with Alzheimer's passes away.
- Having adequate resources makes things better for both the patient who is living with Alzheimer's and their care giving family members and friends.



Important Factors to Consider: Life Expectancy

- The average life expectancy of someone with Alzheimer's is 8-10 years after the onset of symptoms.
- Some individuals with Alzheimer's have lived up to 20 years after the first signs of the illness emerge.
- As a general rule of thumb, a person diagnosed with Alzheimer's can expect to live half as long as someone of the same age who doesn't have the disease.
- The average 75-year-old can expect to live another 12 years. A 75-year-old with Alzheimer's would be expected to live for six more years.



Important Factors to Consider: Life Expectancy

- An NIA-funded study done at the University of Washington (2004) identified several factors that influence life expectancy of individuals living with Alzheimer's dementia
 - **Gender:** women in this study tended to live longer than men (6 years after diagnosis versus 4 years after diagnosis)
 - **Age at diagnosis:** individuals diagnosed with Alzheimer's in their 70s had longer survival times than those older than 85 at the time of diagnosis
 - **Severity of symptoms:** the amount of impairment at the time of diagnosis was inversely correlated with life expectancy
 - **Degree of cognitive impairment:** an MMSE score of 0 is correlated with a life expectancy of 6 months or less
 - **Rate of progression:** a 5 point drop on the MMSE over 1 year was associated with a decreased survival rate
 - **Other health problems:** survival was poorest among those aged 85 or older who had diabetes, congestive heart failure or a history of heart attack



Important Factors to Consider: Life Expectancy

- Individuals over 85 who wander or have trouble walking are among those with the shortest life expectancies



Recognizing and Responding Appropriately to Behavior Changes

- Behavior changes are a form of communication
- When a person with dementia experiences a change in behavior the first goal is to determine the meaning or message being communicated
- Sometimes the meaning or message will be simple or obvious but sometimes it may take a while to understand



The “Differential Diagnosis” of Behavior Changes

- **Differential diagnosis:** a term used to describe the list of all the possible causes of a symptom, problem, or illness
- Separating causes into categories may be helpful:
 - Causes related to the patient
 - Causes related to the caregiver
 - Causes related to aspects of the environment other than the caregiver



Causes Related to the Patient

- Causes related to the patient may be divided into the following categories:
 - **Medical** including uncorrected sensory deficits, hypoglycemia and pain
 - **Psychiatric** including depression, anxiety, and paranoia
 - **Psychological** including frustration, boredom, TV violence and loneliness
 - **Other** causes such as thirst, hunger, fatigue, noise and movement restriction



Medical Differential Diagnosis of Behavior Change

- Exacerbation of pre-existing medical illness
- Onset of new medical problem
- Medication toxicity (e.g. polypharmacy or suboptimal prescribing)
- Drug or alcohol intoxication
- Drug or alcohol withdrawal
- Delirium



Medical Causes of Behavior Change

- Behavioral symptoms should be viewed as a signal of an underlying medical problem until proven otherwise



Possible Causes of Delirium and Behavioral Changes

- UTI
- Insomnia Other infection
- Anemia
- Dehydration
- Diabetes
- Hyperglycemia/hypoglycemia
- Hypoxia
- Respiratory infection
- COPD
- Electrolyte imbalance
- Congestive heart failure
- Neurologic causes
- Medications



Frequency of Unrecognized Medical Illness Associated with Behavioral Changes in Older Patients

- Study Population (N=79)
 - Consecutively admitted from 5/99 – 10/99
 - Mean age = 78 years
 - 92% Caucasian
 - 51 female and 28 male
- Result: 34% had unrecognized medical illness
- Diagnoses (N) included: Obstipation (7); urinary infection (7); hypothyroidism (5); Pneumonia (3); Other (12)



Appropriate Evaluation

- An appropriate medical evaluation includes:
 - History gathering including careful review of medication list
 - Physical examination including Mental Status
 - Lab tests (including serum drug levels)
 - Brain imaging
 - Other tests



Psychiatric Differential Diagnosis of Behavior Change

- Progression of dementia illness
- Exacerbation of some other pre-existing psychiatric illness
- Onset of a new psychiatric illness



Possible Causes of Behavior Change Related to the Caregiver

- Ineffective communication due to:
 - Making more than one request at a time
 - Speaking too fast with poor diction
 - Not allowing time for the patient to respond
 - Not using more than one sensory modality
 - Not maintaining eye contact
 - Not assuming a comfortable, relaxed posture
 - Not identifying and verbalizing the patient's affect
 - Not using simple direct statement



Patient-centered Care

- Keep the focus on the patient
- If a family care giver is stirring up trouble, invite that individual to consider how his or her behavior is impacting the patient with dementia



Causes of Behavior Change Related to the Environment

- The absence of a place to exercise
- The absence of a secure area in which to roam safely without cul-de-sacs and dead-ends which create agitation because patients may not know what to do when stuck
- Lack of access to wandering paths which include places to sit, socialize, or engage in activity



How to Cope with Behavioral and Emotional Changes

Sharing the Burden of Caregiving



Sharing the Burden of Caregiving

- Another important coping strategy when dealing with behavioral and emotional changes is to share the burden of caregiving by creating a caregiving team.



Creating a Caregiving Team

- How to create a successful family caregiving team
 - As much as possible, share the burden of caregiving with as many family members and friends as possible. This strategy helps protect any given family member or friend from stress related illness or burn out
 - Make a list of family members (and friends and neighbors) who are willing and able to help and what special skills and talents they possess
 - Give family members specific tasks or assignments that, when possible, exploit their strengths and talents



Creating a Caregiving Team

- How to create a successful caregiving team
 - Assign out-of-town family members tasks that do not require them to be geographically close to the patient (e.g. using email to keep all those interested in the family member with dementia informed or designing and maintaining a phone tree for efficient communication)
 - Keep in mind that caring for a family member with Alzheimer's or one of the other dementia illnesses can be extremely stressful and that stress has a tendency to cause psychological regression
 - Anticipate that long-standing patterns of behavior and communication between family members may be intensified by the stress of the situation



Creating a Caregiving Team

- How to create a successful family caregiving team
 - Periodically solicit feedback and offer praise and thanks
 - Strive for open honest communication
 - Encourage all involved family members to become as educated as possible about the type of dementia that is impacting their loved one, in general, and the strengths, weaknesses, preferences, needs and priorities of the afflicted family member, in particular
 - Encourage care giving family members to attend support groups



Creating a Caregiving Team

- How to create a successful family caregiving team
 - Do not hesitate to set limits if a particular family member is saying or doing things that hurt more than help
 - Monitor each care giving family member for signs of physical or psychiatric illness or burn out
 - Depending on the family members role, insist that each person has vacations from their caregiving duties
 - Establish clear lines of authority and communication
 - Encourage (require?) care giving family members to attend a course on how best to communicate with someone who has dementia



Effective Communication

- Helpful hints
 - Make one request at a time
 - Speak clearly and slowly
 - Allow time for the patient to respond
 - Maintain eye contact
 - Assume a comfortable posture with arms and hands relaxed
 - Identify the patient's affect and verbalize this for him or her
 - Time communications optimally based on circumstances (e.g. hunger, fatigue, background noise, etc.)
 - Remember that even when words may no longer convey meaning volume, prosody and melody of speech may still convey information



Redirection

- Represents an intentional thwarting of goal directed thought or behavior
- Goal is to help patient refocus in order to be more;
 - calm
 - cooperative
 - content
 - safe
- May trigger frustration or agitation
- Has two forms: simple and complex



Simple Redirection

- **Simple redirection**
 - **Presentation of options:** “This door is closed but this door is open.”
 - **A compliment:** e.g. “My that’s a beautiful sweater!”
 - **A request for help:** e.g. “Please help me fold these towels.”
 - e.g. other possibly helpful distractions include: food, drink, music, humor.



Complex Redirection

- **Complex redirection: 4 steps**
 - **Validate:** “You look worried.”
 - **Join:** “You’re looking for [fill in the appropriate item]. I’m trying to find [fill in an item]. Let’s look together...”
 - **Distract:** “Let’s look over there...”
 - **Redirect:** “That coffee smells good. Do you want a cup?”



Complex Redirection

- Enter the agitated patient's reality
- Approach in a calm manner
- Communicate your desire to help



Complex Redirection

- Example: A patient is trying to get out the door to see his wife.
- Don't say "You're wasting your time. Don't you remember that your wife died a long time ago?"
- Do say:
 - "You seem upset because you can not find your mother. (**Validate**)
 - I haven't seen her but I will help you look. (**Join**)
 - This door is broken. I need to get it fixed. (**Distract**)
 - In the mean time, Let's take a walk and try to find her. (**Redirection #1**)
 - Look, the Padres are on the TV. Are you a Padres fan?" (**Redirection #2**)



How to Cope with Behavioral and Emotional Changes

Common Family Dynamics and Possible Remedies



The Martyrdom Syndrome

- Many factors may trigger or perpetuate the martyrdom syndrome. These factors include:
 - A desire to express love and devotion
 - Guilt regarding past actions or situations
 - Survivor guilt
 - Fear of being judged by others (this may be more likely in blended families)
 - Sublimation of painful feelings
 - Avoidance
- The major risk of the martyrdom syndrome is that the caregiver who has slipped into this pattern is actually jeopardizing the safety and well-being of the patient AND him or herself.



The Martyrdom Syndrome: A Potential Remedy

- Perhaps the most consistently helpful remedy for this pattern of behavior in a caregiver is to explain to the caregiver how essential he or she is to the well-being of the individual who is living with dementia.
- In essence, the caregiver needs to be reminded that, although their devotion may arise from the most noble of motives, it is, ultimately a strategy that is likely to backfire and to cause more harm than good.
- Specifically, the caregiver, especially caregiving spouses, need to be reminded that no one knows the patient better and no one is more qualified to provide care or supervise care. If martyrdom causes the spousal caregiver to become ill or to die, then the spouse with dementia will be placed in a potentially very precarious situation.



The Out-of-Town Family Member

- One fairly common challenge is keeping out-of-town family members accurately informed of the patient's status
- Out-of-town family members are often unaware of the level of impairment of the person living with Alzheimer's disease
- Often this lack of understanding is the result of
 - The family member with Alzheimer's having preserved social skills
 - The style and content of communication between the out-of-town family members and the family member living with Alzheimer's
 - No recent, or only very minimal recent, contact between the patient and the out-of-town family member
 - The common tendency for patients and family members to experience denial in the face of tragic life threatening illnesses like Alzheimer's
 - Pre-existing trust or communication issues between family members



The Out-of-Town Family Member: Remedies

- Invite out-of-town family members to visit as often as possible
- When out-of-town family members do visit, engage them actively in caregiving
- Consider letting the out-of-town family member provide respite care when the primary caregiver is on vacation
- Request that a neutral third-person explain to the out-of-town family member the nature and extent of the cognitive losses that the person with dementia is experiencing
- Look for opportunities to explore with the out-of-town family member what it means to him or her that his or her family member is living with dementia
- Encourage the out-of-town family member to attend a Alzheimer's caregiver support group



The Parent who Refuses Help from Adult Children

- Once a parent, always a parent
- For most parents, regardless of their age and the age of their children, it feels wrong to “lean on” or “burden” their children
- Many patients living with Alzheimer’s and many spousal caregivers of patient’s with Alzheimer’s
 - Minimize the symptoms of the patient
 - Minimize the challenges of care for the patient
 - Refuse offers of help from adult children



The Parent who Refuses Help from Adult Children: A Potential Remedy

- Every stage of life has important psychological developmental tasks.
- An important developmental task for individuals who are middle aged is to adequately thank their parents for all that their parents did to help the child grow up and become a reasonably healthy, successful adult.
- Although this gratitude can be expressed verbally and this is helpful, it is generally not as helpful as actually having opportunities to express gratitude through helpful actions or behaviors.
- If a parent is able to allow for their adult child or adult children to provide help then this parent is doing the adult child or children a favor and helping the child or children accomplish an age appropriate developmental task.



The Adult Child with Unrealistic Expectations

- Watch out for the adult child who, perhaps due to denial, has unrealistic expectations of what the patient with dementia can accomplish
- Another important developmental task of mid-life is to resolve residual conflicts with one's parents
- If the parent who was party to these unresolved or enduring conflicts has dementia then it may no longer be possible for the parent and child to achieve resolution of the conflict and repeatedly attempting to do this will only make matters worse
- Each time the adult child attempts to resolve the conflict the adult child may end up feeling re-injured or re-traumatized



The Adult Child with Unrealistic Expectations: Potential Remedies

- Work to help the adult child understand that their goal may be healthy and reasonable but their method is no longer realistic
- Encourage the adult child to find some other pathway to achieve resolution of the conflict:
 - Individual psychotherapy
 - Group psychotherapy
 - An Alzheimer's support group



Tips for Family Caregivers to Avoid Isolation and Depression



Tips to Avoid Isolation and Depression

- Seek help from professionals
- Use community resources such as support groups and “Meals on Wheels”
- Schedule time for yourself
- Schedule time with people who love you and care for you
- Watch out for the “martyr complex”
- Avoid arguments with your loved one



Tips to Avoid Isolation and Depression

- Challenge yourself to find the good in difficult situations
- Balance realistic expectations with optimism
- Don't be afraid to ask difficult questions
- Be flexible and willing to adjust
- Laugh long and often



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References

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