



Alzheimer's and Other Related Dementias: Addressing Individual and Family Needs

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Purpose and Objectives

The purpose of this course is to provide a review of Alzheimer's disease and other forms of dementia, communication techniques, approaches, and individualized needs of dementia patients and their

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families.

After successful completion of this course, you should be able to:

1. Discuss dementia and Alzheimer's disease
2. Describe communication skills used to connect with dementia patients
3. Discuss techniques and approaches to care of patients with Alzheimer's and dementia
4. Describe components of person centered care
5. Describe social needs and appropriate activities in the care of dementia patients
6. Delineate signs and symptoms of caregiver stress
7. Identify techniques for relieving caregiver stress
8. Identify dietary needs of patients with dementia
9. Identify the needs of families of dementia patients, and strategies for working with them
10. Describe how to prevent, recognize, and respond to abuse and neglect of dementia patients
11. Discuss the importance of current dementia research

Introduction

Dementia is a general term for a decline in mental capacity severe enough to interfere with activities of daily life. Dementia is not a specific disease, but is used to describe the loss of cognitive functioning. While the aging process can cause some loss of neurons, people with dementia experience far greater loss. Dementia patients can lose the ability to think, remember, or reason, which may lead to behavioral complications.

Alzheimer's disease (AD) is a progressive, degenerative disorder that attacks the brain's nerve cells, or neurons, resulting in loss of memory, thinking and language skills, and behavioral changes. AD is the most common cause of dementia, or loss of intellectual function, among people aged 65 and older (Alzheimer's Association, 2015; National Institutes of Health, 2013b).

Prevalence

The prevalence of dementia can be difficult to determine with varied international estimates. This is related to the complexity of diagnosis, as many symptoms can be attributed to the aging process rather than dementia. Many cases can go undiagnosed. One assessment conducted by the Organization for Economic Cooperation and Development (OECD) estimated that dementia affects about 10 million people in 34 OECD member countries. More recent analyses have estimated the worldwide number of people living with dementia is between 27 million and 36 million (National Institute on Aging, 2015).

The prevalence of AD and other dementias is very low at younger ages, and nearly doubles with every five years after age 65. In the OECD review, for example, dementia affected fewer than three percent of those aged 65 to 69, but affected almost 30 percent of those aged 85 to 89. The 2010 World Alzheimer Report by Alzheimer's Disease International estimated that the total worldwide cost of dementia exceeded \$600 billion (National Institute on Aging, 2015).

It is estimated that as many as 5.1 million Americans may have AD, which equates to approximately one in nine older Americans (Alzheimer's Association, 2014).

Of the 5 million people age 65 and older with Alzheimer's in the United States, 3.2 million are women and 1.8 million are men (Alzheimer's Association, 2014). More women than men have Alzheimer's disease and other dementias. Almost two-thirds of Americans with Alzheimer's are women (Alzheimer's Association, 2014).

In the United States, eleven million Americans provide unpaid care for someone with dementia. Older African-American and Hispanics are considerably more likely than older whites to have dementias (related to other health issues, such as hypertension and diabetes). Additionally, people with dementia are high users of healthcare, long-term care, and hospice (National Institute on Aging, 2015).

Did You Know?

The observation that more women than men have AD and other dementias is primarily explained by the fact that women live longer, on average, than men, and older age is the greatest risk factor for Alzheimer's (Alzheimer's Association, 2014).

Review: Types of Dementia

There are various types of dementia. These include:

- Alzheimer's disease (most common)
- Vascular dementia
- Lewy Body dementia
- Frontotemporal disorders
- Mixed dementia
- Cognitive changes associated with Parkinson's disease, Huntington's disease, and multiple sclerosis
- Traumatic brain injury
- Korsakoff Syndrome
- Other conditions

For more in-depth information on Alzheimer's disease and dementia, review the RN.com courses titled "*Alzheimer's Disease: An In-Depth Review*", and "*Dementia: An In-Depth Review*" for RNs and LPNs, and "*Alzheimer's Disease: Awareness for CNAs*" and "*Dementia: Awareness for CNAs*" for CNAs.

Test Yourself

The most common cause of dementia is:

- A. Traumatic brain injury
- B. Alzheimer's disease
- C. Parkinson's disease

The correct answer is: B. Alzheimer's disease.

Dementia Review: What It Is and What It Is Not

Emotional problems, such as anxiety or depression, can make a person more forgetful and can be mistaken for dementia. For instance, someone who has recently retired or who is coping with the death of a spouse may feel sad, lonely and worried. Trying to deal with these life changes leaves some people confused or forgetful (Alzheimer's Association, 2015b).

Dementia is NOT a normal part of aging.

Dementia Review: Cognitive Symptoms

Aphasia is the inability to communicate effectively. The loss of ability to speak and write is called expressive aphasia. An individual may forget words he or she has learned, and may have increasing difficulty with communication. With receptive aphasia, an individual may be unable to understand spoken or written words, or may read and not understand what is read. Sometimes an individual pretends to understand and even nods in agreement; this is to cover-up aphasia. Although individuals may not understand words and grammar, they may still understand non-verbal behavior (National Institute on Aging, 2014).

Apraxia is the inability to do pre-programmed motor tasks, or to perform activities of daily living such as brushing teeth and dressing. An individual may forget all motor skills learned during development. Sophisticated motor skills that require extensive learning, such as job-related skills, are the first functions that become impaired. More instinctive functions like chewing, swallowing and walking are lost in the last stages of the disease (National Institute on Aging, 2014).

Agnosia is an individual's inability to correctly interpret signals from their five senses. Individuals with Alzheimer's disease may not recognize familiar people and objects. A common yet often unrecognized agnosia is the inability to appropriately perceive visceral, or internal, information such as a full bladder or chest pain (National Institute on Aging, 2014).

Dementia Review: Psychiatric Symptoms

Major psychiatric symptoms include personality changes, depression, hallucinations and delusions.

Personality changes can become evident in the early stages of Alzheimer's disease and dementia. Signs include irritability, apathy, withdrawal and isolation. Individuals may show symptoms of depression at any stage of the disease. Depression is treatable, even in the latter stages of Alzheimer's disease and dementia.

Psychotic symptoms include hallucinations and delusions, which usually occur in the middle stage of dementia. Hallucinations typically are auditory and/or visual, and sensory impairments, such as hearing loss or poor eyesight, tend to increase hallucinations in the elderly.

Hallucinations and delusions can be very upsetting to the person with the disease. Common reactions are feelings of fear, anxiety and paranoia, as well as agitation, aggression and verbal outbursts.

Individuals with psychiatric symptoms tend to exhibit more behavioral problems than those without these symptoms (National Institute on Aging, 2014). It is important to recognize these symptoms so that appropriate medications can be prescribed and safety precautions can be taken.

Test Yourself

Depression cannot be treated in patients with dementia.

- A. True
- B. False

The correct answer is: B. False.

Communication Skills

Communication is described as a two-way process in which there is an exchange of information, thoughts, and feelings. Communication is not just verbal, but encompasses nonverbal actions as well. Therapeutic and interpersonal communication is a skill that is vital for the nurse-patient relationship. Communication is a bidirectional process that must be understood by both individuals involved. For communication to be effective it is important for the nurse to understand the patient and the experiences and emotions they wish to express (Kourkouta & Papathanasiou, 2014). This can be difficult when working with patients who have Alzheimer's disease or other dementias.

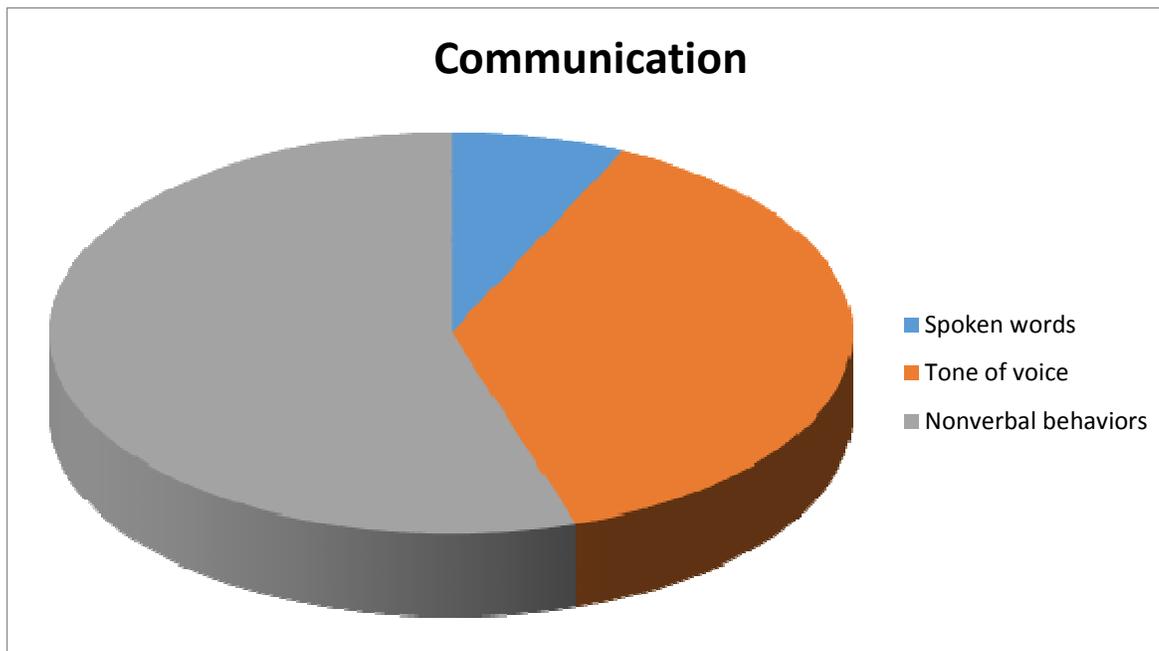
There is purpose, content, and value in communication. It is an intrinsic to human nature, and everyone communicates in some way. Listening and interpreting are important components in communication, so both verbal and nonverbal messages can be understood (Kourkouta & Papathanasiou, 2014).

Verbal and Nonverbal Communication

One theory of communication breaks down the amount of verbal and nonverbal messages that are used. Mehrabian (1981) described the components of communication as:

- 7% of meaning is in the actual spoken words
- 38% of meaning is paralinguistic, or tone of voice
- 55% of meaning is in facial expression and other nonverbal behaviors

Communication is effective when the three components support each other, also known as congruence. When the words, tone of voice, and nonverbal behaviors don't match, this is known as incongruence. When the components of communication are incongruent, people tend to take notice of the tone of voice and the nonverbal behaviors (Nazarko, 2014).



Test Yourself

The highest percentage of communication is done through:

- A. Spoken words
- B. Tone of voice
- C. Nonverbal behaviors

The correct answer is: C. Nonverbal behaviors.

Nonverbal Communication

The nonverbal elements of communication demonstrate feelings and attitude. Forms of nonverbal behaviors include the following:

Facial Expressions

Facial expressions are specific to an individual's culture and reflect a person's feelings and attitudes. Facial expressions can be affected by gender, personality, and the ability to control muscles involved. Common facial expressions include happiness, sadness, anger, surprise, disgust, fear, and interest (Nazarko, 2014).

Gaze and Eye Contact

Expression can also occur through eye contact and gaze. If someone is interested in a conversation their eyes can widen, or they can narrow to demonstrate disapproval. Pupil size and the rate of blinking also change during conversation. Gaze can also determine the reactions of others during communication. Vision or physical problems with the eyes can make eye contact difficult (Nazarko, 2014).

Body Movement

Meaning can be added to verbal communications through the use of nonverbal movements and

gestures. When two individuals align with one another, whether physically, emotionally, or mentally, this can assist with “pacing.” In other words, both individuals become similar in the use of body language, using movement for expression and emphasis. The way that we hold ourselves also adds to communication. For example, a posture that is sitting forward implies interest and engagement (Nazarko, 2014 & 2015).

Spatial Behavior

When we consider a personal boundary or “space,” we are referring to spatial behavior. It is the distance between individuals during communication. This behavior reflects the relationship a person has with another. Intimate distance is up close, generally reserved for those an individual loves or trusts. Personal distance is considered with communications between individuals who have a friendship or collegial relationship. Social distance is usually for individuals who do not know each other well, or at all. Nonverbal behavior can include entering the personal space of another. This may or may not cause a reaction, and should be considered when communicating (Nazarko, 2014 & 2015).

Touch

Sometimes considered the most powerful form of nonverbal communication is the use of touch. The intent behind the touch, along with the perceived meaning of the touch must be considered when using touch. This behavior can communicate caring and listening, but can also be viewed as dismissing or threatening (Nazarko, 2014 & 2015).

Effective Nonverbal Communication

There are some common techniques that are used for effective nonverbal communication. It is important to remember that these will not work for everyone, and should be individualized to the unique needs of each patient. A mnemonic to assist in remembering effective techniques is SOLER:

S- Sit squarely, facing the patient

O- Open posture

L- Lean slightly forward

E- Eye contact

R- Relaxed posture

(Jootun & McGhee, 2011)

Verbal Communication

Verbal communication is much more than just the words that are spoken. How a message is communicated verbally can be more important than the actual message itself.

Elements of verbal behavior include:

Tone

Tone is the quality of voice used during communication. It can convey emotion and intent behind the message itself. Tone of voice can demonstrate caring, warmth, and empathy. Conversely, tone can

convey impatience or irritation with the other person (Nazarko, 2014).

Inflection

Inflection refers to expression, or using “ups and downs” when speaking. This can emphasize words or reflect emotion, particularly when combined with pacing and volume.

Volume

Volume is how loud words are vocalized. This can reflect the temperament of the speaker. It may also be affected by physical impairments of either the sender or receiver in the communication.

Pacing

Pacing is the speed or rate of speech while talking. Pacing of verbal communication may demonstrate emotion. When individuals have a rapport, they tend to speak at the same pace (Nazarko, 2014).

Communication and the Dementia Patient

Nonverbal communication is particularly essential when a person with dementia is losing his or her verbal language skills. Individuals with dementia may behave in ways that are difficult for others to understand, because he or she is trying to communicate something. Difficulties with language occur in all forms of dementia, but vary according to the type of dementia, level of disability, and the individual. In many instances, language skills will fluctuate from day to day and at different times during the day. Other factors that can also impact on the patient’s ability to communicate include pain, illness, medications, discomfort, or physical concerns (Alzheimer’s Society, 2014).

Difficulties with communication can cause frustration and emotion for the patient with dementia, as well as those around them. These communication troubles are associated with changes in cognitive, physical, processing, language, and age-related sensory abilities (Alzheimer’s Society, 2014; Nazarko, 2015).

Changes

Cognitive Changes

Cognitive abilities are affected by dementia, which can alter the patient’s reality. The perception of the individual with dementia can be very different from others. The patient may be disoriented to both time and place, and he or she may not be responsive to others around them. Some dementia patients may perceive themselves at a different point in their life, with memories playing an important factor in their perception (Nazarko, 2015).

Physical Changes

As people age, there is an increased risk of co-morbidities, or other conditions. An estimated 72% of individuals who have dementia have at least one other co-morbidity. Physical conditions, such as a cerebral vascular accident or Parkinson’s disease, can also affect the ability to speak (Alzheimer’s Society, 2014; Nazarko, 2015).

Processing and Language Changes

The ability to process information includes determining what has been said and what an appropriate response is. Dementia impacts the ability to process and articulate. Words may be difficult to find inappropriate, or not grammatically correct. A dementia patient may use incorrect words, use words in the wrong order in a sentence, or even be unintelligible (Nazarko, 2015).

Age-Related Changes

Most people who have dementia are older and have additional age-related changes. These changes can include deterioration in hearing, such as the ability to discriminate words, inability to focus on conversations with background noise, or ability to perceive sounds in higher frequencies. Vision deterioration may include changes in close or far vision, and disorders such as glaucoma or cataracts. It is important to ensure the patient is assessed for vision changes and when applicable have his or her glasses, and the prescription is current.

Impairments in vision or hearing can reduce the quality and effectiveness of communication, as the nonverbal cues or tone may not be understood (Nazarko, 2015).

Importance of Communication with Dementia Patients

It is complex and often difficult to interact with individuals who have impaired communication, such as patients with Alzheimer's or other dementias. Reactions towards another person can be affected by misperceptions.

One possible consequence could be to dehumanize a person with dementia, whether intentional or unintentional, or the perception could be that patients with dementia are baby-like. Dehumanization focuses on the task rather than the patient him or herself. This can create a "neutral" communication, which is mechanistic or task-oriented, and characteristically lacks empathy, genuineness, caring, and warmth.

Another consequence could be disrespectful and negative communications, and in extreme cases, abuse. Just as with most people, poor and harmful communications can affect the mood of dementia patients (Nazarko, 2015).

Personal Reflection

Take a moment and consider that you are unable to care for yourself. This means that you need assistance with even simple activities of daily living- dressing, bathing, grooming, and feeding. How would you feel? What do you think your needs and wishes would be?

Now, add in that you are not able to communicate your needs and wishes to your caregivers. How does that make you feel?

There are times when caregivers treat another person as they wish to be treated. This has the best of intentions, but it doesn't always match the wishes of the actual patient.

Improving Communication Skills

There are many strategies to improve communication skills. A key point for effective communication is empathy. The use of empathy can assist in determining the difficulties the patient has with communication, what his or her experience may be, and how your communication can be adapted to meet his or her needs.

It is important to be at the same level as the patient when communicating, which signifies equal status, and is easier to interpret nonverbal behavior. The environment and lighting should be

appropriate, so that both people can see each other clearly. The timing of the communication is also important to increase effectiveness. Some patients may communicate better during different times of the day (Nazarko, 2015).

Sending and Receiving

Effective communication means that the message is sent successfully, and was received as intended. A patient may not be receptive to a message, especially he or she is in pain, hungry, emotional distressed, or disinterested. Message interruption due to physical changes, such as hearing or vision loss, can also occur. Sitting close and maintaining eye contact will help the patient focus.

As mentioned previously, nonverbal behavior is important. A patient will read your body language. Movements that are agitated or quick, or facial expressions that are tense may cause a patient to become distressed. Being calm and still during communication is important, as this behavior demonstrates respect, and that your full attention is on the patient. Also, speak clearly and calmly, to avoid causing distress. Maintaining personal space will also assist with the communication (Nazarko, 2014 & 2015).

It is also essential to read the nonverbal cues of the patient with dementia, which can help interpret the message. Facial expressions and how a person holds him or herself can indicate how he or she is feeling. These behaviors can assist in determining how the other person should react. Sentences should be simple and short to allow the patient time to process the information. Time should be allowed for a response, and questions should be asked one at a time to decrease distress.

Phrasing questions to allow for a “yes” or “no” answer may also assist in communication. If the patient does not seem to understand the message, attempt different words and methods to communicate, rather than simply repeating the message (Nazarko, 2015).

Interpreting the Message

Speaking is not the essence of communication. Listening, interpreting the message, and determining if the message communicated was received and understood are crucial components.

Misunderstandings can be common when working with dementia patients, so it is important to observe the reactions of the patient throughout the communication. This will assist in knowing that both parties understand one another (Nazarko, 2015).

Test Yourself

Effective communication means that:

- A. Words are spoken
- B. The message is sent successfully and received as intended
- C. Interpretation of the message is complicated

The correct answer is: B. The message is sent successfully and received as intended.

Case Study: Edith

Edith is a 77-year-old female, diagnosed with probable Alzheimer's dementia. She had fallen the week before and fractured her right tibia. Edith had been living in a special care unit of a long term care facility at the time of her fall. Her records from the facility indicate that Edith was able to speak and understand simple, short sentences. She was also able to participate in activities of daily living with verbal guidance. After her hospitalization, Edith is transferred to a skilled nursing facility for rehabilitation.

A nurse is talking with Edith as she sits in a wheelchair in a common area. The nurse is standing behind the wheelchair, and leaning over Edith's shoulder. Another patient is sitting close by. The nurse attempts to engage Edith in a conversation with the other patient. The nurse says "Nancy is our friend" to Edith three times in a high-pitched voice. Edith turns her head away from the other patient and the nurse, frowns, and does not engage in conversation.

Why might have caused Edith's reaction? What communication strategies might work better with Edith?

Answer:

Edith is in a new environment, injured, and surrounded by people she does not know. It appears that Edith does not want to engage in conversation. Although well-intended, the nurse's communications are not effective. Strategies to use with Edith could include the nurse sitting at her level and talking with Edith while maintaining eye contact. Tone of voice should be adjusted so it is calming rather than high pitched. Allowing Edith to respond rather than repeating "Nancy is our friend" would demonstrate respect. Phrases such as this can be interpreted as condescending, even if that is not the intent.

Strategies for Working with Dementia Patients

When working with dementia patients, strategies should be individualized to the patient, based on psychosocial, spiritual, and cultural needs. The behaviors associated with the patient's dementia also require a variety of techniques to use. Strategies can be developed based on the type of impairment the patient is experiencing (AlzBrain.org, n.d.).

Impairment	Strategies
Personality, Reasoning, Movement, Speech, and Attention: Symptoms of dementia can cause a change in personality, inability to plan, poor judgment, diminished attention span, decreased concentration, distractibility, and inability to initiate activity.	<ul style="list-style-type: none">• Give clear, step by step directions• Use cues or prompts• Reduce distractions• Observe and reduce hazards in the environment
Perceptions, Senses, and Language: Symptoms of dementia can cause a decrease or inability to sense, follow visual or auditory cues, recognize objects by touch, or decreased ability to understand the purpose of objects.	<ul style="list-style-type: none">• Use cues or prompts• Use body language or gestures to demonstrate
Vision and Visual Interpretation: Symptoms of dementia can cause a loss of peripheral vision or depth perception, difficulty processing, and rapid movements.	<ul style="list-style-type: none">• Approach the patient from the front• Use and maintain eye contact• Use slow movements• Modify the environment to reduce

	<ul style="list-style-type: none"> designs on the walls or floors
Language: Symptoms of dementia can cause aphasia (impaired language), including ability to speak and understand.	<ul style="list-style-type: none"> • Use cues or prompts • Use body language or gestures to demonstrate
Emotions: Symptoms of dementia can cause fear, outbursts of anger or inappropriate behavior.	<ul style="list-style-type: none"> • Use distraction • Provide reassurance • Redirect the patient with activities
Memory and Learning Processes: Symptoms of dementia can loss of short term memory, challenges with direction and time, and confusion.	<ul style="list-style-type: none"> • Provide reassurance • Answer all questions (even if the question is repeated) • Redirect the patient with activities • Move slowly between tasks, allowing time for the patient to adjust

Tips in Caring for Dementia Patients

Patient caregivers who work with dementia patients know that it can be challenging and rewarding. You might not only deal with people with dementia in the work setting but possibly in your personal life, too. Many of these tips may be effective in both settings. As always, the specific care depends on the dementia patient's symptoms and abilities, and also on the policies and procedures of your organization.

- Try to obtain accurate information about the patient (cognitive level, care ability, safety precautions)
- Introduce yourself to the patient, looking at them face-to-face, and speaking in a caring tone
- Assure the patient that you are there to help
- Assess the patient's level of independence (for example, does the patient needs help walking or using the toilet)
- Assess the patient's activity level (watching TV, doing puzzles, walking)
- Determine ability to consume own meals (observe the person eating)
- Ask if the patient is a wanderer (might require constant monitoring)
- Assess the patient's pain level and intervene appropriately
- Maintain the patient's routine of daily activities (consistency reduces anxiety)
- Provide positive feedback and rewards for accomplishments, especially in early stages of the disease process (this is encouraging)
- Continuously and consistently explain all care and activities
- Provide care in clusters to prevent frustration (e.g. combine assessment and bathing together; this prevents having to interrupt the patient numerous times to perform different skills or care)
- Allow patient independence as much as tolerable and safe
- Always put yourself in the place of patients to appreciate what they might be experiencing from their point of view
- Provide reminders for recognition, such as the use of name tags or labels on objects

Behaviors Associated with Dementia

There are various behaviors seen in patients with dementia. Some behaviors are benign and harmless, while others can be a risk to the patient or others around them (AlzBrain.org, n.d.).

There may be common triggers that cause challenging behaviors with dementia patients. These may be actions of others that frighten, annoy, cause discomfort or pain, or threaten the patient, based on their perception. The physical environment may feel uncomfortable, boring, noisy, threatening, or over-stimulating. The patient may not understand what is happening to them, or they have physical or emotional needs that are not being met. The patient may also demonstrate behaviors based on their own thoughts or emotional responses (AlzBrain.org, n.d.).

Dementia Behaviors

Behavior	Strategies
<p>Repetitive verbal and physical behaviors: Patients may repeat questions, sentences, or stories again and again. Physical behaviors may include rubbing their hands, tapping their feet, or banging.</p>	<ul style="list-style-type: none"> • It is important to remember that it is not personal, and the patient is not trying to purposely annoy you. • Provide distraction or redirection. • Respond to the emotion behind the behavior. • Use written notes and reminders. • Provide an object the patient can stroke or hold.
<p>Wandering: Patients may wander for various reasons. Some patients have a specific goal, some have excess energy and need to move, and others are interested in their environment.</p>	<ul style="list-style-type: none"> • It is important to monitor the patient's behavior, and keep the environment safe at all times. • If needed, create one area that is safe, and redirect the patient to that area. • Use distraction. • Exercise activities may decrease wandering. • Walk with them. • Make sure that their physical needs, such as eating and toileting, are being met.
<p>Aggression: Behaviors may include outbursts of yelling or screaming, throwing objects, or even hitting and biting.</p>	<ul style="list-style-type: none"> • It is important to remember that it is not personal. • Stay calm, as your behavior and reactions can influence the patient's. • Watch the patient's emotions and note when frustration appears to be building up. • Try to reassure and redirect. • Back away if necessary. • The patient should not be restrained unless absolutely necessary for safety.
<p>Paranoia and hallucination: Some dementia patients develop paranoia, demonstrated by high feelings of suspicion and blame for others. Other patients may have actual hallucinations.</p>	<ul style="list-style-type: none"> • It is difficult when patients have delusions or hallucinations, and it is important not to argue with the patient; it will not change their belief. • Use distraction. • Reassure the patients of their fears.

	Evaluate the environment- sometimes rearranging the environment might help.
<p>Labile emotions: Behaviors may be an extreme emotional response that does not correlate to the current situation. This may include uncontrolled crying, screaming, uncontrolled restlessness, anger, and rapid mood swings.</p>	<ul style="list-style-type: none"> • It is important to remember that it is not personal. • Stay calm, as your behavior and reactions can influence the patient's. • Watch the patient's emotions and note when emotion appears to be building up. • Try to reassure and redirect. • Maintain safety of the patient and yourself. Encourage the patient to express their feelings. • Try to understand the event that produced the reaction and determine if it can be avoided in the future.

Test Yourself

Challenging behaviors of a dementia patient may be the result of:

- A. Triggers to the patient
- B. The patient's perception of the situation
- C. Based on the patient's emotional responses
- D. All of the above

The correct answer is: D. All of the above.

Interactive Activity

This brief video demonstrates effective strategies in working with dementia patients, created by Work Safe BC (British Columbia, Canada).

This can be viewed at: <https://www.youtube.com/watch?v=DZ0VMdxtYw4>

(Note: this video discusses a "casual" employee; this is the same as an employee who works "prn" or "per diem").

Tips for Challenging Behaviors

Behaviors of dementia patients are very individualized, but there are some general tips that may be applied in many situations.

- Try to intervene before a behavior or situation becomes a problem
- Identify, remove, or avoid triggers that cause a challenging behavior
- Do not take the behavior personally

- Try to identify the need or purpose behind the behavior- all behavior has meaning
- Be calm, understanding, patient, and reassuring
- Be alert- watch the behavior and the environment, with a focus on patient safety
- Do not argue or try to convince the patient
- Respond to the feelings and emotions of the patient
- Be creative and adapt to each situation
- Respond to the questions and requests of the patient
- Try different approaches, even if one approach worked previously- the same approach may not work each and every time
- Discuss strategies with other staff members- what has worked for them?
- Talk to the family and learn what they suggest
- After the situation, evaluate what happened, to incorporate into future plans. What are the individual needs of the patient? What behavior did they demonstrate? When did it happen? Where did it happen? Why did it happen- What do you think the triggers were? How was the response to your interventions?

Case Study: Bill

Bill is an 83 year old male with a history of vascular dementia. He has been a resident of a long-term facility for three months. Bill is married, and his wife visits three times a week. Before retiring, Bill was a high school teacher. His medical history includes a cerebral vascular accident two years ago with left-sided deficit, and macular degeneration. Bill is incontinent of urine and stool, and requires frequent skin hygiene.

Based on this information, what considerations are there for communicating with Bill? What other information do you need?

Answer:

Communication may be impaired by Bill's dementia and effects from his stroke. His vision impairment with the macular degeneration is another consideration. It will be important to accommodate for these physical concerns as well as the dementia.

It would be helpful to learn what strategies for communication work for staff as well as his wife. Learning more about Bill's likes and dislikes would also assist with communications.

While you are performing skin hygiene, Bill keeps pulling away and yelling "no!". He begins swinging his arms. He is looking towards the closet door, and is mumbling "keep him away from me".

What are some strategies that can be implemented to assist Bill?

Answer:

It is important to be calm, understanding, patient, and reassuring. Bill appears to be hallucinating, so it is important not to argue with him. Respond to his feelings and emotions, and reassure him. Use distraction. Evaluate the environment- it may be if the closet door is opened, it will remove what he perceives is there. If there is a danger of increased aggression, make sure Bill is safe and give him some time to himself.

Interactive Activity

Another brief video demonstrates approaches for redirecting patients, created by Work Safe BC (British Columbia, Canada).

This can be viewed at: <https://www.youtube.com/watch?v=OWIGLFoWrUo>

Models of Care

Knowledge of disease processes and strategies of communication are important when working with patients with Alzheimer's disease and other dementias. How care is provided to these patients is another essential component. Many models of care exist, and it is important to find the most appropriate framework for working with these patients.

Person Centered Care

Traditional medical models of care focus on the disease process and symptomatology. In other words, it is treating or managing the disease, disorder, or symptoms. Person centered care is a cultural shift to a more holistic, humanistic model. The person is viewed as whole, rather than just the disease. This type of care is considered the "gold standard" of providing care with the elderly and patients with dementia (Li & Porock, 2014). Person centered care is also known as patient centered care or person focused care.

History of Person Centered Care

A British gerontologist, Tom Kitwood, first used the term "person centered" for caring with dementia patients after witnessing care in facilities that he noted were dehumanizing. He described what dementia patients needed to have quality of life, and advocated for individualized care to meet needs beyond just the physical or medical needs (Kitwood, 1997).

Kitwood identified the following psychosocial needs of patients with dementia: comfort, attachment, inclusion, identify safeguarding, and occupation. These identified needs guide the principles of person centered care (Kitwood, 1997; Li & Porock, 2014).

Defining Person Centered Care

There are many definitions of person centered care, as the term has redefined through the years. Key components of person centered care are respect for the individual; empowerment, promoting quality of life, viewing the patient in a holistic manner, being responsive to patient's needs, and incorporating

the beliefs, culture, and values of the patient in care. Other factors are participation of the patient in his or her care, upholding dignity, recognizing self-determination, providing information in a manner the patient can understand, transparency with interactions, purposeful living, and enhancing relationships between the patient and caregivers (Entwistle & Watt, 2013; Drick, 2014).

Person Centered Nursing Framework

The conceptual model of the person centered nursing framework was created by McCormack and McCance in 2006, and revised in 2010 (McCormack & McCance, 2010). There are four components within the nursing framework:

- Pre-requisites or nurse attributes: These encompass professional competence, job commitment, interpersonal skills, clear values and beliefs, and knowledge of oneself.
- The care environment: This component looks at the context in which care is delivered.
- The processes of care: These are the processes that operationalize person centered care. Engagement, a sympathetic presence, working with the patient's values and beliefs, providing holistic care, and shared decision making are all included.
- Person centered outcomes: The expected outcomes of patient centered care include patient involvement with care, creating a therapeutic culture, feelings of well-being, and the patient's satisfaction with the care provided

A view of the patient centered nursing framework can be seen at:

<http://www.nursingworld.org/An-Exploration-Figures>

Values in Person Centered Care

There are essential values when providing person centered care. These include:

- Know each person as an individual
- Each person can and does make a difference
- A transformed culture is built on relationships
- Respond to not just the body and mind, but to the spirit as well
- Always put the person before the task
- Each person is has the right to self-determination, no matter where they live
- Community is the remedy to institutionalization
- Promote the growth and development of everyone
- Self-examination is necessary to find creative and new ways to do things better
- The environment can be shaped to use its potential
- Cultural transformation is always a journey

(Entwistle & Watt, 2013; Drick, 2014).

Presence

A core component of person centered care is presence, which is defined as an essential state of healing (American Holistic Nurses Association [AHNA], & American Nurses Association [ANA], 2013). Presence reflects person centered care by:

- Approach: an individual should be approached in a way that honors and respects his or her essence.
- Relationship: relate to an individual in a way that demonstrates a quality of being with that person, and in collaboration, rather than “doing to” that person.
- Sharing: entering into a shared experience which promotes a feeling of wellbeing and promotes healing potential.

Perceiving Presence

According to the American Holistic Nurses Association (AHNA), & American Nurses Association (ANA), (2013), presence may be difficult to define, but is perceived. Presence is described as:

- Around, through, and in everything
- It cannot be contained by words, but rather is a felt perception
- Limitless, reflected in being and doing
- Infinite and all-encompassing
- It is the common denominator between individuals
- Is reflected in deep feelings of peace, love, joy, connectedness and abundance
- By its very nature, we cannot be anything else

Benefits for Others

Person centered care also has positive benefits to the staff and caregivers working with dementia patients. A systematic review of seven studies done with person centered care showed that there was a reduction in stress and emotional exhaustion, as well as reduced job dissatisfaction. Burnout was also significantly reduced in one study included in the review (Barbosa, Sousa, Nolan, & Figueiredo, 2014).

Test Yourself

Key components of person centered care include:

- A. Dependence and making decisions on behalf of the patient

- B. Focus on medical care and decisions
- C. Patient empowerment and purposeful living

The correct answer is: C. Patient empowerment and purposeful living.

Social Needs and Activities

Alzheimer's disease and dementia cause cognitive deficits, which can affect a patient in many ways. Impaired communication is only one negative effect of these deficits. The ability for self-care and participation in activities can also be drastically decreased. Individuals who used to be active and self-sufficient become dependent and withdrawn. Meeting the social needs and maintaining activities for dementia patients is an essential component in addressing the needs of the person as a whole.

Physical Activity

Physical activity is described as exercise, or the movement of muscles and consequent energy expenditure. Physical activity has been noted as being beneficial in patients with cardiovascular disease, depression, and cancer. Physical activity has also been associated with cognitive functioning in dementia patients (Blondell, Hammersley-Mather & Veerman, 2014).

Leading a lifestyle that is physically active can have a substantial impact on well-being. Exercise is valuable for physical and mental health, and can improve the quality of life for people in all stages of dementia. Exercise includes a wide range of physical activities, from walking across the room, to gardening, to dancing.

Benefits of Physical Activity

Physical activity has many benefits, including:

- Improving cardiovascular health by reducing the risk of heart disease and lowering blood pressure
- Reducing the risk of certain disease, such as type 2 diabetes, osteoporosis, stroke, and some types of cancer
- Increasing physical function through maintaining joint flexibility and muscle strength. This can assist the patient preserve independence longer
- Improving cognition
- Assisting with sleep
- Reducing feelings of isolation and increasing opportunities for social interaction
- Improving balance and strength, which can decrease the risk of falls.
- Improving body image
- Providing a sense of achievement

(Alzheimer's Society, 2013b)

Maintaining Activities: Early Stages of Dementia

In the early stages of dementia, the individual may reduce or withdraw from activities he or she used to enjoy. Maintaining engagement in activities important to the person is essential, adding to his or her quality of life. Understanding the desires, needs, and values of the patient can ensure the success of participation. Flexibility is another important factor. For example, a patient may be able to interact in smaller groups, but becomes overwhelmed with larger groups (Alzheimer's Association, 2015a).

Maintaining Activities: Later Stages of Dementia

With the progression of dementia, activities will need further flexibility and adjustments. Here are some considerations:

- It is important to keep the skills and abilities of the individual in mind. For example, a person with dementia may have musical talents, such as the ability to play simple songs on a piano or sing. Be creative, and bring these skills into daily activities.
- Pay particular attention to what the individual enjoys. Observe the patient's behavior, and note when the person appears happy, sad, distracted, anxious, or irritable. Some activities may be enjoyable to one person, but frightening or overwhelming to another.
- Watch for activities the patient initiates. If a patient participates in a task, such as cleaning, include this as an activity with their daily routine.
- Be aware of limitations or impairments that can affect activities. For example, a person may tire quickly, or have physical difficulty performing certain movements.
- Focus on the enjoyment of the patient, rather than achieving goals. For example, a patient may still enjoy looking at the newspaper or having it read to them, even if they have trouble comprehending the content.
- Activities should encourage participation and involvement in daily life. Activities and tasks that are part of a household, such as setting a table, can help the patient feel like they are contributing, valued, and accomplished.
- Relate activities to the patient's life. A person who was an artist or gardener might enjoy activities that relate to their skills.
- Consider the time of day. Everyone functions better at certain times of the day. Patients may be more successful with activities at specific times.
- Adjust the activities as necessary; it is important to be flexible, depending on the individual's needs for that day. It is also vital to evaluate activities based on the stage of the disease. Patients with a more advanced stage of dementia may need to have a less active role, and repetitive tasks may be beneficial.

(Alzheimer's Association, 2015a; Alzheimer's Society, 2013b).

Approaching Activities

The approach of the nurse or caregiver will help ensure success. Some approaches include:

- Make sure the patient is physically able to perform the activity.
- You may need to help get the activity started. Many dementia patients have the desire and even the energy to participate in activities, but do not have the organization or planning skills to initiate and complete the activity successfully.
- Provide support and supervision. The patient may need easy to follow instructions or steps to perform the activity. Supervision may also be needed to ensure patient safety, and observe the person's reaction to the activity.
- The process of the activity is important, not the result. A task or activity may not be performed perfectly, but the individual will feel like he or she has contributed and is useful.
- Flexibility is essential. A person with dementia may not want to perform an activity, or wants to do it differently. Do not insist that the patient does the activity; however, you could alter how it is done to accommodate his or her needs. This is about the person, not the task itself.
- Give assistance as needed. Make it a collaboration, rather than taking over the task or activity. Assist with parts of the task that appear difficult for the patient.
- Reaffirm that the person is needed. Participation in activities and tasks can give the patient a sense of value and belonging. However, do not place too many demands of the individual.
- Emphasize a sense of purpose with the activity. If you tell the person the reason behind a task, it may help motivate. For example, letting them know that you need help may give the patient meaning for the activity.
- Give encouragement. Even if a task appears mundane or meaningless, if a patient enjoys it, the activity has meaning. Avoid criticizing or correcting the person.
- Inspire expression of self. The use of art, music, or even conversation can allow the person an opportunity to express him or herself.
- Communicate during the activity. Even if patients cannot respond verbally, talking with them during a task or activity will help encourage their participation.
- Use an activity as a distraction. Behaviors can also be incorporated into an activity. For example, if a patient rubs his or her hand on a table, a cloth can be given to the person to wipe the table.
- Revisit at another time. If a patient isn't interested in a task or activity, try again. It may be the wrong time of day, or the activity may need to be adapted to meet the individual's needs.

(Alzheimer's Association, 2015a; Alzheimer's Society, 2013b).

Test Yourself

Exercise is valuable for physical and mental health, and can improve the quality of life for people in all stages of dementia.

- A. True
- B. False

The correct answer is: A. True.

Activity Suggestions: Early Stages of Dementia

There are many suitable exercise activities that may be beneficial for patients in earlier stages of dementia. These may include:

Gardening

This is a physical activity that gives an opportunity to get outdoors, and may be enjoyable to many individuals. There are various tasks in gardening that can be implemented, such as weeding a garden, raking leaves, or watering the lawn, and is enjoyed by many people. Satisfaction may also occur by watching plants or flowers grow. The various sensations of smells, textures, and colors can also provide enjoyment. Tending to plants or flowers indoors may be an alternative.

Indoor ball games

Some individuals retain skills such as bowling or golf. Using an indoor bowling or mini-golf set can be an enjoyable activity.

Music and dance

Dancing is a very social activity, and can be enjoyable and therapeutic for dementia patients. Music can be associated with past memories and emotions, which can be shared with others. Dancing can increase strength and flexibility, reduce stress, and help patients stay steady and agile. Dancing can also be done while seated.

Seated exercises

Seated exercises are not as strenuous as those in a standing position. The goal of these exercises is to maintain balance and muscle strength. Some examples include turning the body from side to side, raising the heels and toes, marching in place, bending arms and legs, clapping, making circles with arms, bicycling with legs, alternate movements for extremities, and moving from sitting to standing.

Swimming

With supervision, swimming is a helpful activity for individuals with dementia. It has been said that many individuals find the sensation in the water as calming and soothing.

Martial arts

The gentle forms of martial arts, such as tai chi and qigong, use simple physical movements. Meditation is also used with these arts, with the goal of improving both health and balance. A series of exercises are performed to positively affect the mind, spirit, and body. The focus on stability and balance can increase agility and may reduce fall risk.

Walking

Walking can be beneficial for many individuals. The time and distance with walking should be individualized to the patient. Walks can be done with a few people, in groups, and can be performed indoors or outdoors.

Activity Levels: Early Stages of Dementia

The recommendation is for patients to perform regular physical activity to maximize benefits. Individuals who are not currently active should perform about 30 minutes of activity a day, at least five days a week. This can be broken up into shorter sessions throughout the day.

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Activity Suggestions: Later Stages of Dementia

There are benefits to physical activity with patients in the later stages of dementia as well. Activities focus more on mobility. Some suggestions include:

- When getting out of or getting in to bed, have the patient move along the edge of the bed, in the sitting position, until the end is reached. This type of mobility helps exercise the muscles needed for standing up from a chair.
- Encourage the patient to balance in a standing position. The patient may need support from an object or another person. This can improve the balance of the individual needed for activities of daily living, and may help decrease risk of falls.
- Have the patient sit unsupported for a few minutes each day. This will help strengthen muscles of the back and stomach, and can support posture. This exercise should be supervised, as there may be a risk of falling.
- Place the patient on the bed, and have them lie as flat as they can for 20 or 30 minutes each day. This assists with stretching the body, and relaxation of the neck muscles.
- Get the patient up and moving. Standing and moving regularly helps maintain balance and keep leg muscles strong.

(Alzheimer's Association, 2015a; Alzheimer's Society, 2013b).

Activity Levels: Later Stages of Dementia

Individual in the later stages of dementia should be urged to move regularly. Simple examples include changing chairs or just moving in general. Incorporating mobility strategies into the daily routine can assist with joint flexibility and maintain muscle strength.

Sensory Garden

A sensory garden is strategically designed to stimulate the five senses. Patients should be allowed to wander and explore in a safe environment. Exploration using sight, sound, touch, smell, and even taste can be encouraged with a sensory garden. This can help trigger memory and cognition with dementia patients. A well designed sensory garden should also provide an area for encouraging social interaction and engagement with dementia patients.

Select appropriate items which may be included in a sensory garden to stimulate senses:

- A. Bubbling water urn
- B. Bird feeder
- C. Cactus
- D. An open pond
- E. Pansies
- F. Mint

The correct answer is: A, B, E, F. Cactus and an open pond are incorrect.

Social Needs

Activities not only promote physical mobility, but can also produce intellectual stimulation and socialization. Patients with dementia have been found to demonstrate increased anxiety, depression, withdrawal, loneliness, and low self-worth when they have limited socialization with others. It is extremely critical that dementia patients have interactions with healthy individuals, such as friends and family members. Maintenance of a supportive atmosphere will help the individual feel that they are valued and still have a place in society (Ruthirakuhan, Luedke, Tam, Goel, Kurji, & Garcia., 2012).

The activities previously described can provide opportunities for socialization. Shared mealtimes and conversations are other times when social needs can be addressed. Social groups are another strategy that can help a patient participate in purposeful interactions. Encouraging time spent with friends and families members are an important aspect in meeting the psychosocial needs of an individual with dementia. Studies have demonstrated that social interactions can improve the quality of life of dementia patients, possibly improve cognitive abilities, and ensure self-confidence and worth (Ruthirakuhan et al., 2012).

Individuals with dementia can feel socially isolated and lonely, which can be compounded by living in a residential care facility. It is important to support and facilitate relationships that are meaningful to these patients. Many patients with dementia have lost friends through death or because of the effects of dementia. Social interactions can provide stimulation and make the individual feel loved and appreciated. Without human connection, a patient can withdraw into him or herself and become isolated; meaningful relationships can help patients keep engaged and thriving (Mendes, 2015).

Nutrition and Dementia

Poor hydration and nutrition can lead to acute care hospitalization, increased risk for pressure ulcers, poor wound healing, fatigue, muscle weakness, weight loss, and infections. Malnutrition is a greater risk for patients with dementia, as there may be dysphagia or difficulty chewing food. The cognitive changes in the brain may also affect the patient's desire or ability to eat. Physical and sensory impairments, along with a loss of appetite, can further complicate this issue.

Although eating and drinking problems are commonly seen in people with dementia, each situation is unique to the individual and their situation. The individual's beliefs, culture, and life history should be considered, and solutions should be tailored to meet the person's needs. Offering solutions, being adaptable and increasing knowledge can encourage the person with dementia to eat and drink well. (Alzheimer's Society, 2013a).

Support for Dietary Needs

With the progression of dementia, a person will require more support to meet their dietary needs. Higher calories may be required, and a dietician should be consulted. It is important to determine the reasons behind the problems encountered.

Poor appetite may be the result of many reasons. Loss of appetite may be a sign of depression, which can be common with dementia patients.

Impaired communication can also affect dietary habits, as a patient may not be able to indicate if they

are hungry, or dislike food they have been given.

Pain may also contribute to poor appetite, and should be addressed.

Fatigue may lead to unfinished meals, so it is important to be aware of increased tiredness with a patient. Level of activity will also affect appetite; a person who is not active may not feel hungry.

Changing mealtimes to a different time of day, or providing small portions more frequently may help.

Medications can also cause changes in appetite, and should be evaluated. Dosing may need to be adjusted, or medications changed.

Constipation is a common problem with aging patients. This can create feelings of nausea or bloating, which will decrease appetite. Diet and stool softeners may decrease constipation (Alzheimer's Society, 2013a).

Common Problems

It is important for patients to be able to recognize food and drink. This can be complicated by cognitive changes from the damage to the brain. Vision impairment can cause the patient to be unable to see or recognize food and drink.

People with dementia may be unable to concentrate well, which means they may not be able to focus on a meal. Finger foods and smaller portions can help to make the task easier. If a mealtime goes on for too long, it can turn into a negative experience. The food can become cold or the process may be overwhelming.

Some people with dementia are unable to judge the temperature of food. Make sure food is not too hot, as it could burn the person's mouth and result in eating becoming uncomfortable, or even painful.

The sensation of thirst also changes with aging patients, which can sometimes mean the person isn't aware they're thirsty. A person with dementia may also have similar problems, and may be less able to provide drinks for themselves. The person should be encouraged to drink throughout the day.

Coordination Problems

Lack of coordination for dementia patients may make it difficult to pick up a glass or handle cutlery. This could lead to avoidance of meals because they are embarrassed by their difficulties or want to avoid struggling. They may also have trouble getting food from the plate to their mouth. A person with dementia may not open their mouth as food approaches and may need reminding to do so. Some strategies to assist include:

If the person is struggling with a knife and fork, chop up food so it can be eaten with a spoon. They may also need prompting and guidance of their hand to their mouth to remind them of the process involved. Finger foods such as cheese, sandwiches, or slices of fruit may be easier to eat when co-ordination becomes difficult.

Make sure the patient is able to eat where they feel comfortable. An occupational therapy consult may help with aids for assisting with meals, such as specially adapted cutlery or non-spill cups

(Alzheimer's Society, 2013a).

Encouraging Appetite

There are strategies to help stimulate appetite, as well as interest in food. It is essential to understand the wants, needs, preferences, and routines of the patient. Abilities and physical consideration are also needed. Some strategies include:

- Provide regular snacks or small meals, rather than large meals
- Ensure the food looks and smells appealing. Different tastes, smells, and even colors can encourage eating.
- Observe for opportunities for eating. Food and drink can be incorporated at different times, and with activities.
- Know the likes and dislikes of the person.
- Try different types of food. The likes of the individual may change, so experimenting may help find foods to match the person.
- Don't withhold desserts, even if the person hasn't eaten their meal.
- Keep the food warm.
- If a patient is experiencing dysphagia and has difficulty chewing or swallowing, try soft foods first, rather than pureed. A dietician and/or speech therapist should be consulted.
- Encourage the patient to get involved at mealtime, as in setting the table.
- Give gentle reminders to eat, and communicate what the food is. Provide positive encouragement.
- The environment should be relaxed and friendly for eating and drinking. Use it as an opportunity for social activity.

(Alzheimer's Society, 2013a).

Test Yourself

When coordination is difficult for a patient, a strategy that may assist them is:

- A. Keep the food warm
- B. Provide finger foods
- C. Encourage them to set the table

The correct answer is: B. Provide finger foods.

Encouraging Fluids

There are strategies to help encourage fluids, such as:

- Have a drink available whenever the person is eating something. Offer the patient the cup, or put it within their line of sight.
- Depending on the patient's needs, a clear glass can be used so he or she can see what's inside. A brightly colored cup may be used to draw attention.
- Describe what the drink is, to encourage trust and understanding.
- Tell the patient where the drink is, so that if the person has a problem with their sight they are still able to find the drink.
- Offer a variety of drink, both hot and cold, throughout the day.
- Make sure the cup or glass is accommodating for the patient, and not too heavy or a difficult shape.
- Consider foods that are also high in fluid content.

(Alzheimer's Society, 2013a).

Eating Behaviors

A person with dementia may refuse to eat food or may spit it out. This may be a form of communication, such as they dislike the food, it is too hot, or they do not know what to do with the food. The person with dementia may become angry, agitated or exhibit challenging behavior during mealtimes. This may be due to frustration at any difficulties they are having, the feeling of being rushed, the environment they are in, the people that they are with, or dislike of the food. They may not want to accept assistance with eating. It can be a challenge to identify what the problem is, but it is important to remember that these reactions are not a deliberate attempt to be 'difficult', or a personal attack.

It is important to help the patient maintain as much independence as possible, and not rush them. Observe the non-verbal cues, such as body language and eye contact, as a means of communication. Do not pressure a patient to eat or drink, particularly if a person is agitated or distressed. Wait until the person is calm and less anxious before offering food and drink (Alzheimer's Society, 2013a).

Dietary Changes

Changes in eating habits can happen with dementia patients, including preferences, amount, and when they eat. As a person gets older, the senses of taste and smell may decline, which can lead to food being less palatable. With dementia, damage to specific parts of the brain or a change in taste perception may mean some people start to enjoy tastes they never liked before or dislike foods they always liked, so those providing food should try to be flexible. Dementia patients can show even greater problems with their sense of smell, especially with odor memory. People may develop a preference for additional sugar and salt, or unusual flavor combinations. Individuals may also begin to have a less varied diet, only eating certain types of food.

Strategies for adapting to changing eating habits include:

- For patients with a preference for sweet foods, fruit may be a healthier option.
- Add small amounts of sugar or honey to savory foods. Sweet sauces can be served with savory dinners.
- Flavors can be enhanced through the use of herbs and spices.
- Try new food the person has never eaten before.

Non-Food Items

As dementia progresses, a person may put non-food items into their mouths, such as paper or soap. One reason for this could be that the patient no longer recognizes the item for what it is, or understands what it is for. Remove the items that a patient may confuse from view. Another reason is that the person may actually be hungry. Offer food as an alternative to the item. Ensure that food is available, easy to see (both within eyesight and in clear contrast with the plate or immediate environment) and easy to access throughout the day so the person can eat when they want to (Alzheimer's Society, 2013a).

If a patient develops a pattern of ingesting non-food items, this is classified as a condition called pica. Although pica is associated with dementia, there is no actual known cause. The behavior demonstrated with pica is very individualized to the person. Some individuals with pica may ingest any small item they come across, whereas others look for specific non-food items. Pica is a dangerous condition, placing the patient at higher risk for injury to the mouth or gastrointestinal tract, bowel blockage, poisoning, or infection. This also increases the risk of mortality. Close supervision of patients is essential for safety.

Overeating

Some people with dementia may overeat. This could be related to cognitive changes, when the person has forgotten that they have recently eaten or being concerned about where the next meal is coming from. Overeating may also be associated with eating inappropriate foods or non-food items. Patients may become obsessed with particular food, or frequently ask or search for food. This can be a stressful situation for everyone involved.

Some strategies to address overeating include:

- Ensure that the person has an activity or task, so they do not feel bored or lonely.
- Leave only bite-sized snacks within reach of the person.
- Certain foods may need to be removed from the premises.
- A physician may need to be consulted if the patient has excess weight gain, has drastically reduced their food variety, or is only attempting to consume non-food items.

The Environment

The environment plays an important part in the experience of eating and drinking. It can affect the

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enjoyment and the amount of food they eat. A good mealtime experience can have a positive impact on the person's health and wellbeing. Some strategies for the mealtime environment include:

- Eat with the person. This will create a social situation, and can also help maintain independence.
- Some patients may prefer to eat on their own, and this may vary from one meal to another. Either way, make sure the person has enough space.
- The environment should pleasantly stimulate the senses, such as the scents of food, or colors of the tablecloth. The environment should be calm and not distracting. Background noise should be reduced or eliminated.
- The patient should choose where they wish to eat and what they want to eat, within reason.
- Colors should be used to support the patient, not distract them. The colors of the food, plate and table should be different. Avoiding patterned plates is important.

(Alzheimer's Society, 2013a).

Meal Preparation

It is important to keep people involved in preparing food and drink. This is because it can help to maintain certain skills, and keep the person interested in eating and drinking. Preparation can be broken down into individual tasks. It's important for the patient with dementia to do as much as they can independently.

Case Study: Nick

Nick is a 72 Y male with Alzheimer's disease. He is widowed, and was just transferred to a new long term care facility, so his son and his family can be closer. During the first week at the new facility, the staff note that Nick spends most of his time in his room, his intake of food and drink is minimal, and he has limited verbal communication.

What other information is required to help Nick? What sources are available to find out this information?

Answer:

The staff at the new facility should obtain Nick's records from his previous facility, and speak with his son. It is important to know Nick's preferences and habits, as well as his life history.

Staff should also communicate with Nick, particularly with nonverbal behaviors, to try and identify his emotional needs. All of this information can be used to develop strategies to assist him in meeting his intake and energy needs.

By gathering information from the previous facility and Nick's son, staff have identified that Nick tends to eat small, frequent meals, rather than sitting down for a large meal. He has also developed a "sweet tooth" over the past few months.

What are some strategies to assist Nick meet his needs for food and drink?

Answer:

Staff can offer Nick a variety of choices to determine his likes and dislikes. Having small

portions immediately available, including finger foods, may help encourage him to eat. Adding sugar or honey to his foods may also address his “sweet tooth”. Drinks should also be readily available for him along with the food, to encourage his fluid intake. Sitting with Nick and communicating to him frequently may also help meet his needs.

Families of Dementia Patients

Families are integral to the diagnosis and management of patients with dementia. It can be an emotional experience as they watch their loved ones deteriorate both mentally and physically. It is also difficult for changing relationships and roles within a family that can occur. Responsibilities in a household can also shift, which may add stress to the situation. Most of the care of dementia patients is provided by families. Approaches and interventions to help support caregivers of those with dementia include skills training, support groups, and education.

Providing support and assistance to families of patients with dementia is essential. Good communication and effective listening skills are important. Listen to the caregiver’s fears and concerns without judging. It is also important to recognize when a caregiver is experiencing stress. Be proactive in identifying when a family member needs help, including allowing them to have time for his or herself (Joanna Briggs Institute, 2010).

Interactive Activity

This brief video, created by Hospice of the Valley, shows how Alzheimer’s disease and dementia affects the families of those affected. It can be viewed at:

https://www.youtube.com/watch?v=k_9-D9yFKYQ

Supporting Family Relationships

Cognitive deterioration occurs with the progression of dementia, which affects abilities and memories. However, the emotions of each person are intact. Support and the very presence of loved ones can create wellbeing with dementia patients. This is true even if verbal or nonverbal communication is complicated or limited. It is important to support families and friends of dementia patients, and assist them with connecting with their loved one. Engagement with family members is essential, and identifying their needs is important.

Family members may experience guilt and stress, particularly if they are unable to care for the patients themselves. They may not understand what is happening to the patient, may misinterpret the patient’s behaviors, and may be unsure of what to say or do with the patient. The uncertainties of family members can lead to deterioration in relationships, which negatively affects the family and the patient. Staff can help maintain these relationships by providing the family with information about the disease process, giving reassurance, validation, and facilitating the communication between family members and the patient (Mendes, 2015).

Assisting the Family to Communicate

One of the most difficult experiences of a family member of a person with dementia is observing the

deterioration that occurs, and the effects this can have on relationships. Some key strategies for families to communicate with their loved ones include:

Mendes, 2015

Clear Language

When communicating with a dementia patient, the language should be clear, concrete, and considered. Be aware of communication that sounds patronizing.

Use Closed-Ended Questions

Open-ended questions, or communication that requires many choices for responses may cause confusion and a sense of being overwhelmed. Answers that require a “yes” or “no”, or a limit to two choices can assist the patient in communicating.

Active Listening

Verbal communication with a dementia patient may not always make sense. It is important to allow the patient to take his or her time and process his or her thoughts. Listening closely and with patience, rather than trying to fill in gaps for the patient, can assist in gaining the meaning behind the words.

Watch Nonverbal Communication

It is important for a family member to be aware of his or her nonverbal cues, as the patient with dementia will be sensitive. This can cause anxiety, frustration, or even anger with the patient.

Discover the Patient's Perspective

The patient with dementia can perceive a very different reality. It is important for the family member to try and see the world through the patient's perspective, rather than argue about what the patient is presenting.

Activity and Silence

Some family members may feel that verbal conversation is always necessary. Performing activities together in silence can create positive and enjoyable experiences for both the family member and the patient.

Deal with Challenging Behaviors

It is important for family members to realize that challenging behaviors, particularly those that are out of the patient's character, are part of the illness. Although difficult, these behaviors should not be taken personally.

Accept the Patient

People change and evolve, and patients with dementia may become a person very different from who they used to be. It is important for family members to accept the person as they are today. Resentment is unhealthy for the relationship and the family.

Caregiver Stress

Stress is a common condition for families of patients with dementia. This is particularly true for those who are or have been caregivers of the dementia patients. This can also occur with nurses and other staff who are caregivers for patients with dementia. There are common indicators that caregiver stress is occurring (Alzheimer's Association, 2012).

- **Denial:** The caregiver may deny the diagnosis or the effects of the disease on the patient.
- **Anger:** The anger can be directed to various places. There may be anger in general, that there is no cure available for their loved one. Anger may also be directed at staff or others, with the feelings of helplessness. Also, anger can be directed at the person with dementia; that they developed this condition and are deteriorating.
- **Social withdrawal:** The caregiver may stop participating in activities that usually give him or her pleasure, or avoid seeing friends.
- **Anxiety:** There is an uncertainty with the future of the patient and family. This can cause anxiety related to the unpredictability of what will happen.
- **Depression:** It is common for caregivers to become depressed. Coping abilities can be impaired as a result of increasing or continued stress.
- **Exhaustion:** Fatigue may occur from the physical and emotional energy used to cope with being a caregiver. This can affect the ability to complete even regular, everyday tasks.
- **Insomnia:** Caregivers often have numerous concerns about the dementia patient, family, and the future. Sleeplessness can occur by constant thoughts of these concerns.
- **Irritability:** Moodiness can occur from the continued effects of stress. Caregiver reactions can trigger negative responses in others, including the dementia patient.
- **Inability to concentrate:** Stress negatively affects the brain's ability to concentrate. This can make even performing simple tasks difficult for the caregiver.
- **Health problems:** Stress can create both psychological and physical problems.

(Alzheimer's Association, 2012).

Responding to Caregiver Stress

It is important to recognize caregiver stress as soon as possible, and provide interventions to assist the caregiver. Some strategies to assist caregivers include:

- **Resources:** Help the caregivers learn what community resources are available to them. For caregivers who are caring for dementia patients in their home, resources may include adult day or respite programs, in-home assistance, and meal delivery services. Provide a list of resources to the caregiver.
- **Education:** Learning about the disease process of Alzheimer's disease or dementia can help the caregiver become better prepared. The caregiver will need to learn new skills and strategies to help them with the person with dementia. Staff should provide educational materials and teaching to these caregivers. There may also be training in their community or available online.
- **Assistance:** Caregivers need to be able to get help. They need to be validated that they do not have to do everything themselves. Support may be available through family and friends, and within the community. Support groups may also be available, which are useful for emotional assistance. If stress becomes overwhelming, professional help should be used.
- **Staying healthy:** The caregiver should get plenty of rest and exercise, and monitor his or her diet. Health promotion is essential for the caregiver.

- **Managing stress:** Physical and emotional problems can arise as a result of ongoing stress. The caregiver should monitor their symptoms, and attempt to manage stress levels. Relaxation techniques, enjoyable activities, and exercise can help decrease stress levels.
- **Acceptance:** The wants and needs of patients with dementia will change. It is important to accept changes as they happen. The caregiver should use support systems to help them.
- **Planning:** It is important to plan ahead. A professional should be consulted to assist with advance directives, wills, financial planning, estate planning, housing and long-term care planning. The dementia patient should be involved whenever possible.
- **Positive affirmation:** Guilt is a common feeling, and the caregiver may feel like he or she is not doing enough for the patient. It is important that they know they are doing the best they can, and are trying to adapt to the changing needs of the patient.
- **Regular provider visits:** The health of the caregiver, physically and mentally, is important. Regular checkups and visits with a healthcare provider are essential. The caregiver should also monitor any symptoms of caregiver stress and address as soon as possible.

(Alzheimer's Association, 2012).

Test Yourself

Match the correct words to the blanks in the sentences:

- A. Resentment
- B. Clear
- C. Depressed

1. When communicating with a dementia patient, the language should be _____, concrete, and considered.
2. _____ is unhealthy for the relationship and the family.
3. It is common for caregivers to become _____.

The correct answer is: 1-B, 2-A, 3-C

Abuse and Neglect

Unfortunately, abuse and neglect can be seen with patients who have Alzheimer's disease or dementia. Common terminology is "elder abuse", but the concepts can be applied to vulnerable populations, regardless of their age. Components of elder abuse include:

- It can encompass the physical, psychological, or sexual abuse, neglect, abandonment, or financial exploitation of the older person by another person, or entity.
- It can occur in any setting, such as the home, a facility, or in the community.
- It occurs in a relationship which has an expectation of trust, and/or when a person is targeted

based on his or her disability.

(National Center of Elder Abuse, 2012).

Physical Abuse

Physical abuse is the use of physical force that may result in pain, physical impairment, or bodily injury (National Center of Elder Abuse, 2012). Forms of physical abuse may include:

- Hitting, slapping, shaking, pushing, kicking, or burning
- Inappropriately using physical restraints or medications
- Forceful feeding
- Physical punishment
- Homicide
- Strangulation and suffocation

Recognize Physical Abuse

The person who is being abused may have specific signs. These include:

- Bruises, lacerations and cuts, punctures, open wounds, burn marks
- Sprains
- Dislocations
- Fractures
- Internal injuries and bleeding
- Patterned injuries
- Physical signs of being restrained or strangled
- Injuries that are in various stages of healing, and have not been treated
- Delay in seeking of medical care
- Laboratory results demonstrating sub-therapeutic medication levels, or values consistent with medication overdose
- Changes in speaking, swallowing, or breathing with a report of strangulation
- The report of the patient of being hit, slapped, kicked, or mistreated

It is important to examine the injuries, and see if the “story” of what happened matches the physical evidence (National Center of Elder Abuse, 2012).

Sexual Abuse

Sexual abuse is considered non-consensual sexual contact of any kind with an older adult. Sexual

abuse is under-reported for many reasons. The victims may not be able to report due to physical and cognitive limitations or other medical conditions. Older victims may also feel ashamed, embarrassed, uncomfortable with discussion sexual subjects, have a fear of losing the perpetrator, or may actually be unaware the conduct is sexual abuse. Professionals may not report abuse because they may believe the perpetrator would harm the other person, may have a fear that they will lose their job, may not believe that older adults can be sexually abused, and may not have the knowledge or where and how to report the incident (National Center of Elder Abuse, 2012).

Definitions of sexual abuse include:

- Any form of unwanted sexual contact
- Sexual contact with a person legally unable to give consent

Forms of sexual abuse include:

- Rape
- Sexual battery
- Sodomy
- Oral copulation
- Unwanted touching
- Trafficking
- Forcing an older adult to view pornography or others engaged in sexual activity
- Voyeurism
- Sexually explicit photographing
- Forcing an elder to remove clothing and be viewed by others
- Inserting fingers into an older adult's rectum or vagina
- Application or insertion of creams, enemas, alcohol wipes, soap, and washcloths when not medically prescribed, to areas such as the inner and outer genital areas

(National Center of Elder Abuse, 2012).

Test Yourself

People suffering from Alzheimer's disease may not report sexual abuse because they feel ashamed, embarrassed, or uncomfortable with discussing sexual subjects, or may actually be unaware the conduct is sexual abuse.

- A. True
- B. False

The correct answer is: A.True

Characteristics

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Although both men and women may be victimized, most victims are women. Sexual abuse by a spouse or family member is often part of a domestic violence pattern. When sexual abuse occurs in a facility, victims typically have significant disabilities. If the assault occurs by a stranger, victims are often selected due to perceived physical vulnerabilities.

Perpetrators can be both men and women, but men are primarily sexual abusers of the elderly. The age of perpetrator is variable, ranging minors to older adults. The perpetrator can be a spouse or intimate partner, a family member, facility staff, a volunteer, a visitor, another resident, an acquaintance, a stranger, or even an online predator. Perpetrators justify their behavior (National Center of Elder Abuse, 2012).

Recognizing Sexual Abuse

The person who is being abused may have specific signs. These include:

- Bruises to mouth, outer arms, chest, abdomen, pelvis, genitals, or inside thighs
- Bite marks
- Difficulty walking or sitting
- Torn, stained, and/or bloody clothing including underwear, bedding, or furnishings
- Unexplained sexually transmitted diseases
- Sudden changes in mood or temperament
- Neglecting personal hygiene
- Substance use or abuse
- Regressive behaviors
- Wearing multiple layers of clothing
- Trying to leave or flee a residence or facility
- Disturbances in sleep
- Recent resistance to certain kinds of activities and care, such as bathing
- Hyper-vigilance
- Avoids being touched, or reacts abruptly when touched
- Avoidance or fear of specific people
- “Coded disclosures” by older adult, which are clues that need to be interpreted (e.g. “Could I be pregnant?” “He says I’m his favorite girl.”)
- The potential offender (family or caregiver) behaves in inappropriate or romantic ways

(National Center of Elder Abuse, 2012).

Psychological Abuse

Psychological abuse is the infliction of pain, anguish, or distress on another, through verbal or

nonverbal acts. It is also described as the systematic perpetration of malicious and explicit non-physical acts against a victim. Psychological abuse can be a pattern of tactics used to create fear and undermine the victim's confidence. It often occurs along with other forms of abuse, and can be used to facilitate the commission of other forms of abuse.

Behaviors associated with psychological abuse can be classified as non-criminal and criminal behaviors. Non-criminal behaviors may include calling the victim names, insulting, giving them the "silent treatment", or playing "mind games. Criminal behaviors may include stalking, pet abuse, vandalism, property destruction, and criminal threats.

Forms of psychological abuse include:

- **Isolation:** this can include giving the "silent treatment", or denying the victim access to money or financial support. This can encompass isolating the victim from family, friends, previously enjoyed activities, and information. Withdrawal of affection, preventing the victim from sleeping, eating, and leaving are other tactics. Lying or making misleading comments with the intention to cause emotional pain may also occur.
- **Threats and intimidation:** this can include harassing the victim or damaging their property. Threats to the victim, such as threats for placing in a nursing home, causing injury or disfigurement, or even killing the victim or loved ones can occur. Threats or actual abuse of the family pet is included.
- **Insensitivity and disrespect:** this can include treating the victim like a servant, verbally insulting, humiliating the other person, intentionally disrespecting or disregarding the cultural or religious values/needs of the adult.
- **Shaming and blaming:** components can include treating an older adult like a child, or false claims that an older person is demented. Other behaviors including blaming the older person for accidents, and willfully undermining an older person's abilities to make decisions, control their own life, and remain independent for personal benefit.

(National Center of Elder Abuse, 2012).

Recognizing Psychological Abuse

The person who is being abused may have specific signs. These include:

- Social isolation, withdrawal
- Demonstrating fear
- Defers in the presence of the suspected abuser
- Crying, shaking, trembling
- May question own capabilities
- Difficulty concentrating
- Increased alcohol or substance use
- Suicidal thoughts and/or suicide attempts
- Disturbed eating and sleeping

- Unanticipated decline in functional abilities
- Depression
- Poor work or volunteer performance
- Non-compliance with medical treatment

(National Center of Elder Abuse, 2012).

Neglect

Neglect is described as the refusal or failure to fulfill any part of a person's obligations or duties to an elder. It may also include failure to provide fiduciary care for an elder, or failure of a service provider to provide necessary care. Neglect may be the result of inaction or poor care provided by caregivers who lack the necessary resources, skills or support. In some circumstances neglect may be a crime. Regardless of the reason, suspected neglect should be reported or referred in order to increase health care and services for the older adult and to trigger an investigation.

Victims of neglect are often frail and dependent on others. They are isolated and unable to report the neglect. The victims are often physically and/or cognitively impaired (National Center of Elder Abuse, 2012).

Other Considerations

Abandonment is the desertion of an older adult by an individual who has assumed responsibility for providing care for the adult, or by a person with physical custody of the adult. Typical situations of abandonment include an older adult who is confused or has dementia and has been left alone for days, is found wandering, or is left in a public place such as a mall or a hospital emergency department.

In addition to neglect, always consider if financial exploitation is occurring or has occurred. An abuser may keep the assets of an elder to protect his or her anticipated inheritance. Assets needed to provide for the needs of the older adult may be gone as a result of the financial exploitation (National Center of Elder Abuse, 2012).

Test Yourself

Which of the following might indicate a sign of psychological abuse:

- A. Development of a pressure ulcer
- B. Defers in the presence of the suspected abuser
- C. Wearing multiple layers of clothing

The correct answer is: B. Defers in the presence of the suspected abuser

Recognizing Neglect

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The person who is being neglected may have specific signs. These include:

- Dehydration and/or malnutrition
- Confusion or delirium
- Poor dentition or decayed teeth
- Matted hair, overgrown nails
- Lice
- Unexplained weight loss
- Pressure ulcer

Signs may also be noted with the caregiver:

- Missing or absent
- Living in significantly better conditions than elder in same residence
- More focused on cost of care than needs of older adult
- Feels overburdened and/or resentful

Conditions of the Environment

The environmental conditions can also provide information about potential neglect. For a residence, these can include:

- Lack of heating or cooling
- Lack of appropriate food
- Poor maintenance of the residence, including unclean or unsafe conditions
- Foul odors
- Infestations of insects and/or vermin
- Lack of assistive devices (e.g., hearing aids, glasses, dentures, mobility aids)

Signs at a facility may include:

- Failure to provide adequate nutrition and fluids
- Lack of safety measures, such as bedrails
- Failure to provide hygiene, mobility, and other needed care
- Failure to notify a responsible party when a significant change has occurred, or if the patient is injured
- Withholding services to punish or discipline the patient
- Ignoring calls for assistance

(National Center of Elder Abuse, 2012).

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Financial Exploitation

Financial exploitation is described as the illegal or improper use of the funds, assets, or property of a vulnerable adult. The exploitation may occur along with physical abuse, neglect, or psychological abuse (known as hybrid financial abuse), or may be a singularity (known as pure financial exploitation).

Forms of financial exploitation include:

- Theft of valuable or cash
- Withdrawals from bank accounts
- Use of credit cards
- Transfer of deeds
- Misuse of a power of attorney
- Misappropriation of income or assets
- Identity theft
- Sale of fraudulent investments (such as pyramid schemes)
- Mail, telephone, Internet, door-to-door, or lottery scams

(National Center of Elder Abuse, 2012)

Recognizing Financial Exploitation

The person who is being financially abused may have specific signs. These include:

- Changes in appearance or personal habits
- Deterioration in general health
- Changes in long time banking or spending patterns
- Signing documents without understanding consequences

Behaviors of the perpetrator can consist of:

- Cashing the victim's check
- Using a credit or debit card without authorization or permission
- Forging the victim's signature
- Coercing or deceiving the victim into signing any document

Other indicators include:

- Unexplained changes in wills or other legal documents
- Increased telephone solicitations for funds
- Missing personal property

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- Funds wired out of country for mysterious reasons
- Missing or redirected mail
- Names added to bank accounts

Interactive Activity

Watch this brief video on the signs of elder abuse, found at:

<https://www.youtube.com/watch?v=dHI5KjfXfiM>

Questions to Ask

When assessing the situation, it is important to ask the patient questions. Phrasing questions appropriately and concentrating on nonverbal behaviors can assist in communicating. It is important to ask questions related to possible abuse privately, in an area where you will not be overheard.

Some questions to ask may include:

- Are you afraid?
- Are you worried?
- Is anyone hurting you?
- Is anyone frightening you?
- Is anyone threatening or intimidating you?
- Are you taking all your medications as prescribed?
- How do the medications make you feel?
- Has anyone done something to you that caused you pain or discomfort?
- I noticed the bruises on your arm. Can you tell me what happened?
- Have you seen your doctor or received medical care?

(National Center of Elder Abuse, 2012)

Interventions

It is important to respond and intervene with suspected abuse. Considerations and prioritization of safety of the victim is essential. It is helpful to remember the mnemonic RAR.

R- Recognize the signs of abuse

A- Ask

R- Report or refer

Reporting includes:

- 911 or law enforcement (if the abuse is life threatening or a possible crime)

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- Adult protective services
- Licensing board (if abuse occurs in a facility)

Referring includes:

- Domestic violence or sexual assault organization
- Aging network agency
- Ombudsman (if abuse is in a facility)

(National Center of Elder Abuse, 2012)

See also the list of resources provided at the end of this course.

Test Yourself

After recognizing potential signs of abuse, the next step is to:

- A. Refer
- B. Ask
- C. Research

The correct answer is: B. Ask.

Case Study: Martha

Martha is a 78 year old female who has early stage Alzheimer's disease. She currently resides at an assisted living facility. One of the staff overhears a conversation between Martha and her daughter. The daughter is telling her mother that she wants to live in Martha's old home. She gets very close to Martha, and tells her that she needs to let her live in the house, or she will kidnap and torture Martha's cat.

What type of abuse is demonstrated? What are your next steps?

Answer:

Martha's daughter is psychologically abusing her. This may not be the only type of abuse that is occurring. The next step is to ask Martha questions, and further investigate for signs of physical abuse or financial exploitation. Martha will need referrals to support agencies, and adult protective services should be involved.

Current Research on Dementia

In 2011 a national effort, the National Alzheimer's Project Act (NAPA), was created for research on Alzheimer's disease and related dementias, including Lewy body dementia, frontotemporal, mixed, and vascular dementias.

The National Plan calls for increased federal funding for dementia research support for patients and families affected by dementia, increased public awareness, and improved data collection and analysis to better understand the impact of dementia.

Clinical studies offer an opportunity to help researchers find better ways to safely detect, treat, or prevent dementias. Clinical studies supported by the National Institutes of Health focus on Alzheimer's disease and related dementias, and are conducted at medical research centers throughout the United States.

For information about clinical studies for Alzheimer's disease and other dementias, check out:

- www.nih.gov/health/clinicaltrials
- www.nia.nih.gov/alzheimers/clinical-trials
- For a comprehensive list of all trials, go to www.clinicaltrials.gov

Conclusion

Patients with Alzheimer's disease and dementia have needs that are sometimes challenging to meet. Cognitive changes can influence the ability of the patient to communicate and care for his or herself independently. Effective communication takes time to develop strong skills such as listening and nonverbal techniques. It is important to be calm, understanding, patient, and reassuring when faced with challenging behaviors, and remember not to take it personally.

The needs of patients with Alzheimer's disease and dementia go beyond meeting the medical requirements. Psychosocial, activity, and dietary needs are just a few that also must be addressed. It is also vital to prevent, recognize, and respond to abuse and neglect of patients with dementia, to promote patient safety.

Relationships with staff, friends, family, and other social contacts can be vital to the person's self-worth and functioning. Family members also require reassurance, encouragement, education, and insight, as they learn to adapt to the changing needs of the dementia patient.

It is important to remember that each individual has unique wants and needs, and the focus must be on the person. Essential components of caring for dementia patients are respect, dignity, and quality of life. Holistic, person centered care takes time and effort, but is well worth it.

Resources

- A listing of clinical trials, sponsored by the National Institutes of Health (NIH), other federal agencies, and private industry: www.ClinicalTrials.gov
- Alzheimer's Association: www.alz.org. There is also a helpline available 24 hours a day, at 800.272.3900
- Alzheimer's Foundation of America: www.alzfdn.org
- Fisher Center for Alzheimer's Research Foundation: www.alzinfo.org
- Keep Memory Alive: www.keepmemoryalive.org
- MedlinePlus, a Service of the NIH and National Library of Medicine: <http://medlineplus.gov>
- National Center on Elder Abuse (NCEA) www.ncea.aoa.gov or www.centeronelderabuse.org

- National Adult Protective Services Association <http://www.napsa-now.org>
- National Domestic Violence Hotline: 1-800-799-SAFE
- National Clearinghouse on Abuse in Later Life (NCALL) <http://www.ncall.us>
- The National Consumer Voice for Quality Long-Term Care <http://theconsumervoice.org>
- National Long-Term Care Ombudsman Resource Center <http://ltcombudsman.org>
- National Institute on Aging: www.nia.nih.gov
- National Institute of Mental Health: www.nimh.nih.gov
- National Institute of Neurological Disorders and Stroke: www.ninds.nih.gov
- U.S. Administration on Aging's Eldercare Locator: www.eldercare.gov

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