Health Literacy and Dementia

Chronic Condition Management

Presented by UIC-CON
Objectives

- Develop a basic understanding of client chronic conditions and evidenced based screening tools used to assess for dementia (cognitive decline) and poor health literacy
- Gain an awareness of strategies for effective consultation of clients with cognitive impairment and/or poor health literacy
- Develop greater empathy and understanding of persons with chronic conditions and poor health literacy
- Identify risks and mitigation strategies to support and manage persons with complex chronic medical, emotional, and behavioral needs
- Develop skills of cultural sensitivity showing an ability to match appropriate interventions and prevention strategies with appropriate chronically ill populations, allowing transition coordinators to understand and intervene as an advocate
**Health Literacy**

- **Definition:** Health literacy is the ability to read, understand and effectively use basic medical instructions and information. Low health literacy can affect anyone of any age, ethnicity, background, or education level.

- **According to the American Medical Association,** poor health literacy is "a stronger predictor of a person's health than age, income, employment status, education level, and race".

Low literacy—what’s it like?

The text in the box on the right, provides basic information about a colonoscopy procedure.

These instructions provide a sense of what it might be like for a person with limited literacy skills to read a handout similar to those usually given to colonoscopy patients. The words are spelled backwards—can you read it?

Your naicisyhp has dednemmocer that you have a ypocsonoloc. Ypocsonoloc is a test for noloc recnac. It sevlovni gnitresni a elbixelf gniweiv epocs into your mutcer. You must drink a laiceps diuqil the thgin erofeb the noitanimaxe to naelc out your noloc.
Blood in the stool
Bowel
Colon
Growth
Lesion
Polyp
Rectum
Screening
Tumor

Scope of the Problems experienced by persons with limited literacy skills:

- 26% of patients do not understand when their next appointment was scheduled.
- 42% did not understand instructions to “take medication on an empty stomach”.
- 78% misinterpret warnings on prescription labels.
- 86% could not understand rights and responsibilities section of a Medicaid application.
Persons with limited health literacy can be difficult to identify, but look for the following red flag behaviors and responses that may indicate limited literacy*

**Behaviors**
- Registration forms/Forms that are incomplete or inaccurately completed
- Frequently missed appointments
- Noncompliance with medication regimens
- Lack of follow-through with laboratory tests, imaging tests, or referrals to consultants
- People say they are taking their medication, but laboratory tests or physiological parameters do not change in the expected fashion

**Responses to receiving written information**
- “I forgot my glasses. I’ll read this when I get home.”
- “I forgot my glasses. Can you read this to me?”
- “Let me bring this home so I can discuss it with my children.”

**Responses to questions about medication regimens**
- Unable to name medications
- Unable to explain what medications are for
- Unable to explain timing of medication administration

Because you can’t tell by looking at someone whether he/she has sufficient skills to understand and carry out health care instructions—you should screen clients for health literacy

- Screening can be done with the quick health literacy assessment tool, the “Newest Vital Sign” (NVS). The NVS is a nutrition label that is accompanied by 6 questions and requires 3 minutes for administration!
"The Newest Vital Sign" screening tool

The Newest Vital Sign Assessment

<table>
<thead>
<tr>
<th>Nutrition Facts</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Serving Size</td>
<td>½ cup</td>
</tr>
<tr>
<td>Servings per container</td>
<td>4</td>
</tr>
<tr>
<td>Amount per serving</td>
<td></td>
</tr>
<tr>
<td>Calories</td>
<td>250</td>
</tr>
<tr>
<td>Fat Cal</td>
<td>120</td>
</tr>
<tr>
<td>%DV</td>
<td></td>
</tr>
<tr>
<td>Total Fat</td>
<td>13g</td>
</tr>
<tr>
<td>Sat Fat</td>
<td>9g</td>
</tr>
<tr>
<td>Cholesterol</td>
<td>28mg</td>
</tr>
<tr>
<td>Sodium</td>
<td>55mg</td>
</tr>
<tr>
<td>Total Carbohydrate</td>
<td>30g</td>
</tr>
<tr>
<td>Dietary Fiber</td>
<td>2g</td>
</tr>
<tr>
<td>Sugars</td>
<td>23g</td>
</tr>
<tr>
<td>Protein</td>
<td>4g</td>
</tr>
<tr>
<td></td>
<td>8%</td>
</tr>
</tbody>
</table>

*Percentage Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

Score Sheet for the Newest Vital Sign Questions and Answers

READ TO SUBJECT: This information is on the back of a container of a pint of ice cream.

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer Correct?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. If you eat the entire container, how many calories will you eat?</td>
<td></td>
</tr>
<tr>
<td><strong>Answer</strong>: 1,000 is the only correct answer</td>
<td>yes</td>
</tr>
<tr>
<td>2. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have?</td>
<td>yes</td>
</tr>
<tr>
<td><strong>Answer</strong>: Any of the following is correct: 1 cup (or any amount up to 1 cup), Half the container. Note: if patient answers “two servings,” ask “How much ice cream would that be if you were to measure it into a bowl.”</td>
<td>yes</td>
</tr>
<tr>
<td>3. Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day?</td>
<td>yes</td>
</tr>
<tr>
<td><strong>Answer</strong>: 33 is the only correct answer</td>
<td>yes</td>
</tr>
<tr>
<td>4. If you usually eat 2500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving?</td>
<td>yes</td>
</tr>
<tr>
<td><strong>Answer</strong>: 10% is the only correct answer</td>
<td>yes</td>
</tr>
<tr>
<td>READ TO SUBJECT: Pretend that you are allergic to the following substances: Penicillin, peanuts, latex gloves, and bee stings.</td>
<td></td>
</tr>
<tr>
<td>5. Is it safe for you to eat this ice cream?</td>
<td>yes</td>
</tr>
<tr>
<td><strong>Answer</strong>: No</td>
<td>no</td>
</tr>
<tr>
<td>6. (Ask only if the patient responds “no” to question 5): Why not?</td>
<td></td>
</tr>
<tr>
<td><strong>Answer</strong>: Because it has peanut oil.</td>
<td></td>
</tr>
</tbody>
</table>

**Interpretation**

Score of 0-1 suggests high likelihood (50% or more) of limited literacy
Score of 2-3 indicates the possibility of limited literacy.
Score of 4-6 almost always indicates adequate literacy.
Poll Question

- What percentage of individuals misinterprets warnings on prescriptions labels?
Questions on Health Literacy?
Dementia
Dementia definition

- **Decline in cognition** *(memory, executive function (planning / organization), language, or orientation)* that interferes with everyday function.
- **Permanent loss** of mental abilities caused by damage to brain cells.
- **DSM IV Criteria** for dementia *(Acquired loss of intellectual functions in at least 3 of the following: Memory, Language, Visuo-spatial function, Cognition, Emotion)*.
Dementia cause

- 2 abnormalities in the brain: amyloid plaques and neurofibrillary tangles.
- Amyloid plaques—clumps of a protein called beta amyloid along with degenerating bits of neurons and other cells. Neurofibrillary tangles made up of a protein called tau. Researchers do not know if amyloid plaques and neurofibrillary tangles are harmful or if they are merely side effects of the disease process.
Types of Dementia

- Alzheimer’s disease
- Vascular Dementia (multi-infarct dementia)
- Dementia with Lewy Bodies (DLBD)
- Frontotemporal Dementia (FTD)
  a.k.a. frontal lobe; Pick’s disease one type
- HIV associated Dementia
FACTS:

- Most common form of dementia
  - 4 million people in the United States (One in ten people over the age of 65 - 1 out of 45 by year 2050)
- Nearly half of those over 85 have Alzheimer's disease!
- 80% of population in nursing homes

PRESENTATION:

- Gradual onset and progressive decline over years. (average is 8 years, but progression may occur as short as 3 years or as long as 20 years)
- Alzheimer's disease usually causes a gradual decline in thinking abilities
  
  NOTE: Short term memory loss occurs first and later long-term memory loss

- Must have deficits in at least 2 of the following areas of cognition
  - Memory, Orientation, Judgment and Problem Solving, Community Affairs, Home and Hobbies, Personal Care
  - Eventually nearly all brain functions, including memory, movement, language, judgment, behavior, and abstract thinking are affected

*Early-onset form of the disease, usually linked to a specific gene defect, may appear as early as age 30
FACTS:

- Vascular dementia is the second most common type of dementia (up to 20% of all dementias)
- Caused by brain damage from cerebrovascular or cardiovascular problems - usually strokes. In many cases, it may coexist with Alzheimer's disease (“mixed dementia”)

PRESENTATION:

- People maintain their personality and normal levels of emotional responsiveness until the later stages of the disease
- Sudden onset, slower course, more variable
- Focal neurologic signs
- Stepwise progression, “Patchy” loss of abilities
- Gait difficulties, urinary incontinence, Parkinsonian features
- Subcortical dementia (Slowing of thought, Apathy, depression)
- Wander at night
Facts:
- Occurs sporadically, in people with no known family history of the disease
- Typically live 7 years after symptoms begin

PRESENTATION:
- Symptoms overlap with Alzheimer's disease (memory impairment, poor judgment, and confusion).
- More fluctuation in impairment/cognition
- Visual hallucinations **common**, often vivid
- Parkinsonism symptoms (shuffling gait, flexed posture)---**Repeated falls common**
- Particular sensitivity to antipsychotics
Frontotemporal dementia (FTD)

FACTS:
- 2% to 10% of all cases of dementia
- Symptoms appear between the ages of 40 and 65. Usually there is a family history of dementia, suggesting that there is a strong genetic factor in the disease.
- Duration varies, with some patients declining rapidly over 2 to 3 years and others showing only minimal changes for many years. Average 5 to 10 years after diagnosis

PRESENTATION:
- People have problems maintaining normal interactions and following social conventions. They may steal or exhibit impolite and socially inappropriate behavior, and they may neglect their normal responsibilities
- Other common symptoms include loss of speech and language, compulsive or repetitive behavior, increased appetite, and motor problems such as stiffness and balance problems
- Memory loss also may occur, although it typically appears late in the disease
FACTS:
- HIV-associated dementia (HAD) results from infection with the human immunodeficiency virus (HIV) that causes AIDS
- There is no specific treatment for HIV-associated dementia, but AIDS drugs can delay onset of the disease and may help to reduce symptoms

PRESENTATION:
- This leads to a type of dementia that generally includes impaired memory, apathy, social withdrawal, and difficulty concentrating
- People with HIV-associated dementia often develop movement problems as well
Contributing factors to cognitive decline

- Older adults
- Hospitalization
- Co-morbid conditions (multiple and complex DX)
- Medications, polypharmacy
- Change in environment
- Sensory Impairment
Dementia Risk Factors

Risk Factors that can’t be changed:
- Age (50% > age 85)
- Family history
- Downs Syndrome
- Hx of head trauma, assoc. with loss of consciousness

Risk factors you can change:
- Alcohol use
- Atherosclerosis
- Blood pressure
- Cholesterol
- Depression
- Diabetes
- High estrogen levels
- Homocysteine levels
- Smoking
## Stages of Dementia

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild cognitive impairment (MCI)</td>
<td>Mild memory problems but able to perform all their usual activities successfully, without more assistance from others</td>
</tr>
<tr>
<td>Early Stage</td>
<td>Forgetful</td>
</tr>
<tr>
<td>Middle Stage</td>
<td>Increasingly confused</td>
</tr>
<tr>
<td>Late Stage</td>
<td>Still ambulatory, but is very disabled and confused</td>
</tr>
<tr>
<td>End Stage</td>
<td>Person is terminal</td>
</tr>
<tr>
<td>Dementia Symptoms</td>
<td></td>
</tr>
<tr>
<td>-------------------</td>
<td></td>
</tr>
<tr>
<td><strong>Onset</strong></td>
<td>Insidious, over months, years</td>
</tr>
<tr>
<td><strong>Duration</strong></td>
<td>Progressive and irreversible</td>
</tr>
<tr>
<td><strong>Awareness/alertness</strong></td>
<td>Unaffected, normal</td>
</tr>
<tr>
<td><strong>Attention</strong></td>
<td>Usually unaffected</td>
</tr>
<tr>
<td><strong>Orientation/Thinking</strong></td>
<td>Impaired; loss of ability to recognize everyday objects</td>
</tr>
<tr>
<td><strong>Perception</strong></td>
<td>Prone to hallucinations</td>
</tr>
<tr>
<td><strong>Memory</strong></td>
<td>Impaired immediate and short term, inability to learn new information</td>
</tr>
</tbody>
</table>
Rule out medical etiology: A review of systems, past medical history, physical exam, and neurological exam (balance, sensory function, reflexes, etc), brain scans (computed tomographic (CT) scans and magnetic resonance imaging (MRI), etc.), laboratory tests (blood tests, urinalysis, toxicology screen, thyroid tests, etc.). Review medications

Cognitive testing-Neuropsych Evaluation (memory, language skills, math skills, problem solving, executive function, etc.), depression testing

Genetic tests

Rule out psychosocial changes
Note: While memory loss is a common symptom of dementia, memory loss by itself does not mean that a person has dementia.

For diagnosis: Two of five domains must be impaired:
✓ Memory
✓ Language
✓ Visuospatial (Spatial ability /orientation /agnosia)
✓ Handling complex tasks
✓ Judgment/reasoning

Decline from cognitive baseline

Decline in function
Definitive diagnosis at autopsy of brain

**MMSE:**
- 24/30 suggestive of dementia (sens 87%, spec 82%)
- Not sensitive for Mild Cognitive Impairment (MCI)
- Spuriously low in people with low educational level, low SES, poor language skills, illiteracy, impaired vision
- Not sensitive in people with higher educational background

**Clock Drawing Test more accurate**
Clock drawing test

- Normal: Score 10
- Mild Cognitive Impairment (Numbers error and placement of hands): Score 8
- Moderate Cognitive Impairment: Score 4
- Severe Cognitive Impairment
Poll Question

- Which of the following are contributing factors to cognitive decline? (choose all that apply)
### Brief Tests to Detect the Cognitive Impairment of Dementia*

<table>
<thead>
<tr>
<th>Cognitive Tests</th>
<th>Time required (Minutes)</th>
<th>Likelihood of Dementia with Positive Test Compared to Negative Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mini-Mental State Exam</td>
<td>7-10</td>
<td>4-13 times more likely</td>
</tr>
<tr>
<td>Clock Drawing</td>
<td>1-3</td>
<td>4-8 times more likely</td>
</tr>
<tr>
<td>Memory Impairment Screen</td>
<td>4</td>
<td>15-72 times more likely</td>
</tr>
<tr>
<td>Abbreviated Mental Test</td>
<td>5-7</td>
<td>6-12 times more likely</td>
</tr>
</tbody>
</table>

*Arizona Reynolds Program of Applied Geriatrics, “Don’t Forget Dementia”
# Stages of Dementia & MMSE scores

<table>
<thead>
<tr>
<th>Dementia Stage</th>
<th>MMSE score</th>
<th>Communication skills/ impairments</th>
</tr>
</thead>
</table>
| **Mild Cognitive Impairment (MCI)** | 26-30      | • Problems with concentration/decreased attention span.  
• Starting to have word finding difficulty.  
• **No impairments would be recognized in an interview of person**  
• Usually are aware of problems and may try to hide or compensate. |
| **Mild Dementia**       | 22-26      | • Diminished visual/spatial abilities  
• Inappropriate social cues (e.g. stand too close to person during conversation).  
• Word finding difficulty  
• Lose train of thought in conversation,  
• Repeats oneself  
• **Usually aware of problems and may try to hide or compensate.** |
| **Moderate Dementia**   | 10-21      | • Difficulty following a conversation.  
• **Loss of vocabulary, especially proper nouns.**  
• More word finding difficulty  
• **Word substitution or making up new words**  
• Difficulty following a story or movie.  
• Poor recall  
• Difficulty following directions.  
• Tendency to talk about nothing or ramble. |
| **Severe Dementia**     | 0-9        | • **Tendency to ramble or repeat words.**  
• Increasing loss of vocabulary  
• Difficult to follow anything but simple conversation/instructions.  
• Unable to follow a story or movie  
• Major personality/behavioral changes. |
| **Terminal Dementia**   |            | • **Inability to speak**  
• Difficulty understanding when spoken to  
• Mostly nonverbal communication |
Dementia is incurable – not untreatable

Medications:

- Acetylcholinesterase inhibitor such as donepezil (Aricept), rivastigmine (Exelon), or galantamine (Razadyne): indicated for mild to moderate dementia. Increases acetylocholine in synapses.

- NMDA receptor antagonist: Memantine (Namenda): indicated for moderate to severe dementia and used with ACI. Selective blocks the excitotoxic effects of glutamate while allowing the physiologic transmission for normal cell function.

New Drugs coming:

- Tau related Tx (prevention of tau phosphorylation & aggregation)
- Immunotherapites: clear AB from the brain and most promising are:
  - IV immunoglobule (IVIG) or Gammagard
  - Bapineuzumab (human monoclonal antibody against AB)
  - Solanezumab
Treatment

- **Pharmacological**
  - Cholinesterase inhibitors (ChEI)
  - Antiglutametergic
  - For vascular dementia, medicines to control high blood pressure, high cholesterol, heart disease, and diabetes may be prescribed

- **Non-pharmacologic**
  - Optimize environmental, behavioral, non-pharmacologic interventions
  - Cognitive treatments
Studies suggest people who engage in intellectually stimulating activities, such as social interactions, chess, crossword puzzles, and playing a musical instrument, significantly lower their risk of developing Alzheimer's disease and other forms of dementia.

Other preventive actions include lowering homocysteine (amino acids), lowering cholesterol levels, lowering blood pressure, exercise, education, controlling inflammation, and long-term use of nonsteroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen, naproxen, and similar drugs.
Assess for/treat depression
Assess cause for increased symptoms (caregiver, environmental changes, medications, infection)
Assess for caregiver depression
ID and avoid triggers of negative behavior
- Depression, agitation, aggression, wandering, sleep disturbance, paranoia, anxiety
Redirection
Environmental modification for wandering
Sleep hygiene
TC’s
Appropriate Communication Techniques

- Validate - give value to the person’s behavior
- Emotion - being aware of the emotional content in one’s communication
- Reassure - give assurance that the person is safe
- Distract (activity) - engage the person in a structured activity

- Video
  http://www.youtube.com/watch?v=OWlGLFoWrUo&feature=related
  video of nurse’s correct communication and redirection with patient with dementia
**TCs**

**Appropriate Communication Techniques**

**Do’s**

- Allow for extra time in working with people with dementia
- Reduce environmental distractions that compete for attention when conversing with the patient
- Identify yourself
- Approach from the front, make eye contact, address the person by name, and speak in a calm voice
- Ask one question at a time/ one thought at a time
- Use direct sentences instead of asking questions
- Treat everyone, including those with Dementia, with dignity and respect- do not talk down to the person or talk as if they aren’t there
- Use nonverbal cues and communication
- Disruptive behavior in dementia is usually a form of communication in trying to express unmet needs
Don’ts

- Use little touch as possible, always ask permission to touch
- Avoid use of direct pronouns such as “it”, “he”, “she”
- Avoid verbal testing or questioning beyond the person’s capacity
- Do not argue or insist that the patient accept your reality
- Don’t use reality orientation
- Avoid use of the in-room intercom which may confuse and frighten the patient
Managing ‘Behavioral Symptoms of Dementia’

A downloadable application of an algorithm
3 electronic tools developed:

Web site

www.uic.edu/nursing/bsd

FREE download for:

Android

iOS based mobile devices (Apple ‘App’ store)
Understand the presentation of common behavior symptoms of dementia (BSD)

Discuss an evidence based treatment algorithm for managing persons with BSD

New digital application of the BSD treatment algorithm for managing persons with behavioral symptoms of dementia
5 Sections of App

1. Homepage
2. About page
3. Contact page
4. the full algorithm
5. the documentation & step by step
bsd >
all results for bsd >
8 of 23 >
“Evidenced Based Treatment of bsd”
‘bsd’ App now available on CMS website 😍😍

- CMS’ “National Partnership to Improve Dementia Care in Nursing Homes”

  (go to ‘CMS Dementia Care Advancing Excellence > Individual Tools & How To’s > Behavioral Assessment Treatment Tools >
Develop greater empathy & understanding for persons with dementia

- **ASSESS**: for modifiable risk factors, assess the environment is safe and participant has ability to self manage medications, appointments, caregivers. Assess for changes in cognition.

- **PREVENT**: hospitalizations, changes in environment

**Resources/Services:**

- **Social Worker**: assists the participant with dementia to obtain needed services, arrange supportive services, advocate for participant
- **Community Nurse**: assists participant with dementia and complex chronic disease management in attaining maximum optimal health, minimize contributing factors, and maintaining a safe environment.
Critical incidents: Hospital Stays with dementia

Hospital stays per 1,000 Medicare beneficiaries aged ≥ 65 with selected medical conditions by presence or absence of Alzheimer’s disease and other dementias, 2006.
ABCDF

- Affects other diseases
- Bounce backs (d/c planning)
- Capacity for decision making
- Delirium
- End of life issues

Dementia Summary

- Compassionate, knowledgeable care coordinators can improve the likelihood that persons diagnosed with dementia will obtain the appropriate information to make lifestyle changes, good food choices, and improve their own health risks related to cognitive impairment.

In summary, Transition Coordinators should:

- Have providers verify treatment protocol for participant
- Have participant consult with Gerontologist or Neurologist when ‘red flags’ are present and/or treatment protocol is not effective
- Reassure participant that with adherence to therapy their quality of life is much improved
Questions
Resources

- Alzheimer’s foundation: alzfdn.org
- Alzheimer’s association: www.alz.org/index.asp
- www.alz.org/professionals
- CMS Advancing Excellence: www.nhqualitycampaign.org/star_index.aspx?controls=dementiaCare
- www.johnshopkinshealthalerts.com
- National institute on aging: www.nia.nih.gov/alzheimers/alzheimers-disease-caregiving-resource-list
References

  First published online: September 19, 2007
- Fick, D., Cooper, J.W., Wade, W., Waller, J. Maclean, R., Beers, M.H. *Updating the Beers Criteria for Potentially Inappropriate Medication Use in Older Adults Results of a US Consensus Panel of Experts.*
- www.pogoe.org, Hartford, Portal of Geriatric Online Education.
- www.pogoe.org/productt/20875 HGIN: Geriatric Mental Health Series - "When You Forget That You Forgot" Recognizing and Managing Alzheimer's Type Dementia
- CMS
- Medscape
- CDC cdcinfo@cdc.gov