Section 7

Cognitive Loss CAP

Problem

The cognitive hallmarks of an independent life include the ability to remember recent events and the ability to make safe daily decisions. The aging process may be associated with mild impairment. Otherwise, the decline in cognition is likely the result of other factors such as delirium, a mental health problem, a mass lesion, a stroke, a metabolic condition, or dementia.

Dementia is not a unique disease, but a syndrome. It may be linked to several causes. According to DSM-IV-TR, the dementia syndrome is defined by the presence of three criteria:*

- a short-term memory problem,
- **and** trouble with at least one cognitive function (abstract thought, judgment, orientation, language, behavior, personality change, and so on),
- **and** these troubles have an impact on the performance of daily life activities.

Declining or worsening cognitive abilities threaten personal independence and increase the risk for long-term care facility admission. Whatever the reason for cognitive decline, care based on a proper diagnosis is necessary for proper planning.

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Overall Goals of Care

- Optimize the ability to perform activities of daily living and to live an active social life.
- Prevent further cognitive and physical decline.
- Support safe and independent decision making.

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*The notion of decline and chronicity should also be considered: (1) if there is a decline but without the presence of the three criteria together that are described above, one can talk of cognitive impairment or cognitive loss; (2) if the troubles are not chronic but fluctuating, a delirium is more probably involved.

Cognitive Loss CAP Trigger

This CAP focuses on helping persons with reasonable cognitive skills, characterized by a CPS score of 2 or lower (corresponding to a Mini-Mental State Examination [MMSE] score of 19 or higher), to remain as independent as possible, for as long as possible. It triggers for focused care planning the subgroup of persons who are at higher risk of losing their retained cognitive abilities. These persons will have, or will be at risk of having, a form of dementia. Loss of instrumental or basic activities of daily living (ADL) function, in the absence of a physical illness, should raise

suspicion of emerging cognitive impairment. Therefore, careful observation of a person's performance of these activities over time may provide an important clue to suggest the presence of cognitive decline.

TRIGGERED TO PREVENT DECLINE

This group includes persons who exhibit **both** of the following:

- Cognitive Performance Scale (CPS) score of 0, 1, or 2 (equivalent to a MMSE of 19 or higher), **and**
- The presence of two or more of the following clinical risk factors for cognitive decline:
  - Alzheimer's disease
  - Dementia other than Alzheimer's disease
  - Sometimes or never/rarely able to understand others
  - Sometimes or never/rarely able to make self understood
  - Repetitive daily complaints or concerns
  - Repetitive questions
  - Repetitive daily verbalization that something bad is about to happen
  - Wandering
  - Physically abusive
  - New indications of being easily distracted—this element is not assessed in RAI-HC
  - New episodes of altered perception — this element is not assessed in RAI-HC
  - New episodes of disorganized speech — this element is not assessed in RAI-HC
  - New periods of restlessness — this element is not assessed in RAI-HC
  - New periods of lethargy — this element is not assessed in RAI-HC
  - New indication that mental function varies over the course of the day (sudden change in mental function)
  - Declining cognitive status over the past 90 days (or worsening decision making as compared to status of 90 days ago is different than declining cognitive status over the past 90 days)*
  - Increased care needs over the past 90 days (in P6–CS ask participants to remove "receives more support" in code 2 and tell them to focus on the word "deterioration")
  - Six or fewer months to live

These persons have early indications of cognitive problems and are at a higher risk of declining further in the near future. This group includes about 5% of persons in long-term care facilities, 10% of persons receiving home care, and less than 1% of older adults living independently in the community. In a long-term care facility setting, about 25% of the persons triggered into this group will experience a decline in cognition over a 90-day period (with proportional declines in memory and

independence in daily decision making). The rate of decline in home care is about 16%.

TRIGGERED TO MONITOR FOR RISK OF COGNITIVE DECLINE

This group includes persons who exhibit **both** of the following:

- Cognitive Performance Scale (CPS) score of 0, 1, or 2 (equivalent to a MMSE score of 19 or higher), and
- The presence of **none or only one** of the previously mentioned risk factors for cognitive decline (listed under "Triggered to prevent decline").

These persons tend to decline as they subsequently acquire two or more of the risk factors. **The approach to care for these persons is to observe their performance for the onset of these factors.**

This group includes about 35% of persons in long-term care facilities, 75% of persons receiving home care, and 98% of older adults living independently in the community. In a long-term care home setting, about 13% of the persons triggered into this group will tend to decline in cognitive performance over a 90-day period. The rate of decline in home care tends to be about 10%.

NOT TRIGGERED

Includes all persons with a Cognitive Performance Scale (CPS) score of 3 or higher (equivalent to a MMSE score lower than 19).

This group includes about 60% of persons in long-term care facilities, 15% of persons receiving home care, and 1% of older adults living independently in the community. In both long-term care facility and home care settings, only about 8% of persons in this group tend to experience a decline in cognitive performance over a 90-day period.

Cognitive Loss CAP Guidelines

Initial Diagnostic Workup When There Is No Dementia Diagnosis Present

It is possible for a person to be in the early stages of dementia, even though the CPS score is low. If there is suspicion of cognitive impairment, it is recommended that further evaluation be completed and referrals put in place. In cases where the information provided by the person or family members is unclear, it may be necessary to consult the physician directly.

Persons without a known diagnosis of dementia should be considered for referral to a physician for further assessment when

- The CPS score is 1 or 2 **or** 0 but there is other evidence of cognitive impairment (for example, a recent cognitive loss). In such a case, persons who do not have a proper explanation for their decline in cognition function should have a comprehensive medical evaluation to rule out (or in) treatable reasons for cognitive impairment and to identify optimal medications.
- Other evidence of cognitive impairment includes the symptoms listed in the "clinical risk factors" referenced under the triggers. It might also include reduced performance in instrumental and basic ADLs that is not explained by a physical illness or impairment.

If the need for assistance is still unclear, consult a physician. Review the person's clinical records and most recent interRAI assessments for possible reasons, other

than impaired cognition, that are contributing to this need for assistance in ADLs. These might include

Physiological disorders, for example:

- Musculoskeletal diseases
- Neurological diseases
- Post-trauma conditions

Factors associated with lifestyle and adopted habits, for example:

- Excessive use of alcohol
- Use of psychotropic medications [see Appropriate Medications CAP]
- Household roles (for example, in many relationships, partners may assume responsibilities for specific tasks such as housekeeping and managing finances)

If the need for assistance is still unclear, consult a physician. Even if a reasonable explanation for impaired performance is found, continue to observe for signs of declining cognition or physical performance.

However, all persons with a CPS of 1 or 2 who do not have a proper explanation should have a comprehensive medical evaluation to rule out (or in) treatable reasons for cognitive impairment and to identify optimal medications.

The assessment follow-up may range from a single consultation with a physician to a comprehensive process involving neuropsychological testing, haematologic investigations, and brain imaging.

Look for Reversible Causes of Cognitive Loss

Almost any new medication can have a negative impact on cognition. [See Appropriate Medications CAP.]

Some types of cognitive loss, such as those due to low levels of serum vitamin B12, disorders in calcium metabolism or thyroid function, or excessive use of alcoholic beverages, may be reversible. For those triggered to prevent cognitive decline, review the following clinical risk factors for possible links to subsequent cognitive loss.

Signs of fluctuating cognitive status. Delirium, or acute confusion, is a potentially reversible condition. However, it can result in the wrong impression about the nature of the person's typical or usual cognitive limitation. Improved cognitive performance can be expected in many persons as delirium resolves. [See Delirium CAP.]

For persons with a diagnosis of any dementing disease, assess for signs of declining cognitive performance.

- Caregivers should be asked to identify potentially reversible causes (other than the dementia-causing disease itself) for recent losses in cognitive status. The actions of caregivers and family may overly compensate for a modest decline in function. The goal is to allow the person to make maximal use of retained cognitive abilities in daily life. It would be incorrect to assume that recent loss of this type is not reversible.
- Identifying these changes can heighten caregiver awareness of the person's cognitive and functional limitations, while offering an opportunity to re-engage the person in making decisions and performing

everyday activities of daily life. Knowledge of cognitive decline will help others develop practical expectations of the person's capabilities and aid in designing approaches to maximize the person's involvement in making daily decisions.

Are there behavioral symptoms (for example, wandering or physical abuse of others) that interfere with daily life, care delivery, or activities involvement? [See Behavior CAP.]

- Specific treatments for behavioral problems and treatments for delirium may effectively address these conditions and improve cognitive capabilities. [See Delirium CAP and Behavior CAP.]
- Pain has a negative impact on cognition. Pain in persons with impaired cognition can also cause behavioral problems, irritability, and function loss. [See Pain CAP.]
- Some behavior problems will not be reversible. [See Behavior CAP.] If this is the case, and the behaviors occur daily, another environment for the person might be appropriate. However, in the mild stages of cognitive impairment, the person should be able to make many of his or her own life decisions, including where to live.
- Some behavior problems may pose no threat to the person's safety, health, or activity pattern or the safety of others and do not require intervention. But if there is a temporal relationship between behavior and cognitive decline, consider treating the behavior. The following issues may be considered:
  - Have cognitive skills declined after beginning a behavior management program (for example, psychotropic drugs)?
  - Is the decline due to the treatment program (for example, a side effect of a drug)?
  - Have cognitive skills improved following the onset of a behavioral management program?
  - Has caregiver help strengthened the person's self-performance patterns?

Does the person suffer from symptoms of depression?

- Depressive symptoms may cause a cognitive decline that is mistakenly interpreted as dementia. [See Mood CAP.]

Are there other medical problems?

- Identifying and treating other medical problems may improve cognitive functioning and a person's quality of life. For example, therapy for congestive heart failure or chronic obstructive pulmonary disease may lead to functional and cognitive improvement, while conditions such as chronic liver disease and renal failure can cause or worsen a cognitive loss. These conditions are almost always under a physician's care. Thus, if the person begins to experience a new cognitive loss, discuss with the physician the possibility of a relationship to these conditions or a new or changed treatment for them.

- An increase in pain can lead to decreased involvement in functional activities, and this mistakenly may be assumed to indicate cognitive decline. [See Pain CAP.]

Can the person communicate effectively with others? Many persons suffering from cognitive deficits seem incapable of full meaningful communication. As a result, seemingly incomprehensible behaviors (for example, screaming) may represent a person's only form of communication. [See Communication CAP.] Be certain that the failure to communicate effectively is not due to hearing impairment or a neurological deficit (for example, aphasia).

- Speak with the caregiver and family about the best methods of communicating with the person. Sometimes it will be these individuals who best understand how to make contact with the person; in other instances, they will need help in adopting a new approach for the person who has recently declined.
- Is the person willing or able to engage in meaningful communication?
- Does the caregiver use nonverbal communication techniques (for example, touch, gesture) to encourage the person to respond?

Review the person's medication record for drug(s) that might affect cognition. Consider a discussion with the physician or a referral to a consulting pharmacist to aid in this review.

- Many medications, particularly psychoactive drugs, may cause cognitive decline. [See Appropriate Medications CAP.]
- A person may show a sudden decline in cognitive function because a drug has been either started or stopped. A thorough review of the medication record, including both prescribed and over-the-counter drugs, will help to identify any recent change in drug consumption practice.
- Some medications may be marginally helpful in preventing a decline in cognitive status in some people with Alzheimer's disease. If these medications are not being taken, or have never been tried, discuss this option with the physician.
- Be alert for evidence of chronic or acute alcohol ingestion or the use of street drugs.
- Be alert for the use of herbal remedies or alternative medications the person might be taking.

Continued Involvement in Daily Life

Are there opportunities for independent activity? Decline in one functional area neither signals the need for the caregiver to assume full responsibility in that area nor should it be interpreted as an indication of a definitive decline in other areas. Review information in the assessment while considering the following issues:

- Are there factors that suggest the person can be more involved in his or her care (for example, instances of greater self-performance; wish to do more independently; retained ability to learn; retained control over trunk, limbs, or hands)?
- Can the person participate more in decisions about daily life?

- Does the person retain any cognitive ability that would allow greater involvement in decision making?
- Is the person passive?
- Does the person resist care?
- Are activities broken into manageable subtasks?

What is the extent and rate of change of the person's functional abilities? Functional changes are often the first indicators of cognitive decline and suggest the need to identify reversible causes. [See IADL CAP and ADL CAP.] Consider the following:

- To what extent is the person dependent in locomotion, dressing, and eating?
- Are there problems with standing balance and risk for falls? [See Falls CAP.]
- Could the person be more independent with appropriate cueing or restorative programming?
- Nutritional status and weight loss are associated with decline in physical function and may prevent physical improvement. [See ADL CAP and Undernutrition CAP.]
- Would an appropriate referral prevent further decline?

What is the person's extent of continued involvement in ADLs and daily life? Programs focused on physical and social aspects of the person's life can sometimes lessen the disruptive symptoms of cognitive decline. Consider the following:

- Can adjusting task demands or the environmental circumstances under which tasks are carried out be helpful?
- Are small group programs encouraged?
- Are special environmental stimuli present (for example, directional markers, special lighting, color coding)?
- Do caregivers regularly help the person in ways that permit him or her to maintain or attain the highest level of functioning? For example, are verbal reminders, physical cues, and supervision regularly provided to aid in carrying out ADLs; are ADL tasks presented in segments to give the person enough time to respond to cues; and is assistance provided in a pleasant and encouraging manner?
- Has the person experienced a recent loss of someone close (for example, the death of a spouse, a change in the primary caregiver, a recent move to a more dependent living environment, or decreased visiting by family and friends)?

Is the person experiencing a failure to thrive? There is a point at which the accumulated health and neurological problems of cognitively impaired persons can place them at an elevated risk of complications (for example, pressure ulcers) as well as death. As this disability approaches, review the following:

- Do emotional, social, or environmental factors play key roles in the management of these problems?

- If a person is not eating, to what can it be attributed? Examples include a reversible mood problem, a negative reaction to the physical and social environment in which eating activity occurs, or a neurological deficit such as the loss of hand coordination that might be overcome with specially designed utensils.
- Can an identified problem be corrected through caregiver education, a trial of antidepressant medication, referral to occupational therapy (OT) for training, or a counseling program?
- If a cause cannot be identified, what clinical conditions may be reversible or preventable as death approaches (for example, fecal impaction, pain, and pressure ulcers)? What interventions could prevent, or at least decrease, the likelihood of such complications?

Persons with developmental disabilities. Increasing numbers of persons with developmental disabilities live longer lives. Some may develop dementia as they age. With declining cognition, families and other caregivers may have to adjust the living environment or other aspects of the person's life to help him or her live as independently as possible.

Note that many of the above guidelines also are helpful when care planning for those with a CPS score of 3 or higher.

Additional Resources

Mace N, Morris JN, Lombardo NE, Perls T. 1997. Cognitive loss. In Morris JN, Lipsitz LA, Murphy KM, Belleville-Taylor P, eds. *Quality care in the nursing home*. St. Louis, MO: Mosby.

The Web site maintained by the Alzheimer's Association (www.alz.org) is an excellent resource. It contains much information, including lists of recent articles, books, and videos, a summary of tips for caregivers, and links to many other Web sites (such as www.alzheimer.ca).

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