FACULTY GUIDE

Core Module 10:

Effective Care Transitions to and from Acute Care Hospitals

November 2018

This module was developed under a contract from the U.S. Department of Health and Human Services, Health Resources and Services Administration. Some of the views expressed in this presentation module are solely the opinions of the author(s) and do not necessarily reflect the official policies of the U.S. Department of Health and Human Services or the Health Resources and Services Administration, nor does mention of the department or agency names imply endorsement by the U.S. Government.
Slide 1:

- For persons living with dementia (PLwD), transitions (admission and discharge) between home and the acute care hospital, including the emergency department, can be challenging. This module will address how to facilitate smooth transitions between the home and an acute care hospital. Specifically, this module reviews when persons living with dementia are most at risk for hospitalization and rehospitalization, what information should be provided by persons living with dementia or care partners upon admission, and what information should be provided to them upon discharge.

Slide 3:

- In this module (10), we will examine the issues involved in providing and optimizing continued care as persons living with dementia transition between home and a hospital.
- We will examine when persons living with dementia are at elevated risk of being hospitalized, common causes for hospitalizations and rehospitalizations, and the kind of care and information that will facilitate smooth transitions—for the persons living with dementia, for any care partners, and for all providers.
- We will also address the components of a good discharge plan.
- However, we will not be addressing transitions to non-acute care facilities, such as nursing homes and assisted living and rehabilitation facilities, because the primary focus of these modules is on persons living with dementia who reside at home and are mainly cared for in the primary care setting.

Slide 4:

- Our goal, by the time we finish with this module, is for you to be able to:
- Identify the risks associated with care transitions for persons living with dementia.
- Identify basic post-discharge information needs for persons living with dementia upon hospital discharge.
- List immediate actions that should be in place upon discharge.

Describe how to minimize potential post-discharge setbacks.

Slide 6:

- Transitions are dangerous times. Communication is critical.
- Smooth transitions between home and acute care hospitals require a modest amount of information about persons living with dementia—but require the information immediately.
- Referring organizations/facilities have a responsibility for good communication.

Slide 7:

- Persons living with dementia are at higher risk than those without dementia to experience multiple transitions between home and other care facilities. This module is limited to transitions between home and an acute care hospital.
Slide 8:

- There are many different levels of care for persons living with dementia.
- Many persons living with dementia remain at home as long as possible—relying on either formal services (such as paid home care) or informal care provided by family, friends, neighbors, or other unpaid care partners.
  - They may require emergency medical care in an emergency department or acute care hospital.
  - They may require rehabilitation care in specialized facilities.
- Some persons living with dementia will not be able to remain at home and are transitioned to a nursing home, assisted living facility, or other long-term care facility.
- Hospice care, which will be discussed in Module 12, can be provided at home or in a care facility.

Slide 10:

- Transition has been defined as a physical move from one location to another involving at least one overnight stay.
- Transitional care refers to those actions that are designed to ensure the coordination and continuity of health care as patients transfer between different locations or different levels of care in the same location.
- Transitions between care settings (e.g., home, emergency department, acute care hospital, nursing home or other long-term care facility, hospice) occur frequently for persons living with dementia.
  - The most common transitions for persons living with dementia are between home and hospital or between home and emergency departments.
  - Other transitions involve moves to a rehabilitation facility or long-term care facility; we will not be discussing these in this module.

Slide 11:

- Overall, the number of transitions is greater for persons living with dementia than for those without dementia.
- For persons living with dementia, transitions are most likely to occur during the year of the diagnosis, the year before death, and the year of death.
  - A study found that in the 2 years preceding death, people living with dementia at home had 32 percent more care transitions than did people living at home without dementia. In addition, the average number of transitions was greatest during the final 3 months of life.
  - Another retrospective study found transitions were most likely to occur in the year of the diagnosis and the year before and year of death.
    - More than 60 percent of persons living with dementia were hospitalized during the year in which they were diagnosed with dementia.
    - Persons with dementia who remained living at home had more hospitalizations in the year prior to death and the year of death compared with persons with dementia living in long-term care facilities.
The majority of transitions after a diagnosis of dementia were associated with hospitalizations.

- Study on Medicare decedents found that they had approximately three health care transitions within their last 90 days of life.

Factors that have been associated with hospitalizations include increasing age, use of benzodiazepine or antipsychotic agent, overall poor health, and comorbidities.

Slide 12:

- The Centers for Disease Control and Prevention (CDC) reported that more persons are dying at home than out of the home.
- A study randomly sampled 20 percent of the more than 848,300 fee-for-service Medicare decedents in the years 2000, 2005, and 2009. The study was not limited to persons living with dementia:
  - Throughout the study time, the proportion of deaths occurring in acute care hospitals decreased from 32.6 percent to 24.6 percent from 2000 to 2009, but there was an increased use of the intensive care unit in the last month of life (from 24.3 percent to 29.2 percent).
  - Hospice use at the time of death nearly doubled, from 21.6 percent to 42.2 percent.
  - However, 28.4 percent used hospice for ≤3 days in 2009, indicating that hospice was initiated late.
- A diagnosis of dementia is associated with earlier times to first nursing facility use and earlier times to death compared with matched persons without a diagnosis of dementia.
- The retrospective Health and Retirement Study was based on data from nearly 16,200 respondents over age 65 who were followed for a decade. The study included approximately 3,400 persons (21 percent) with a diagnosis of dementia.
  - The participants experienced frequent transitions, with more than half (52.2 percent) going home without home care services after a hospital stay.
  - Persons living with dementia were at higher risk for preventable transitions because of comorbid medical conditions and severity of cognitive impairment.

Slide 13:

- Good dementia care stresses continuity, familiarity, and coordinated care, which are all often absent in transitions.
- Persons living with dementia have difficulty processing new information and stimuli. Consequently, transitions represent disruptive situations that can cause anxiety and agitation.
- Any transition can be difficult for both the persons living with dementia and their care partners.
  - Any change in the environment and routine can be difficult and can trigger unanticipated behaviors.
  - Family may not agree on the next steps during these emotional times.
  - Cost and coverage issues vary with circumstances.
  - Medical records and critical information are typically not effectively shared and updated among primary care clinicians and other providers (specialists). Examples include changes in medications, suggestions for behavior management, triggers of behavioral issues, and non-Alzheimer’s dementia behaviors.
In general, older persons visit the emergency department (ED) more than do younger persons, and they are at greater risk of harm from errors in care. Dementia further complicates these episodes. Several stresses add to the stress of medical issues that prompted the ED visit in the first place:

- Long wait times in the ED lead to additional confusion, worry, anxiety, and restlessness.
- Noise, activity, and general chaos of the ED can be overwhelming to persons living with dementia.
- The ED represents a different environment without any of the cues and comforts of home.
- Persons waiting to be cared for in an ED often have minimal contact with the hospital staff.
- Personal care needs, such as food, hydration, and toileting, are often overlooked or neglected, especially with persons unable to recognize and communicate such needs.
- Often, persons living with dementia receive indwelling catheters because of a lack of time to attend to them, or they are restrained because of staff concerns regarding wandering or agitation.

Transitions represent a high risk setting for medical errors, additional patient and family burdens, and medical treatments that are not concordant with persons living with dementia’s desired goals of care. Even planned care transitions or relocations (scheduled procedures or transitions to another facility) for persons living with dementia are associated with an increase in undesirable outcomes—particularly immediately after the transition has been made.

- This increase is because the care partner is often underutilized in care planning and because both the care partner and the persons living with dementia are underprepared for care transitions.
- Support is needed for persons living with dementia and their care partners.
- Providers should help the care partner manage any behavioral and psychological symptoms of dementia that arise because of transitions.

Successful transitions involving persons living with dementia require more time, information, and resources than do those for persons without dementia. Whenever possible, it is recommended to prepare persons living with dementia for the transition, to minimize fear, confusion, and other behavioral symptoms.

Optimal transitions require getting the right information to the right people in a timely way.

Depending upon the stage and type of dementia, not all persons living with dementia who have been admitted to an ED or hospital are immediately identified as persons living with dementia. This can occur if the care partner is missing or there is no care partner, or because of a lack of communication between the ED and the primary clinician.

A retrospective study of nearly 1,260 patients hospitalized for hip fracture, of whom 383 (28.1 percent) had dementia, reported higher 12-month mortality and less functional recovery with
increasing severity of dementia. Specifically, compared with patients with preserved cognitive functioning, persons with severe or advanced dementia had:
  - A significantly lower probability of functional recovery at discharge (P<0.001) or at 6 months’ post-discharge (P=.04).
  - A greater probability of dying within 12 months (P=0.04) of the hospitalization.

Another study reported that hospitalized persons with advanced dementia often receive care that is of limited clinical benefit and often inconsistent with their preferences:
  - Often, the care partner or proxy had stated that the goal of care was to provide comfort.
  - However, these patients had high rates of intravenous antibiotics, radiological exams, and venipunctures.
  - Outcomes were improved for those persons living with dementia when the medical staff consulted with their care partner or proxy, providing counseling and an information booklet to the family along with the post-discharge follow-up.

Persons living with dementia who suffer delirium while in the hospital have a more than twofold increased risk of mortality in the 12 months following discharge than do patients with dementia alone, delirium alone, or neither delirium or dementia.

Slide 16:

- We now will examine transitions between home and an acute care hospital: the reasons for hospitalization, and how to facilitate smooth transitions from home.

Slide 17:

Common reasons for hospitalization for persons living with dementia can include:

- Falls
- Urinary tract and other infections
- Comorbidity management (diabetes, hypertension, cardiovascular concerns)
- Seizures
- Behavioral and psychological symptoms (agitation, sleep disorders, depression)
- Care partner burnout

Risks of rehospitalization include:

- Poor understanding of discharge instructions
- Little or no communication between hospital providers and family/care partner regarding care
- Medication mismanagement
- Mismanagement of medical care
- Care partner lacking understanding regarding dementia and limitations of the capacity of persons living with dementia
- Care partner burnout
- In general, risk factors for rehospitalization include older age, cognitive impairment, and having functional impairments (in activities of daily living)—all factors common to persons living with dementia
- Dementia is rarely documented as a cause for readmission, but it is likely to be a contributing factor.
- However, there are minimal data on all-cause readmissions related to dementia.

**Slide 19:**

The persons living with dementia or any care partners should be able to provide the following information:

- Baseline medical, legal, and health care coverage information about persons living with dementia, including prior medical care and medications
- Contact information for the primary care provider, specialists, and other dementia team members (addressed in detail in Module 9).
- Description of any limitations affecting the capacity of persons living with dementia to make decisions or provide informed consent (addressed in detail in Module 11). It should be noted this may be underestimated by the person or care partner.

Upon admission, or as soon as possible after admission, persons living with dementia and any care partners should be provided with the following information:

- The anticipated duration of the hospital stay
- Any expectations or goals (long- and short-term) with regard to post-discharge
- If the hospitalization (and the underlying need for hospitalization) will affect the level of care required upon discharge
- If the hospitalization will lead to a need for additional care upon discharge, in what way and how much, and what support can be provided to the care partner

**Slide 20:**

- Ask the family to provide familiar touches, such as blankets, photographs, and pajamas.
- Review current routines of persons living with dementia (speaking with either the person or the care partner), and discuss ways of maintaining those routines.
- Inquire about potential triggers of agitation or anxiety, and ask about how they have been managed.
- Obtain any advance directives when the person transitions from home to any other facility.
- Obtain contact information of all primary and specialty providers.
- Obtain care partner contact information. Module 14 addresses issues for persons living with dementia who are hospitalized.

**Slide 22:**

- Facilitating consistent medication management is a vital component of all transitions.
- Persons living with dementia may not be aware of all their medications, vitamins, and supplements:
  - If the person is seeing multiple prescribers, the records of all medications may not be current or up-to-date.
  - Hospital staff will need to verify the list for inaccuracies. That may require them to reach out to the person’s pharmacist.
Comprehensive discharge instructions are needed regarding all medications.

Slide 23:

- A study found the average number of discharge medications for a patient population of persons over age 65 with either a risk for delirium or having a prescription for dementia medication was nearly 15 medications (+6), with up to 3 medication changes while in hospital.
- Research shows that involving a pharmacist to provide follow-up medication review and reconciliation shortly after hospital discharge is associated with fewer hospital readmissions.
- All medication changes instituted in the hospital need to be communicated to the persons living with dementia, their care partners, and the primary care provider:
  - Medication discharge instructions must be clear and comprehensive. They must take into account the health literacy of the care partner and/or the PLwD. In other words, clear and comprehensive does not always mean that the instructions are understood.
  - Persons living with dementia, their care providers, and primary providers need to be properly informed regarding all medications to ensure that the person takes the right medication at the right dose and at the right time.
- Additional information about this can be found in Module 15.

Slide 24:

- Persons living with dementia require continuous care and support when transitioning between hospital and home.
- Hospitals need to include the care partner throughout the entire hospital stay, from admission through discharge. However, many hospitals are not sufficiently equipped to handle dementia on top of the primary admission diagnosis (e.g., broken hip or cardiac event).
- Care partners are often expected to deliver the care for persons living with dementia after hospital discharge, but they are typically overlooked or ignored with regard to any decisions regarding the care.
- Care partners often report that they received no advance information or warning regarding the anticipated discharge and that the discharge had not been coordinated with them:
  - They report they are unprepared for post-discharge medication management.
  - Care partners are required to assume responsibility for post-discharge care but are not provided with guidance and support. They need to be able to interact and communicate with hospital staff, providers, and administration to best advocate for persons living with dementia.
- Care partners are challenged by the need to keep track of all recommendations from the various specialists now involved in the care of persons living with dementia. For example, a person hospitalized because of hip repair will require physical therapy post-discharge, which will need to be integrated into the pre-hospital regimen.
  - Hospital providers can facilitate smoother transitions by helping care partners coordinate the new care requirements:
  - The care partner and hospital providers need to communicate in order to maintain any already established routines, such as managing incontinence by scheduling bathroom times.
Many hospital providers and staff may be involved with the care of persons living with dementia. Therefore, it is difficult to consistently maintain established routines.

It is important to assess the care partner’s ability, willingness, and understanding to provide the necessary care needed upon hospital discharge for persons living with dementia. If there are any gaps, it is important to recommend alternatives.

Slide 25:

- In the final segment, we examine optimal discharge planning from an acute setting to the home.

Slide 26:

- Post-transition planning to home should begin shortly after admission to the hospital and should involve prompt follow-up with the primary care provider.
- Home health care or home care may be needed.
- Rapid links to primary care are critical.
- Many persons living with dementia and their families are not prepared for discharge.
- Because of the 30-day re-admission rule, hospitals have a strong incentive to improve transitions.
- A range of governmental and nongovernmental organizations provide services, resources, and support for persons living with dementia and their care partners.

Slide 27:

- Discharge planning can and should start with admission to a hospital. Ideally, persons living with dementia and any care partners should be included in all steps while the person remains in hospital, maintaining good and open communication throughout the entire stay.
- Discharge planning involves thoughtful decisions.
- Discharge plans should include written information on warning signs and symptoms associated with the complaint of persons living with dementia:
  - Home care instructions should be clearly communicated.
  - Information regarding any potential side effects or consequences associated with the direct need for hospitalization should be discussed. This information can encompass signs of delirium as well as possible medication side effects.
  - All medications need oversight and reconciliation.
  - There needs to be a discussion regarding who will be responsible for administering any medications.
  - All providers need to discuss whether or not the medication is appropriate and necessary upon hospital discharge. This discussion is particularly important for antipsychotics and other antidepressant medications prescribed for late-stage dementia.
- The needs of persons living with dementia can change from day to day, not just over months to years. Consequently, discharge plans need to be reevaluated regularly.
- Discharge plans also need to consider the needs, availability, and capability of any care partners to provide the recommended post-discharge care to persons living with dementia. Ideally,
discharge planning should consider the ability of persons living with dementia and any care partners to provide self-care.

- Persons living with dementia and the care partner must be provided with a written copy of the final discharge plan in understandable language, even if the discharge is to a long-term care facility instead of to the home.
- Discharge plans should include information from all members of the hospital care team, such as the geriatrician, psychiatrist, and other therapists.

Slide 28:

- Ideally, discharge plans should be jointly developed by the providers and persons living with dementia and/or the care partners.
- Persons living with dementia (and their care partners) need comprehensive written discharge instructions in plain language.
- Discharge instructions should cover all of the following:
  - Whether any additional care will be required for persons living with dementia; if so, the plan should include what kind of care is required, who will provide the care, and how will the care be scheduled
  - Whether home health services are required, and if so, who will provide it and how will it be scheduled
  - If there are any potential concerns or problems, persons living with dementia and/or the care partner should be on the lookout for what to do about them
  - A review of all medications, vitamins, and supplements recommended for persons living with dementia upon discharge:
    - Plans should include what the medication looks like, how often it should be administered, how it should be administered, when it should be administered, and by whom it should be administered
    - Discharge instructions should include what to do if medication is taken incorrectly
    - Instructions should address possible side effects of medications and how to manage the side effects
  - Discussion of dietary restrictions or changes
  - Instructions identifying possible activities of daily living that may now be difficult for persons living with dementia, or tasks for which the persons may now require assistance (such as bathing, toileting, mobility, transportation)
  - Support services for the family care partners such as individual, family and/or group counseling for assistance in coping and managing over the course of the illness
- Discharge assessment should review a discussion of what to do if persons living with dementia or the care partner are unable to provide the necessary services.

Slide 29:

Before persons living with dementia are discharged, numerous tasks must be completed to facilitate a smooth transition. Various specialties may be involved in providing this information for these tasks, including physicians, nurses, geriatricians, social workers, and other care coordinators.
Nurses can arrange for a home assessment (if appropriate), home health care, or other home care, as needed.

When appropriate, the care partner may need to receive training for new care regimens, such as those involved in medication management or exercises. This should be done prior to the date of discharge.

While persons living with dementia are still in the hospital, it is recommended to schedule a follow-up visit with the primary care provider for after discharge and to address transportation arrangements.

Persons living with dementia and all care partners should be educated about any changes to watch for, especially changes in cognition associated with delirium.

A care coordinator (such as a case manager, social worker, advance practice nurse, or patient navigator) can be recommended if persons living with dementia do not already have one.

Slide 30:

- Home health care involves skilled care provided at home that is aimed to return a person to health.
  - It is initiated after a doctor’s visit or emergency department or hospital stay.
  - It is provided by medical professionals and may include:
    - Skilled nursing care
    - Physical and/or occupational therapy
    - Speech language therapy
    - Social work
    - Pain management
    - Wound care
    - Medication management
  - Such care may be covered by Medicare under the Homebound Requirement
- Home care, which can be out of reach for many care partners or too costly, focuses on sustaining and maintaining the quality of life of persons living with dementia in the home. The aim is to keep the person safe and comfortable:
  - It can—but need not be—initiated after medical events.
  - It need not be provided by medical professionals and is often provided on an informal, unpaid basis by friends or family.
  - Home care services include:
    - Personal grooming (bathing, toileting, getting dressed)
    - Mobility assistance: transferring in/out of bed or shower
    - Medication reminders
    - Behavioral assistance for persons living with dementia—such as grounding, distraction, cues to help manage behavioral and psychological symptoms of dementia
    - Running errands (grocery shopping, picking up prescriptions)

Slide 32:

- It is important for the hospital providers and primary care providers to coordinate care upon admission and discharge of persons living with dementia. However, time limitations, poor
communication processes, and interrupted information feedback loops interfere with good care coordination.

- Primary care providers may not be informed of a hospitalization and may not receive records and medication changes stemming from the hospitalization.
- The clinicians need to have open exchange of patient information in order to help limit post-discharge setbacks.
- Continued and consistent care post-discharge often requires access to necessary support services. Upon discharge, it is important that persons living with dementia (or care partners) are able to access the recommended providers and schedule necessary appointments to provide continued care.
- As with admissions (and throughout a hospital stay), discharges represent potential times of additional anxiety and agitation for both persons living with dementia and the care partners:
  - Persons living with dementia commonly exhibit behavioral changes upon discharge.
  - Care partners can be counseled to return to old pre-hospitalization routines, if possible, and to modify the environment as needed.
- Care partners and persons living with dementia should be educated regarding signs of pain and delirium and what to do in the event these signs appear.
- Individual, family, or group counseling may be recommended for persons living with dementia and care partners to help them deal with the stresses of living with dementia as well as the underlying cause of the hospitalization.
- It is important for primary care providers to maintain open communication with the care partners and other providers throughout these transitional times.

**Slide 33:**

- Numerous models have been proposed to help facilitate optimal transitions across health care settings, but most require additional funding, staffing, and other institutional support.
- These models are based upon principles of good transitional care.
- Many of the models focus on older persons with chronic illness, but they do not necessarily address the needs of persons living with dementia:
  - Care Transitions Intervention
  - Transitional Care Model (TCM)
  - Patient-Centered Medical Home (PCMH)
  - Quality Cost Model of APN Transitional Care
- A CMS Community-based Care Transitions Program (CCTP) was specifically developed for transitions of persons living with dementia.
- In general, the models integrate a care partner into the transition, particularly for older adults.
- Nurses or other health care providers or coaches also assist with the transition.
- In many cases, the approaches help inform the care partner about medication safety, recognition and management of worsening symptoms, and collaborating with the (dementia) care team to develop and implement a new care plan to meet the needs and goals of persons living with dementia.
- Other facets of these models include promoting consistency of providers across the health care settings and good communication between the primary providers at the various settings.
Online and in-person support groups are available for persons with dementia, their care partners, and their families/children:
  - Although they vary in structure, membership, and leadership, support groups offer a forum for learning as well as a positive, safe, and nonjudgmental place to share experiences and discuss concerns.
  - In-person support groups are often led by professionals (often social workers) or trained volunteers.
- Online support groups are widely available and are especially helpful for persons who live in rural areas who do not have in-person groups.
- Many government- and non-government-funded resources are listed in the resource segment of this module.

These items are provided to allow faculty to evaluate what students have learned. The items can be used in several ways including given at the end of the lecture to assess knowledge or as a pre-post test to assess knowledge gain. These items have face validity. Psychometric testing was not conducted on these items.

Answer:
1. d. All of the above

Answer:
2. b. Clear instructions for all medications

Answers:
3. d. All of the above
4. b. Should always involve the care partner