Providing and Discussing a Dementia Diagnosis with Persons Living with Dementia (PLwD) and Their Care Partners

MODULE 4

LIGHT
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GERIATRIC HEALTH TEAM

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Outline

- Benefits of providing early diagnosis
- Providing a diagnosis of dementia
- Discussing the diagnosis

Learning Objectives

After completing this module, you will be able to:

- List discussion points to address with persons who have a dementia diagnosis.
- List discussion points to consider when discussing a dementia diagnosis with care partners.
- Summarize Health Insurance Portability and Accountability Act (HIPAA) rules affecting the disclosure of a diagnosis of dementia to an individual’s family members, friends, or other care partner(s) involved in the care or payment for care of persons living with dementia (PLwD).
- Describe when to refer PLwD to a neurologist, geriatric psychiatrist, neuropsychologist, or a national Alzheimer’s Disease Center.

Key Take Home Messages

- The diagnosis of dementia is provided by members of the health care team in a person-centered manner that helps identify and honor the personhood, life goals, and care preferences of the person living with dementia (PLwD).
- The PLwD is at the center of the care-partnering team.
- It is vital for health care team members to encourage continued meaningful engagement for enhanced quality of life and wellbeing.
- Early diagnosis affords an opportunity for PLwD to develop their individualized care plans based on their care preferences and life goals.
- HIPAA requires that a provider obtain an individual’s informed consent to disclose that individual’s protected health information; a provider can disclose protected health information in specific cases.
- Care partners are valuable members of the health care team whose mental and physical health needs are equally important.

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Medical and Psychosocial Benefits of Providing a Dementia Diagnosis During Early Stages

- Early diagnosis has many benefits. It:
  - Provides an opportunity for early interventions and care (Dubois et al., 2015; Psota, 2015).
  - Allows PLwD to participate in the decision-making process (Grossberg et al., 2010).
  - Gives time to assemble a dementia interprofessional care team (Grossberg et al., 2010).
  - Enables appropriate assessments of PLwD (Grossberg et al., 2010; Lecouturier et al., 2015; Psota, 2015).
  - Enables early initiation of pharmacotherapy (Beusterien et al., 2004; Cummings et al., 2004; Dubois et al, 2014; Geldmacher et al., 2006; Geldmacher et al., 2003; Grossberg et al., 2010).

Potential Cautions for Providing Early Diagnosis

- As with other life-changing diagnoses, early diagnosis is not always welcomed by PLwD and their family members.
- The PLwD and their family members typically do not know what functional and cognitive changes to expect over time or how to respond to these changes to minimize distress, enhance calm, maximize independence, and increase satisfaction. This takes instruction.
- Some cultural groups do not see any benefit to an early diagnosis (Guo et al., 2000; Hinton et al., 2006; Hinton et al., 2005).
  - Dementia is highly stigmatizing.
  - Can lead to disconnection from family and friends
    - Misperception that dementia is contagious
    - Fear of marrying into a family with ‘defective genes’
- Family fears financial obligations and strain.

Legal and Financial Benefits of Providing a Dementia Diagnosis During Earlier Stages

- An early diagnosis gives persons living with dementia and their care partner(s) time to make arrangements or obtain necessary financial and legal assistance (Fisk et al, 2007; Grossberg et al., 2010, Kim et al., 2011):
  - Develop legal documents.
  - Identify a proxy decision-maker.
  - Arrange and mobilize financial resources:
    - If appropriate, apply for Medicare or Medicaid.
    - Arrange for long-term care needs including home and community-based services.

Benefits of Providing a Diagnosis of Middle-Stage Dementia

- Many persons may not receive a diagnosis until they are in the middle stage of dementia.
- There is no research available at this time about benefits of providing a diagnosis during this stage.

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How to Provide a Diagnosis of Dementia: Overview

- Disclosing a diagnosis of dementia is a process that is best accomplished over several visits (Dhedhi et al., 2014; Fish et al., 2007; Grossberg et al., 2010; Holmes & Adler, 2005; Lecouturier et al., 2008; Wald et al., 2003).
  - It may require time to obtain the necessary information needed to make a diagnosis (Fisk et al., 2007; Grossberg et al., 2010).
  - Timing of disclosure should balance the needs and concerns of both the PLwD and their families (Dhedhi et al., 2014).
  - Persons receiving a diagnosis often prefer to have it provided by their primary care provider instead of a specialist (Grossberg et al., 2010; Spiegel et al., 2009). However, an individualized, person-centered approach, consistent with the wishes, knowledge, and personality of the PLwD, is oftentimes the best approach (Dhedhi et al., 2014; Fisk et al., 2007; Grossberg et al., 2010).
  - Include care partners in all discussions, while also being mindful of applicable privacy policies (e.g., HIPAA) (Fisk et al., 2007).

How to Provide the Diagnosis: Expert Panel Recommendations

- 2008 expert panel consensus/recommendations on how to communicate a diagnosis of dementia (Grossberg et al., 2010):
    - Agree that disclosure is a process (Holmes & Adler, 2005; Lecouturier et al., 2008; Wald et al., 2003).
    - Encourage the family and/or care partner(s) to be involved (Grossberg et al., 2010).

Best Practices For Disclosing a Dementia Diagnosis

- Use a private location with sufficient time and no distractions.
- Provide culturally sensitive care and use appropriate language.
- Use proper terminology for the diagnosis such as--“Alzheimer’s disease” or “Lewy body dementia.”
- Emphasize the current capabilities of PLwD and discuss the benefits of healthy lifestyle changes, staying active and engaged in life, and letting family and friends know when help is needed and when it is not.
- Emphasize the pros and cons of medications and realistic expectations for it’s effectiveness. Emphasize non-pharmacological care approaches.
- The healthcare provider should serve as an advocate and a source for encouragement, referrals and resources.
- Provide guidance and realistic expectations for the next 6 months, and schedule follow-up visits for every 3 months or as needed.

Challenges of Providing a Diagnosis of Dementia

- Availability and access to appropriate dementia care services and resources are often a challenge in both urban and rural America.
- Diagnostic criteria have been updated, but guidelines for sharing a diagnosis are outdated (Doody et al., 2001; Gattmann & Seleski, 1999; Grossberg et al., 2010; Lecouturier et al., 2008).
- PLwD differ in their readiness, desire, and capacity for receiving a diagnosis of dementia (Bunn et al., 2012; Dastidar & Odden, 2011; Grossberg et al., 2010).
- Even if PLwD are unwilling to receive their actual diagnosis, providers must still inform them of the presence of illness that will progress and require additional assistance in the future (Grossberg et al., 2010).

Assessing Medical Decision-Making Capacity

- Competency is a legal determination made by a judge in court at the local level (Dastidar & Odden, 2011).
- Capacity is a functional assessment made by a healthcare provider. Capacity encompasses 4 decision-making abilities (Appelbaum & Grisso, 1988; Dastidar & Odden, 2011; Karlawish, 2008):
  - Understanding
  - Appreciation
  - Expressing a choice
  - Rationalization or reasoning

Assessing Medical Decision-Making Capacity (continued)

- As with other major diagnoses, providers need to determine a person's capacity to consider and agree to medical treatments and care options.
- PLwD may have a lower decision-making capacity if they are unaware of their impairments (Cosentino et al., 2011).
- There are numerous tools for assessing capacity (Dastidar & Odden, 2011).
- Providers can use a directed clinical interview or formal capacity assessment tools to determine the capacity of PLwD (Tunzi, 2001).
- If capacity cannot be easily determined, a formal assessment may be required.

Primary Care Provider Barriers to Providing a Diagnosis of Dementia

- Primary care providers are often reluctant to make a diagnosis of Alzheimer’s disease (or another dementia) (Boise et al., 1999; Bunn et al., 2012; Carter et al., 2004; Dubois et al., 2015; Grossberg et al., 2010; Phillips et al., 2012). There are often a few reasons for this:
  - Uncertainty about the need and the utility of the diagnosis.
  - They may not know whether or not it is in the person’s best interest.
  - Fear of the potential harm of a dementia diagnosis (Bunn et al., 2012; Phillips et al., 2012).
- To overcome barriers, providers need to recognize the benefits of disclosure (especially if the diagnosis is early-stage) on progression and quality of life (Bunn et al., 2012).

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Discussing the Diagnosis of Dementia with PLwD

- Discussing a diagnosis of Alzheimer’s disease or other dementias is challenging.
- The primary care provider needs to address PLwD directly, while maintaining eye contact (if culturally appropriate) (NIA, 2016; NIH, 2016).
- The primary care provider needs to assess PLwD, by:
  - Assessing and emphasizing their strengths (Grossberg et al., 2010).
  - Assessing their risk for depression and referring them to pharmacotherapy or psychotherapy if needed.
  - Assessing their risk of attempting/committing suicide (Dubois et al., 2015).
  - Assessing their level of understanding, including sensory impairments that may interfere with dialogue (NIA, 2015).

Discussing the Diagnosis of Dementia With PLwD

- If the PLwD are capable of consent, the primary care provider should include their care partner(s) in discussions (within adherence to applicable privacy (e.g., HIPAA) policies) and document the discussions (Grossberg et al., 2010).
- PLwD will need resources, referrals, written material, and scheduled follow-up visits.
- **Living Beyond Dementia** – This compelling 5-minute video, produced, directed, filmed and edited by individuals living with dementia, shares personal stories about the affect of receiving the diagnosis of dementia and that helpful information and encouragement are needed.

https://daanow.org/an-extraordinary-video-about-dementia/

Discussing the Diagnosis with a PLwD with an Intellectual Disability

- The discussion with a PLwD who has an intellectual disability has to be handled with care.
- Determine that person’s capacity to understand what is dementia.
- Most PLwD with an intellectual disability will understand that something is going on and be receptive to having someone offer an explanation.
- The person may have already said that their “thinker may not be working” (NTG, 2012).
- Try to explain dementia and its consequences in easy to understand language and concepts.
- There are useful aids available to help with this discussion.
- ‘What is Dementia?” is available from www.aadmd.org/ntg.
- “Talking About Dementia: A Guide for Families and Caregivers and Adults with Intellectual Disability” is available from the Seven Hills Foundation (Woonsocket, Rhode Island).

Willingness to Receive a Diagnosis of Dementia

- Many surveys indicate that the majority of persons with or without memory impairments would want to know if they had dementia (Elson, 2006; Fowler et al., 2015a; Fowler et al., 2015b; Oimet et al., 2004; Robinson et al., 2014; Turnbull et al., 2003).
- Greater understanding of the consequences of a such a diagnosis may lessen that desire (Fowler et al., 2015a, 2015b; Robinson et al., 2014; Van den Dungen et al., 2014).
- Persons reluctant to undergo a screening assessment perceive a minimal benefit of screening, and are also less likely to undergo testing for other conditions (Fowler et al., 2015b).

Addressing Denial

- Fear of the consequences associated with dementia can lead to a denial of symptoms (Alzheimer's Association, 2011).
    - Emphasize that some treatable conditions can result in the same symptoms as dementia
- Memory impairment associated with dementia can lead to anosognosia—lack of awareness of impairments (Grossberg et al., 2010).
- Lack of insight is not the same as denial.
- The primary care provider must find a way to inform PLwD and/or their care partner(s) about the diagnosis and its consequences.

Addressing Perceived Negative Attitudes and Misperceptions

- Perceived negative attitudes associated with dementia can prevent PLwD from obtaining a diagnosis (Aminzadeh et al., 2012; Psota, 2015).
- Cultural beliefs or misperceptions can also lead to a resistance or unwillingness to receive a diagnosis of dementia.
- A diagnosis of dementia has considerable impact on the identity of PLwD (Macrae, 2010; Steeman et al., 2007):
  - The effect may differ among ethnicities (Bunn et al., 2012).
  - A diagnosis of dementia oftentimes requires considerable adjustment for PLwD and their care partners (Bunn et al., 2012).

HIPAA Rules and Discussing a Diagnosis of Dementia

- HIPAA provisions dictate when and how to share information about a diagnosis with an individual’s family, relatives, or other care partners.
- Providers must obtain informed consent from PLwD to disclose their protected health information to others.
  - If PLwD refuse to disclose their health information to others, providers can (and should) address the request during subsequent visits.
  - In specific instances, such as when the individual is incapacitated, providers can disclose information despite the absence of consent.
  - Providers must document all of these discussions and decisions.

Discussing the Diagnosis with Care Partners

- A diagnosis of dementia also affects the spouse, family members, and care partners.
- Providers can use the same recommended best practices of disclosing dementia diagnosis as discussed earlier (Grossberg et al., 2010; Lecouturier et al., 2008).
- The interprofessional health care team must monitor the health of care partners as well as the health of the PLwD (Grossberg et al., 2010).
- Care partners need time to adapt to the diagnosis and its consequences, and to develop new norms and a new identity (Bunn et al., 2012).
- The health care team can, and should, provide resources and guidance to care partners.
- The health care team should be cognizant of and sensitive to issues of ethnic, cultural, and racial diversity when discussing the diagnosis.

Addressing Care Partner Needs

- The consequences related to a diagnosis of dementia may affect care partners both medically and psychologically, and substantially reduce their quality of life (Covinsky et al., 2003; Markowitz et al., 2003; Stokes et al., 2014).
- There are also many positive aspects of providing care to a significant other with dementia.
- The health care team should assess the care partner(s) for depression and other stress-related conditions, and provide referrals to appropriate mental health providers in the community if warranted.
- Providers should provide the care partner(s) with sufficient information about the disease, along with resources, as the care partner(s) may be afraid to reach out for assistance (Grossberg et al., 2010).

Effect of Care Partner Health on the Quality of Life (QoL) of a PLwD

- Studies have shown that the care partner(s)' health and quality of life influences the health and QoL of PLwD (Bakker et al., 2014; Black et al., 2012; Orgeta et al., 2015).
- Specifically, research has indicated that increased stress related to caregiving burden negatively affects the QoL of PLwD (Orgeta et al., 2015).
    - Findings from the Resources for Enhancing Alzheimer's Caregiver Health (REACH) studies demonstrate the effectiveness of tailored multi-component interventions for reducing caregiving burden and depressive symptoms in the care partner(s) of PLwD (Gitlin et al., 2003).

When to Utilize Additional Resources

- Some circumstances require referral to a specialist, memory clinic, or other specialty center for additional evaluation (Shinagawa et al., 2016).
- It is best to develop a referral network if possible, to ensure continuum of care from diagnosis to end-of-life palliative care and hospice care.
- Given gaps in the continuum of accessible and affordable care, it is important to include telemedicine options in your network.

Evaluation

1. **When providing a diagnosis of dementia, the physician or other primary care provider should:**
   a. Always use the name of the dementia (e.g., Alzheimer’s disease or Lewy body dementia)
   b. Require that a loved one or other care partner(s) be present
   c. Provide an estimate of how much time the person has before cognitive impairment will likely become debilitating
   d. Avoid medical jargon

Evaluation (continued 1)

2. **When discussing a diagnosis of dementia with a significant other or care partner(s) (within HIPAA rules), the provider should:**
    a. Emphasize the urgent need for appropriate medical treatment
    b. Provide realistic expectations of disease progression over the next 3 to 6 months
    c. Complete the discussion in one meeting
    d. Encourage the care partner(s) to make all of the financial decisions

Evaluation (continued 2)

3. Which of the following accurately explains HIPAA rules?

a. A provider must obtain the individual's informed consent before disclosing any information, unless the individual is incapacitated.

b. A provider must inform an individual that he/she has received information from their loved ones about dementia-related concerns.

c. If a person living with dementia refuses to provide consent to share the diagnosis with others, the provider should not and cannot revisit the issue at future visits.

d. A provider must seek legal guidance before disclosing protected health information if the person is incapacitated.

Evaluation (continued 3)

4. **A referral to a specialist is likely warranted if:**
   a. The person with likely dementia refuses to provide consent to disclose the diagnosis to family
   b. The person with likely dementia is younger than the age of 65
   c. The person with likely dementia refuses medical treatment for the dementia
   d. All of the above

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