Ethics and Capacity Issues

MODULE 11

LAKE ERIE INTEGRATED GERIATRIC HEALTH TEAM

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Outline

- Overview
- Legal and financial considerations
- Capacity considerations
- Ethical considerations
- Elder abuse

Learning Objectives

After reviewing this module, the learner will be able to:

- List legal and financial considerations to discuss with a patient and appropriate care partner(s) upon a diagnosis of dementia.
- Identify domains that are included in a capacity assessment for a person living with dementia.
- Identify ethical issues related to participation in dementia research.
- Recognize signs of elder abuse.

Key Take-Home Messages

- Have a high level of suspicion for elder abuse or neglect.
- Do not underestimate the ability of PLwD to express opinions about their care.
- Older people have the right to take informed risks.
- Primary care providers (PCPs) have an important role in determining a person's decision-making capacity.

Outline

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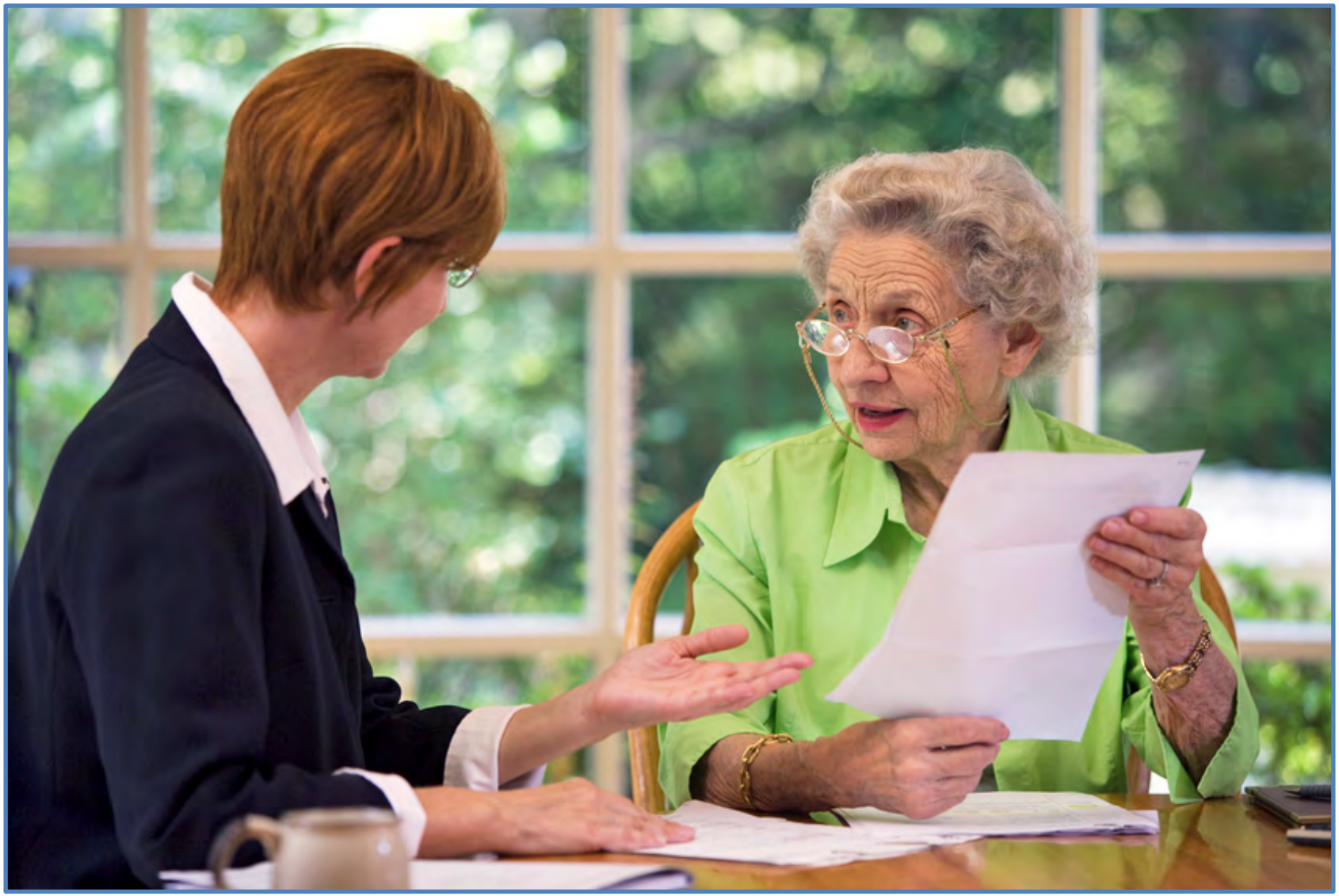
Overview

- Person living with dementia (PLwD), care partner(s), and families face many decisions after receiving a diagnosis of dementia:
  - Legal
  - Financial
  - Medical
  - Ethical

Roles and Responsibilities of Primary and Health Care Providers

- Treatment team: Recommend that PLwD and care partners seek professional help to navigate legal and financial decisions.
- Primary care providers (PCPs): Assess PLwD for capacity (if appropriate); competence determined by judge (Dastidar & Odden, 2011).
- PCPs and other health care providers (HCPs): Have a global understanding of issues facing PLwD and care partners; recommend professional assistance to help address these issues.
- PCPs and other HCPs: Recognize signs and symptoms of elder abuse and report accordingly.



Outline (2)

- Overview
- **Legal and financial considerations**
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Legal and Financial Planning: Overview

- Recommend to begin planning for future as soon as possible so PLwD can participate in decision-making process (Fisk et al., 2007; Grossberg et al., 2010).
  - Communicate health care wishes.
  - Make long-term care arrangements.
  - Make plans for finances and property.
- Identify "proxy" to take over decision-making when PLwD no longer have capacity to make decisions (Kim et al., 2011).

Identifying Nonmedical Professionals for the Dementia Team

- Elder law attorney
- Accountant and/or financial planner
- Geriatric care manager
- Other

Financial Burdens Associated With Dementia Diagnosis

- Direct costs of medications and doctor visits (for dementia and comorbidities)
- Potential future costs (Hurd et al., 2013)
  - Future need for home and community-based services
  - Safety-related expenses
  - Personal care supplies
  - Costs associated with assisted living or nursing home care
- Costs associated with specialty teams (lawyers, accountants, case manager)
- Many PLwD do not have the financial resources to cover these costs.

Financial Considerations: Medicaid

- Average costs for long-term care services in U.S. are substantial; many PLwD are unable to afford costs without financial assistance (Genworth, 2015; Alzheimer's Association, n.d.).
- Medicare coverage is for acute, not chronic, needs.
- PLwD may need to apply for Medicaid (medical assistance) benefits to cover costs; need to understand state-specific rules (Healthcare.gov, n.d.).

Understanding the Necessary Legal Documents

- Standard will
- Living trust
- Advance medical directive
- Living will (Mayo Clinic, 2014)
- Durable powers of attorney
- Research advance directives (Muthappen et al., 2005)
- POLST (physician or provider orders for life-sustaining treatment) or MOLST (medical orders for life-sustaining treatment)

Guardianship

- Not a common occurrence
- In absence of power of attorney, courts appoint guardian (or conservator) if person no longer capable of making own decisions (Karlawish, 2008)
- An alternative to guardianship: supported decision-making
  - The PLwD receives help to make decisions
  - Supported Decision-Making Pilot Project

Outline (3)

- Overview
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Capacity: Overview, Issues

- Assessment of decision-making capacity is needed when a person living with dementia is required to make decisions involving risks.
- Capacity laws differ by state.
- Capacity is functional assessment of 4 abilities: understanding, appreciation, expressing a choice, and rationalization (Dastidar & Odden, 2011; Karlawish, 2008; Lai et al., 2008; Woods & Pratt, 2005).

Capacity Considerations in Dementia

- PCPs are able to make clinical determinations of capacity (Dastidar & Odden, 2011; Karlawish, 2008).
  - Competency is a legal determination (Dastidar & Odden, 2011).
- Memory impairments may influence capacity, which is not static (Mitty, 2009).
- PLwD who lack insight have impaired decision-making capacity (Cosentino et al., 2011).
- Consider capacity to receive a diagnosis (Dastidar & Odden, 2011), and document if PLwD lack capacity (Grossberg et al., 2010).

When To Assess Capacity

- Assess for capacity if any provider or care partner questions the PLwD's decision-making capacity.
- Send for formal assessment by a psychologist or a psychiatrist if capacity is not clear.
- Talk to the PLwD about capacity issues during the course of the illness.

Tools to Assess for Medical Decision-Making Capacity

- Numerous clinical tools can be used to assess medical decision-making capacity (Dastidar & Odden, 2011):
  - McArthur Competence Assessment Tools for Treatment (MacCAT-T) (Grisso et al., 1997)
  - Capacity toC onsent to Treatment Instrument (CCTI) (Marson et al., 1995)
  - Hopemont Capacity Assessment Interview (HCAI) (Edelstein, 1999; Pruchno et al., 1995)

Outline (4)

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Ethical Considerations

- Ethics: human values, what constitutes good and moral life (Whitehouse, 2000)
- 4 primary considerations with regard to decisions concerning PLwD (Strech et al., 2013; Whitehouse, 2000):
  - Beneficence
  - Nonmaleficence
  - Respect for autonomy
  - Privacy and confidentiality

Specific Ethical Concerns in Dementia Care

- Ethical issues arise across all stages of dementia (Whitehouse, 2000).
  - Safety, tracking/monitoring devices, medications
- Care partners face many ethical challenges, particularly dilemma of caring for persons living with dementia versus meeting own needs (Hughes et al., 2002).

Sexual Consent

- Sexual consent issues are typically of greatest concern in long-term care facilities and may also be pertinent to persons living at home.
- Ability to consent to sexual activities is defined by states; it must be continuously reassessed as the person progresses through dementia (Wilkins, 2015).

Ability to Consent to Enroll in Research

- Some PLwD (and their care partners) are willing to participate in clinical studies or trials.
- It is important to discuss the pros and cons of the research and to ensure that the PLwD has the capacity to provide consent.
- A proxy may provide consent—but it should be consistent with the PLwD's desires (Muthappan et al., 2005) and any legal arrangements.

Outline (5)

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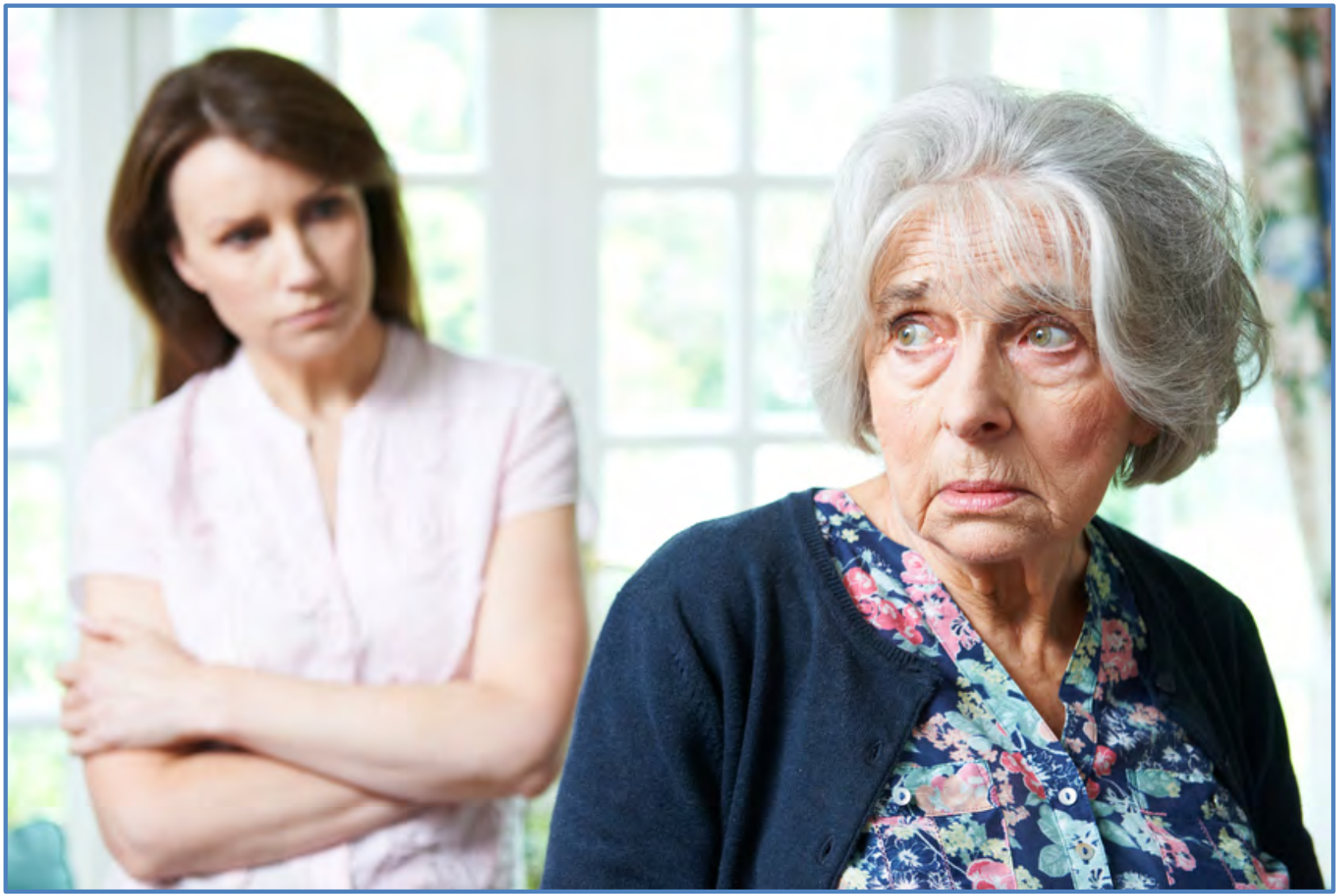
- **Elder abuse**

Elder Abuse: Overview and Prevalence

- Elder abuse can occur in any setting.
  - It includes physical, emotional, sexual abuse, neglect, abandonment, financial exploitation, and fraud (U.S. DoJ, 2015).
  - Definitions differ by state (NCEA 2015; NIA 2015).
  - It is common but underreported (Ahmad & Lachs, 2002; Acierno et al., 2010; Lifespan, 2011).
- According to a recent literature review (Dong et al., 2014):
  - Psychological abuse is the most common form (62% of the elderly).
  - Up to 23% of persons with dementia are victims of physical abuse.
- However, many studies exclude financial abuse from their estimations (Acierno et al., 2009).
  - Financial exploitation may be the most common form (Acierno et al., 2009).



Risk Factors and Likely Perpetrators of Elder Abuse

- Risk factors for elder abuse include low income, unemployment/retirement, lack of social support, and needing assistance with activities of daily living (ADL) (Acierno et al., 2009).
- PLwD are at even greater risk for elder abuse than general population (Cooney et al., 2006; Vande Weerd & Paveza, 2006).
  - Approximately 1 in 2 PLwD experience elder abuse (Cooper et al., 2009),
    often by caregiver (Wiglesorth et al., 2010).
- The majority of perpetrators are family members (Acierno et al., 2009; Cooper et al., 2009; U.S. DoJ, 2009).

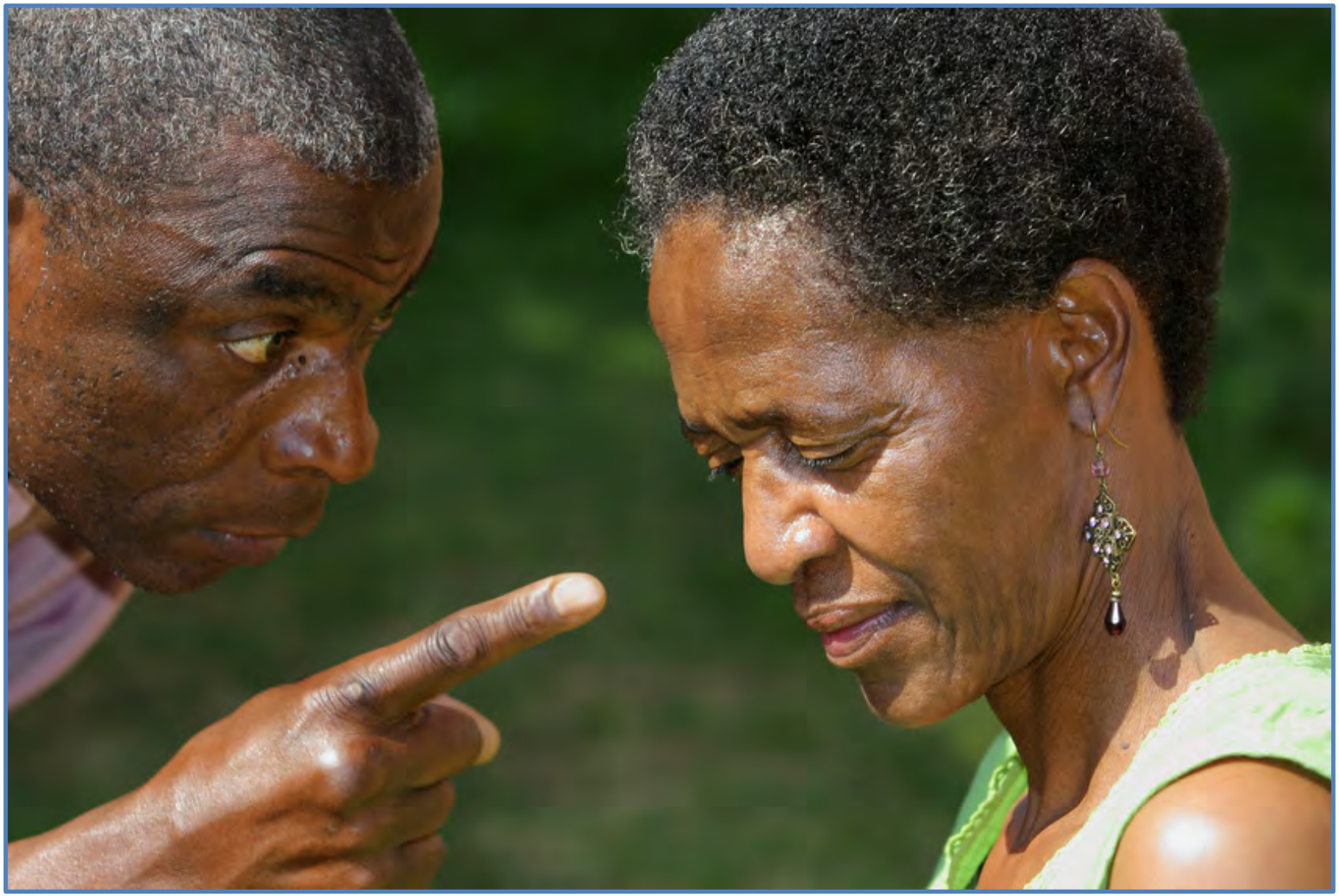
Case Study

- *Mr. Marcus was living alone in his own home. He was in the early stages of Alzheimer's disease (MMSE 24), and his daughter was his primary caregiver. They spoke on the phone daily and she saw him about once a week. He also was receiving help from three young women who lived next-door to him. He had good retirement benefits and Social Security, yet he reported that he never had any money. His daughter found that his bank account was dwindling, and no one could understand how he was spending his money. Mr. Marcus felt that someone in the bank must be stealing money.*

- *After some investigation, it turned out that the "helpful neighbors" were not only helping him get to the supermarket and drug store, but also to the cash machine, several times a week. Mr. Marcus did not recall these episodes* (Budson & Solomon, 2016).

Elder Abuse: Signs and Red Flags

- All clinicians need to be aware of signs of possible elder physical abuse or neglect (Ahmad & Lach, 2002; Bonnell, 2012; Hoover & Polson, 2014; NCEA, 2013; NIA, 2015).
- It is difficult to recognize signs of financial abuse.
- Guidance on abuse recognition and reporting for persons living with dementia and intellectual disability can be obtained from each state's protection and advocacy system (under the Developmental Disabilities Assistance and the Bill of Rights Act of 2000, each state has a protection and advocacy system agency designated by the state's governor), as well as from the state's developmental disabilities authority (state agency).
- Establishment of proper guardianship (of some kind) is needed to keep people safe from such harms

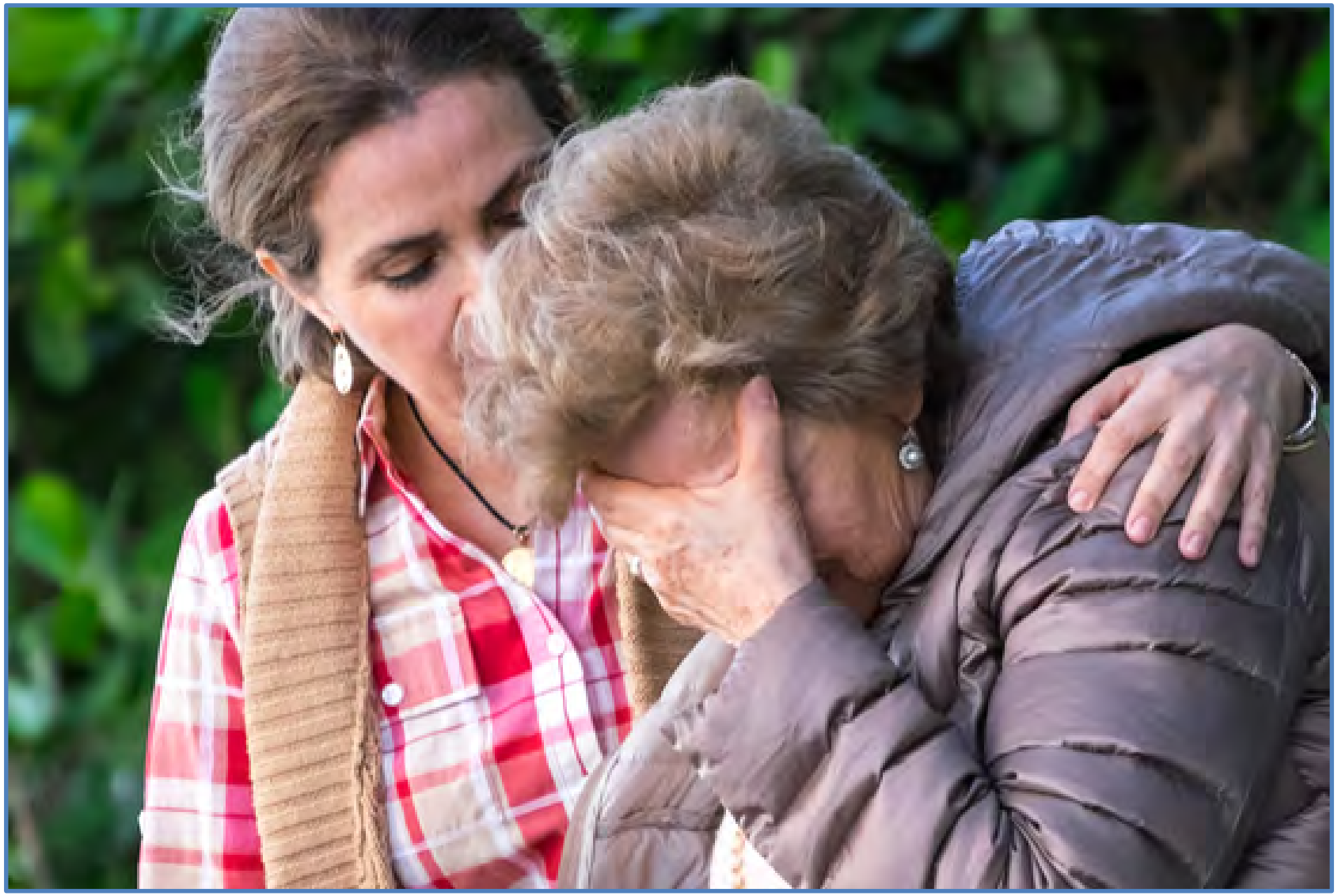


Elder Abuse in Diverse Populations

- Ethnicities and cultural groups may define elder abuse in their own terms.
- Black/African American elders are most vulnerable to financial exploitation by strangers (Beach et al., 2010; Peterson et al., 2014).
- Despite few studies on Hispanic/Latino American elders (NCEA, 2016), they are apparently vulnerable to psychological abuse (Deliema et al., 2002) and reluctant to report abuse to authorities (Laumann et al., 2008).
- Persons in the LGBT community are at increased risk of elder abuse by a caretaker because of homophobia (Frazer, 2009).
- Persons living with dementia and intellectual disability are susceptible to various forms of abuse, including financial, sexual, verbal, and physical, which can occur in a variety of care settings (Jokinen et al., 2013).

Elder Abuse: Barriers to Reporting

- Patient barriers to reporting involve fear of consequences (Selwood et al., 2007).
- Care partner and provider barriers involve lack of knowledge of what constitutes “abuse” (Selwood et al., 2007).
- Reporting requirements vary by state and include requirements of timely reporting (Ahmad & Lachs, 2002; Hoover & Polson, 2014; NCEA, n.d.; NIA, 2015). State laws govern in large part the reporting conditions and requirements when abuse is suspected or observed in PLwD and intellectual disability (Jokinen et al., 2013).
- State Protection and Advocacy System agencies in a state also have the authority to investigate abuse and neglect in any setting where a person with intellectual or developmental disability receives services under the Developmental Disabilities Assistance and the Bill of Rights Act of 2000.



Strategies for Intervening: Elder Abuse

- Ethical dilemmas:
  - What is goal of intervention?
  - How to balance confidentiality versus patient safety?
- Strategies depend on need for involving judicial system (Ahmad & Lachs, 2002).

Summary

- Ethical, legal, and financial considerations are associated with diagnosis of dementia.
- Providers can recommend that PLwD and family/care partners seek professional counsel.
- Objectivity is needed in discussing participation in clinical research.
- All providers must be alert to possibility of elder abuse.

Evaluation

1. **A person with dementia can designate a person of his/her own choosing to make legal or financial decisions on his/her behalf for the time when he/she is no longer able to; this person is called a:**
   a. Guardian
   b. Executor
   c. Proxy
   d. Conservator
2. **All but which of the following abilities is evaluated in a capacity assessment?**
   a. The ability to understand key facts about a choice
   b. The ability to appreciate the benefits and risks of a problem
   c. The ability to make the right decision
   d. The ability to rationalize or reason

Evaluation (continued)

3. Which of the following is not one of the four primary ethical considerations that should guide decision-making regarding participation in dementia research:

a. Beneficence (do good)
b. Nonmaleficence (do no harm)
c. Respect for autonomy
d. Respect for cultural beliefs

4. Which of the following might suggest a case of elder abuse?

a. Dirty clothing or hair
b. Bills not being paid or not paid in a timely manner
c. Unexplained weight loss
d. All of the above

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