

Neglect by Care Giver and Abandonment

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Module Overview

As elders live longer, many have chronic medical needs and need assistance in managing their activities of daily living. Due to these dependency issues, many older adults are in the care of their spouses/partners, adult children or other family members. Others rely on paid caregivers who may not have the qualifications to provide the type of care that is needed. What kind of care should elders expect? What do we expect of those who care for them? In this module we will examine the factors that put an elder at risk, including the history and dynamics of the relationship as well as external and internal issues which affect the individuals involved. We will learn how to recognize caregiver neglect, how to approach both elder and caregiver, and discuss intervention strategies to deal with caregiver neglect.

Learning Objectives

By the end of this module, you will be able to:

- Define caregiver neglect
- Discuss the difference between passive and active neglect
- Describe the risk factors for caregiver neglect
- Identify the indicators of caregiver neglect
- Discuss techniques to engage and interview caregiver
- Discuss the assessment process in caregiver neglect
- Identify types of resources that may help lessen the risk of caregiver neglect

Study Steps

1. Review the content of this section.
2. Complete the case study exercise at the end of the module.
3. Review recommended Acts, Laws and Regulations.
4. Complete the self-evaluation quiz and use the answer key to review your answers.
5. Review the content of any of the questions you answered incorrectly.
6. Plan with your supervisor to complete transfer of learning activities.

Content

Read the module, Neglect by Care Giver and Abandonment

Overview of Caregiver Neglect

As elders live longer, many have chronic medical needs and need assistance in managing their activities of daily living. Due to these dependency issues, many older adults are in the care of their spouses/partners, adult children or other family members. Others rely on paid caregivers who may not have the qualifications to provide the type of care that is needed. What kind of care should elders expect? What do we expect of those who care for them? In this module we will examine the factors that put an elder at risk, including the history and dynamics of the relationship as well as external and internal issues which affect the individuals involved. We will learn how to recognize caregiver neglect, how to approach both elder and caregiver, and discuss intervention strategies to deal with caregiver neglect.

Definition of Caregiver Neglect

According to the National Center on Elder Abuse, caregiver neglect is defined as the refusal or failure to provide life necessities such as food, water, medicine, shelter, hygiene to an elder, including financial responsibilities by someone who has implied or agreed-upon responsibility to an elder. The PA Older Adults Protective Services Act defines caregiver neglect as the failure of a caretaker to provide goods or services essential to avoid a clear and serious threat to physical or mental health (35 P.S. § 10225.103).

Types of Caregiver Neglect

- Active Neglect
 - Willful behavior
 - Intentional withholding of care or necessities
 - Motivated by financial gain (inheritance) or interpersonal conflicts
- Passive Neglect
 - Not intentional
 - Inability to fulfill care giving responsibilities
 - Illness
 - Disability
 - Stress/coping mechanisms
 - Ignorance/lack of information
 - Immaturity
 - Lack of resources

Exercise

Do this alone, or, better yet, do it with a friend. Think of a time when you were a care receiver and had to depend on another person to do things for you. Write down all the feelings that this situation caused in you. Then think of a time when you were the person providing care, whether to a parent or disabled relative. Write down the feelings that this situation caused in you. Be honest, now. Think about it or discuss with your friend: what were the circumstances, relationships, etc that influenced those feelings? When you have completed the two lists, compare them. What conclusions did you reach?

Risk Factors for Caregiver Neglect

- Stress/Burden
 - No desire to be caregiver
 - No inclination to be caregiver
 - Lack of knowledge/information about nature of caregiving responsibilities
 - Lack of knowledge/information about available services and how to access them
 - Lack of understanding of illness/disability of client
 - Unrealistic expectations
 - Lack of appreciation
 - Lack of cooperation
 - Financial hardship
- Individual problems of caregiver (*see Mental Health module for more info*)
 - Mental health/psychiatric problems
 - Depression
 - Cognitive impairment
 - Schizophrenia
 - Bi-polar disorder
 - Personality disorder
 - Physical disability
 - Frail elders caring for disabled adult children
 - Disabled spouses caring for each other
 - Aging caregivers in their 70s caring for parents in their 90s
 - Alcoholism/substance abuse
- History of family relationship problems
 - Dysfunctional relationships
 - Emotional “baggage” carried over the years
 - Sibling rivalry
 - “Good child,” “bad child”
 - Inheritance issues
 - Marital discord
 - Previous infidelity
 - History of domestic violence
- Social isolation of caregiver
 - Lack of family support
 - From adult children
 - From siblings
 - Recent loss
 - Outlived friends and family
- Dependency
 - Financial
 - Caregiver dependent on elder due to unemployment/underemployment or disability
 - Elder dependent on caregiver due to low or lack of income
 - Neither elder nor caregiver able to survive financially alone

- Emotional
 - Lifestyle
 - History
- Physical
 - Bedbound
 - Needs assistance in and out of wheelchair
 - Needs total care with bathing and feeding
- General Issues around dependency
 - Caregiver dependent on client: results in feelings of powerlessness
 - Client dependent on caregiver: results in resentment
 - Codependency issues: can't live together, can't survive alone

Indicators of Caregiver Neglect

- Neglectful Actions by Caregiver
 - Failure to wash or bathe
 - Failure to shop, prepare meals or feed
 - Failure to assist in toileting, administering medications, changing bedpans
 - Mismanagement of finances
 - Eviction or abandonment
 - Lack of supervision
- Questionable Explanations
 - Explanation does not fit with conditions observed
 - Conflicting accounts between elder and caregiver
 - History of similar conditions reported
 - Behavior rationalized as "discipline"
 - Minimization of seriousness of situation by caregiver or elder
- Behavior of Caregiver
 - Fears losing control
 - Is exhausted, overwhelmed, physically incapable of providing care
 - Shows frustration and blaming elder or others for problems
 - Is angry/resentful that others aren't helping
 - Ignores, isolates elder
 - Threatens or intimidates elder
 - Speaks for elder, dominates interview, refuses to let elder be interviewed alone
 - Denies that there is a problem
 - Has poor self control, impulsivity
 - Manipulates elder
 - Overreacts, is defensive
 - Has emotional or financial dependence on elder
 - Conflicts with others in the community, family members, service providers
 - Shows negative attitude toward aging
 - Refuses or resists outside help
 - Has unrealistic expectations of elder/others
 - Has psychiatric or substance abuse history

- Is overly concerned about finances and how money is spent
- Was abused as a child
- Behavior of Elder
 - Has symptoms of depression; appears hopeless, exhibits suicidal ideation
 - Has unrealistic expectations, magical thinking
 - Denies problem despite evidence
 - Has stress-related illnesses, rapid progression of physical deterioration
 - Exhibits fear in front of abuser
 - Is anxious about own performance; fears displeasing caregiver
 - Is dependent on alcohol
 - Is confused about medication and medication management
 - Distrusts others
 - Resists taking medications, being bathed, eating, or allowing caregiver to provide care
 - Has poor personal hygiene, incontinence leading to smell
 - Is excessively demanding on caregiver
 - Abuses caregiver through criticism, emotional outbursts, cursing, hitting, scratching
 - Speaks of caregiver in glowing terms, despite apparent mistreatment
 - Is emotionally numb, withdrawn, detached

Special Considerations: Neglect by Paid Caregivers

- Lack of knowledge/experience in hiring process
- Lack of qualifications and skills of paid caregiver
- Paid caregiver unsupervised
- Paid caregiver isolates elder from family/friends
- Paid caregiver uses “undue influence”
- Elder changes will/bank accounts to benefit paid caregiver

Interviewing and Engagement Skills

- Interviewing the victim
 - Bring your L.O.A.F. (*see Self Neglect module*)
 - Interview elder alone first
 - Show concern
 - Stay positive
 - Do not “badmouth” caregiver
 - Reflect the feelings expressed
 - Use open-ended questions
- Sensitive issues
 - Fear
 - Caregiver anger/reprisal
 - Caregiver abandonment
 - Of getting caregiver into trouble
 - Devil they know is better than devil they don’t know

- Loyalty
 - To spouse
 - To adult child/family member who is caregiver
 - To paid caregiver who elder believes is the only person who is concerned
- Guilt
 - Putting demands on spouse
 - Gender roles
 - Value conflicts
 - Putting demands on adult child/family member
 - “Sandwich generation” conflicts
 - Time and geography concerns
- Shame
 - Depending on caregiver for intimate personal care
 - Loss of independence
- Anger
 - At caregiver for not doing enough
 - At caregiver for not acting appropriately or meeting standards
 - At extended family, other adult children, for not being involved
- Depression
 - Helplessness
 - Hopelessness
- Interviewing the caregiver (spouse, adult child, family member)
 - Planning/Timing
 - Interview victim first whenever possible
 - Interview caregiver/perpetrator as soon as possible after the victim. Try not to allow time for coaching, consultation, or collusion between interviews.
 - Introduction
 - Prepare your tactics
 - Have proper identification
 - Know what resources may be available to assist in the situation
 - Prepare introductory statement
 - Have photo ID/business card
 - Use tact
 - Do not confront or be accusatory
 - Stress your desire to assist the entire family
 - Be diplomatic but perseverant
 - Be friendly. Stay friendly.
 - Speak in a calm manner
 - Use L.O.A.F. techniques to make caregiver comfortable
 - Perspective
 - Ask about a typical day
 - Demands placed on the caregiver

- His/her response to these demands
- Coping abilities
- Manage your own feelings
 - Watch your body language
 - Don't be judgmental
- Provide reality testing
 - Is caregiver in denial?
 - Be prepared with facts and your own observations
- Look for strengths in the caregiver.
- Assess for pathology, depression, and isolation
- Support
 - Pay attention to the caregiver as a person
 - Take an educational approach
 - Teach caregiver about the aging/disability process
 - Refer to support groups
 - Provide literature
 - Provide resources to relieve caregiver
 - Reduce social isolation of caregiver
 - Support the ability of the caregiver to control his/her own behavior
 - Do not collude with intentional behavior
 - Do not accept excuses
 - Give caregiver tools to keep elder safe
- Special considerations for interviewing paid caregiver
 - Stay factual and focused
 - Do detective work at the office

Assessment *(please refer to Self Neglect and Mental Health Issues Modules for further information)*

- Functional
 - Which ADLs (Activities of Daily Living) and IADLs (Instrumental Activities of Daily Living) can elder do independently
 - With which ADLs and IADS does elder need assistance?
 - Which needs are lacking or NOT being met?
 - Does caregiver have the ability, skills, will to meet the elder's needs?
- Cognitive
 - Does client have a cognitive impairment or mental health issue?
 - How does this influence the care he/she is receiving?
 - Does caregiver have a cognitive impairment or mental illness?
 - How does that influence his/her ability to provided needed care?
- Risk
 - Description
 - How does elder see situation?
 - What does elder want done about it?

- What are your observations?
- Who else is involved?
 - Other family members
 - Home health agency /VNA/ Physician
 - Community agency
 - Agency that supervises paid caregiver
- History
 - Length of time situation has existed
 - Why was it referred at this point in time?
- Ability of elder to protect self
 - Physical
 - Cognitive
- Future progression
 - Elder's wishes and ability to make decisions
 - Impact if no action taken

Ethical Considerations *(see Self Neglect module)*

- Autonomy/ Self-Determination
 - Respect elder's wishes unless she/he lacks capacity to make a decision
 - Include elder in plan of intervention
- Beneficence/ Protection
 - Strengthen elder's support system
- Non-maleficence/ Do No Harm
 - Evaluate consequences of intervention
 - Weigh benefits and drawbacks of each
 - Make sure elder is not left at more risk as a result of the intervention

Cultural and Value Considerations *(see Self Neglect module)*

- Is family caregiver "chosen" by cultural values?
- Gender roles
- Social expectations
- Filial expectations
- Marital expectations
- Caregiver expectations
- Beliefs about accepting help from strangers

Interventions and Resources

- In home support for family caregivers
 - Home health aide
 - Visiting nurse
- Support groups
- Respite care
- Training on how to provide appropriate care

- If paid caregiver, contact supervising agency if any

Preventing Caregiver Abuse

- Counsel family members on what to expect before they except the caregiving responsibilities
- Educate elders and family members on how to hire paid caregivers
- Refer families to geriatric care manager

Case Study:

Katherine Myers, age 88, has been admitted to the hospital for complications to diabetes. She is a right leg (above the knee) amputee and is at risk of losing her other leg. Her vision is becoming impaired and she is at risk of losing her sight. Patient presents as tearful and angry, at times confused, stating that her daughter Mary Jackson (with whom she lives) doesn't feed her properly. She states the refrigerator is often locked so that she does not have access to food. She also complains that she is often left alone while her daughter goes out and has a good time. She states she is unhappy in her daughter's home.

Mary Jackson, the client's 62-year-old daughter, is the oldest of 4 siblings. As a child she cared for her 3 younger brothers while her mother worked to support the family. Her mother favored her brothers and was critical of Mary. Her brothers moved to other states and call once in a while. When Mrs. Myers became more frail, Mary felt responsible to take her in. Mary's husband has not been very happy about the situation and has begun staying away from the house, often drinking with friends.

The discharge planner called Mrs. Jackson to discuss Mrs. Myers' condition. Mrs. Jackson became angry and defensive, stating that her mother was never satisfied and that she was an ungrateful, crazy old woman. She later apologized and became tearful. The discharge planner was concerned and referred the case to APS for follow up.

Questions:

1. What are the risk factors for abuse, neglect, and/or exploitation? What are the indicators?
2. How would you engage Mary/ Katherine? What techniques would you use?
3. What assessments are needed to be able to develop an intervention plan?
4. What agencies/ programs/ systems could be of assistance to you?
5. What are the legal/ ethical dilemmas evident in this case? How would you address them?

Abandonment

- Abandonment is the desertion of an older adult. (6 Pa. Code § 15.2). Abandonment involves a caretaker leaving the older adult...so as to no longer act responsible for the older adult. Frequently, in our community, this type of elder abuse is becoming a bit more sophisticated than previously noted.

- Places where you may find an abandoned older adult
 - Local Transportation center (bus or train depot).
 - The older adult likely has confusion or is only minimally oriented to time or place. He or she is not always able to provide any information about themselves or medical conditions.
 - Quite often the person leaves the elder at such a location
 - They will ensure the elder gets into a waiting room area. Then the AP “goes to move the car” or “get the medial ID cards” from the car, at which time they drive away and abandon the elder.
 - Hospital or medical center
 - Quite often the person leaves the elder at such a location
 - They will ensure the elder gets into a waiting room area. Then the AP “goes to move the car” or “get the medial ID cards” from the car, at which time they drive away and abandon the elder.
 - Public Parks
 - A local eatery
 - Drop-in clinics
 - Poorly planned discharge from a facility
- These spots appear to be consideration made by the AP when acting without concern for the older adult.
- Situations that may cause abandonment
 - Poorly planned discharge from a facility
 - Family who leaves on “vacation” and fails to provide for the older adult who without assistance is at risk.
 - Burned out caregiver
 - Incarceration of caregiver

Self-Evaluation Quiz

1. Passive neglect can be caused by caregiver ignorance.

T	F
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2. Being dependent on an elderly parent provides a sense of power to the adult child.

T	F
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3. Overwhelmed caregivers are not responsible for their actions.

T	F
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4. Isolating the elder from family members raises a red flag for neglect by a paid caregiver.

T	F
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5. Providing personal care such as bathing and toileting for a parent may be culturally not acceptable.

T	F
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6. The caregiver should always be interviewed first.

T	F
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7. Asking the caregiver about a typical day is just small talk and does not get to the heart of the problem.

T	F
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8. It is the job of the Protective Service worker to support the caregiver's ability to control his/her own behavior.

T	F
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9. When assessing for caregiver neglect it is important to evaluate if the caregiver has the skills to provide what the elder needs.

T	F
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10. Caregivers who are socially isolated can dedicate more time to their elderly relatives.

T	F
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Transfer of Learning Activities

- Read the case study at the end of the module and answer the questions. Discuss your answers with your supervisor.
- Accompany a more experienced worker on a home visit where there is alleged caregiver neglect. Observe the interview and the interaction between the elder and the caregiver. Share your observations with the worker.
- Go on a home visit with a more experienced worker. Using the strategies you learned in this module, interview the caregiver while your coworker interviews the client. Back at the office, discuss the intervention plan with the coworker.

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<p style="text-align: center;">ANSWER KEY Neglect by Care Giver and Abandonment</p>

1. Passive neglect can be caused by caregiver ignorance. **True.**
2. Being dependent on an elderly parent provides a sense of power to the adult child. **False.** *Dependence causes feelings of powerlessness and can lead to resentment.*
3. Overwhelmed caregivers are not responsible for their actions. **False.** *Caregivers are responsible for their actions even if neglect is passive and unintentional. It is the worker's job to help caregivers remediate the situation through education, support groups, in-home services, etc.*
4. Isolating the elder from family members raises a red flag for neglect by a paid caregiver. **True.**
5. Providing personal care such as bathing and toileting for a parent may be culturally not acceptable. **True.**
6. The caregiver should always be interviewed first. **False.** *Every effort should be made to interview the elder/victim first and separately from the caregiver.*
7. Asking the caregiver about a typical day is just small talk and does not get to the heart of the problem. **False.** *Asking the caregiver about a typical day is a non-threatening way to get information on tasks, expectations, and feelings.*
8. It is the job of the Protective Service worker to support the caregiver's ability to control his/her own behavior. **True.**
9. When assessing for caregiver neglect it is important to evaluate if the caregiver has the skills to provide what the elder needs. **True.**
10. Caregivers who are socially isolated can dedicate more time to their elderly relatives. **False.** *Caregivers who are socially isolated often lack the supports they need to provide adequate care.*