Ethical Issues Related to Self-Neglect Among Older Adults

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Overview of Self-Neglect
Case Study

Esther preferred to die rather than take life-sustaining medications.
Labels: Self-neglect has been given many names.

- Social breakdown in the elderly
- Senile breakdown
- Diogenes syndrome
- Squalor syndrome
- Indirect self-destructive behavior
- Passive suicide
Context: Self-neglect may or may not be seen as an aspect of elder abuse [1].

Levels (An Updated version of Margaret Hudson’s Elder Abuse Definition Taxonomy)

Problem Elder Abuse

Perpetrator
Self Trusted Stranger or
other acquaintance

Setting Domestic Institutional

Form Neglect Abuse

Perpetrator motivation Intentional Unintentional

Locus of harm Physical Psychological Social Financial Sexual
Case Study

#070 was a 79-year-old widow living alone, progressively withdrawing, refusing to leave her apartment, unable to keep up on housework, crying almost constantly because neighbors and friends were all dead and no one was available to help, and resisting eviction by a landlord concerned about her poor housekeeping.
Definition: Self-Neglect is variously defined.

- National Center on Elder Abuse: Elders neglecting their own care, which can lead to illness or injury [2].
- National Adult Protective Services Association: Involves seniors or adults with disabilities who fail to meet their own essential physical, psychological or social needs, which threatens their health, safety and well-being [3].
Definitions: Self Neglect (con’t)

• Consortium for Research in Elder Self-Neglect of Texas (CREST): Inability or unwillingness to provide for oneself the goods and services needed to live safely and independently [4].
Recognition History: Early concern about self-neglect came from physicians and social workers.

- Medical syndrome/public health issue
  - 1960s and 1970s publication of scholarly articles in British and American medical journals

- Social problem
  - 1950s dialogues in select urban centers regarding the growth of a vulnerable older adult population
  - 1960s and 1970s development and spread of adult protective services (APS)
Case Study

Celia made national news living with 127 dogs.
Prevalence and Incidence: Self-neglect is not rare and sometimes is found in association with other aspects of elder abuse.

- The prevalence rate is estimated at 9% [5].
- Incidence is low—7 per 1000 older adults annually or fewer [6].
- Self-neglect occurs 3x more often than physical abuse or caregiver neglect [7].
- Among APS cases, 30-40% of older adults experience multiple elder abuse forms, with self-neglect found to increase the likelihood of financial exploitation [8].
Reporting: Self-neglect may be the most reported aspect of elder abuse to APS, but it is reported less frequently than it occurs.

• At 37.2% self-neglect represents the most common category of substantiated APS reports [9].
• Only one in five instances of self-neglect is reported to APS, with friends and neighbors the most frequent reporters [10].
Case Study

Mary Northern’s situation was considered by the Tennessee Supreme Court.
Risk Factors: There are multiple risk factors that have been found associated with self-neglect [6, 11, 12, 13].

- Advanced age
- Physical illness
- Cognitive or mental disorder
- Living alone
- Few social relations
- Lower income/resources
- Hoarding
- Substance abuse
- Functional limitation
- Lack of concern
- Reluctance to seek/accept help
Signs: There are three domains of indicators for self-neglect that are used to measure the severity of the problem [14].

- Personal hygiene
- Impaired function
- Environmental neglect
Consequences: The effects of self-neglect can be severe for the older adult and costly for society.

• Older adult
  - More self-reported pain [15]
  - Nutritional deficiencies [16]
  - Greater risk of death in the short term [17]

• Society
  - Increased hospitalization and readmissions [18, 19]
  - Greater emergency department utilization [20]
  - Higher risk of nursing home placement [21]
Ethical Concerns in Addressing Self-Neglect
Distinctly Challenging: Perhaps no elder abuse aspect is more subject to ethical debate than self-neglect.

- M. Blenkner (1974): “…among the risks the professional and his agency must face up to…is not only the risk of doing nothing but the risk of intervening, especially when that intervention entails drastic changes in the client’s way of life…” [22, p. 183]

- W.D. Callender (1982): “The role of the protective services worker is fraught with such conflict. The two most prominent examples are the conflicts between community expectations…and the actual expectation of the job holders; and, two, the conflict between the client as decision-maker and surrogates (such as social workers) as decision-makers.” [23, p. 2]

• C.J. Heisler and Q.D. Bolton (2006); “…a significant number of self-neglecters are able to understand their actions and their impact on others. Under rules of criminal responsibility, they may be held accountable for effects of the self-neglect. However, the ability to hold self-neglecters accountable may not assist in remedial efforts with self-neglecters likely due to their resistance.” [25, p. 98]
Self-Neglecter Profile: The characteristics of self-neglecting older adults raise ethical questions about intervention [26].

- Living alone: Is society more responsible for protecting those who have no family or other informal support? (#070)
- Social isolation: Should lifestyle choices take precedence over community standards for housing and the environment? (Celia)
- Mental impairment: What happens when mental impairment is intermittent or relevant only to certain areas of functioning? (Mary)
- Physical health problems: Does failure to comply with traditional medical practice signal the need for protective intervention? (Esther)
• Self-care incapacity: Whose standards of self-capacity apply? (All)

• Failure to recognize limitation: Should self-awareness be an individual expectation under all circumstances? (All)

• Life-threatening incident: Can individuals freely choose substantial risk? (All)
Professional Role: Every professional role confronts its own ethical questions when considering the situation of self-neglecting older adults [26].

- Reporter: Should I report the situation when I don’t believe that reporting will make any positive difference?
- Investigator: How honest am I with the older adult as to the purpose of my visit?
- Service provider: What separates establishing rapport with the older adult in an effort to offer services from cajoling that person into compliance with my service plan?
• Program administrator: How much in the way of staffing should be devoted to situations of repeated self-neglect?

• Community planner: Should community education on self-neglect be initiated when insufficient resources exist locally for addressing the problem?
Ethical Principles: Individual situations of self-neglect can confront ethical principles commonly held by service professionals, like social workers.

- Autonomy
- Beneficence
- Justice
- Privacy
- Universality
- Respect for persons
- Non-maleficence
- Accountability
- Fidelity
- Utility

Esther
Celia
Mary
#070
Guidance for Ethical Decision-Making: Direction for trying to resolve ethical questions regarding self-neglect situations can be found from several sources.

- Consultation with supervisors and colleagues
- Multidisciplinary ethics committees
• Professional/organizational values and principles, e.g.:

National Adult Protective Services Association Ethical Principles [27]

*Guiding Value*: Every action taken by Adult Protective Services must balance the duty to protect the safety of the vulnerable adult with the adult’s right to self-determination.

*Secondary Value*: Older people and people with disabilities who are victims of abuse, exploitation or neglect should be treated with honesty, caring and respect.
Principles

✓ Adults have the right to be safe.
✓ Adults retain all their civil and constitutional rights unless these rights have been restricted by court action.
✓ Adults have the right to make decisions that do not conform to societal norms as long as these decisions do not harm others.
✓ Adults are presumed to have decision-making capacity unless a court adjudicates otherwise.
✓ Adults have the right to accept or refuse services.
Ethical Dilemma: Should health and social service professionals be mandated to report a known or suspected abuse situation?

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| • Report when suspicion of elder abuse exists along with a belief that reporting will produce more good than not reporting for the older adult and family.  
• Report when suspicion of elder abuse exists and the potential harm caused by reporting is less than the harm caused by the situation in question (See “Principles of Adult Protective Services”). | • Encourage Adult Protective Services to establish quality improvement and inspection systems, including regular opportunity for professionals to assess the agency service delivery system.  
• Maintain good relations with Adult Protective Services, working with the agency to address problems in report receipt and investigation. |
**Ethical Dilemma: Should the civil liberties of the abused elder be removed in the interest of providing protection?**

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| • Provide comprehensive assessment of mental stability:  
  ✓ Understanding the individual in the context of lifestyle and capacity to make life-supporting decisions is essential.  
  ✓ Community and Adult Protective Services Social Work input are needed as well as in-patient observations.  
  ✓ Mental stability may exist in some areas and not in others.  
  • Insure that primary responsibility is to the client, and not the community (See “Principles of Adult Protective Services”).  
  • Give the benefit of doubt to the client (See “Principles of Adult Protective Services”).  
  • Guard against ageism in responding to this dilemma.  
  • Make change in the older adult’s lifestyle as slowly as possible, measuring the “cost” of intrusion. | • Offer community education focused on self-determination and individual rights. |
Questions?
References


