PERSPECTIVE SELF-NEGLECT IN OLDER PEOPLE

Self-Neglect in Older People — A Clinical, Social, and Ethical Dilemma

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s. G. is an 87-year-old woman Whith moderate dementia. Her adult daughter, who is her caregiver, contacts her primary care physician (PCP) expressing concern that Ms. G.'s health has worsened since she was last discharged from the hospital. Ms. G. has been hospitalized several times recently, including hospitalizations for heart failure precipitated by not taking her medications, for chest pain, and after a fall at home. She doesn't recall these hospitalizations. Although she reports having no problems with her living situation, Ms. G. is unable to perform most of the instrumental activities of daily living. Her daughter recognizes that it is dangerous for her to live alone but cannot provide the fulltime care she needs. Ms. G. repeatedly refuses a live-in caregiver, even though her daughter is willing to pay for one. Outpatient and

hospital social workers have been unable to persuade Ms. G. to accept additional help. After conferring with Ms. G.'s PCP, an outpatient social worker files an Adult Protective Services (APS) report, citing self-neglect.

Concern about self-neglect is the most common reason for APS maltreatment reports.1 Navigating situations like that of (the fictional) Ms. G. is complicated for older adults and for the family members, clinicians, and social and legal services professionals involved in ensuring their well-being. The term "self-neglect" can inappropriately place blame on people who may be unable to care for themselves or who don't have access to needed resources.1 Self-neglect differs from maltreatment by others and intersects with issues of ageism, mental health, trauma, decision-making capacity, and the

right to self-determination. Autonomy, including the right to take risks, is essential for maintaining dignity and self-esteem. Many people of all ages have beliefs or engage in behaviors that lie outside the mainstream, and self-neglect can be difficult to distinguish from a person exercising the right to make choices that many people would consider unwise or unsafe.

Health care professionals are expected to recognize signs of self-neglect and to intervene, but they face clinical, social, and ethical dilemmas when considering whether, when, and how to take action. Older people with serious psychiatric conditions or advanced dementia (major neurocognitive disorder) are often considered to lack decision-making capacity and generally aren't permitted to make most decisions about their lives. In other situations, such as in cases

Potential risk of self-neglect

Patient is not capable of self-care. There is no caregiver, or an existing caregiver is unable to provide the necessary care. There is no immediate safety risk.

RECOMMENDED ACTIONS

- Monitor for concerning behaviors and safety risks
- Discuss risk and risk mitigation with the patient and family members

Imminent risk of self-neglect

Patient is not capable of self-care. There is no caregiver, or an existing caregiver is unable to provide the necessary care. Patient engages in concerning behavior that poses a substantial safety risk.

RECOMMENDED ACTIONS

- Assess cognitive function, psychological symptoms, and relevant aspects of decisional capacity
- Discuss risk with the patient and family members
- Consider a formal competency assessment
- Report case to APS if there is a high likelihood of harm to the patient or others

Confirmed self-neglect

Patient is not capable of self-care. There is no caregiver, or an existing caregiver is unable to provide the necessary care. Patient has experienced medical or social harm that can reasonably be linked to lack of self-care.

RECOMMENDED ACTIONS

- Assess cognitive function, psychological symptoms, and relevant aspects of decisional capacity
- Consider a formal competency assessment
- Report case to APS
- Discuss APS report with the patient and family members

A Framework for Assessing and Addressing Self-Neglect.

Recommended actions are specific to reporting concerns about self-neglect and shouldn't preclude other appropriate interventions and approaches. APS denotes Adult Protective Services.

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of mild cognitive impairment or early dementia, it can be difficult to determine whether decisions that seem unhealthy or unwise (e.g., refusing medical care, not paying bills, or misusing alcohol) constitute poor judgment or selfneglect. Clinicians are trained to assess a person's capacity for making specific medical decisions, but a formal competency determination, which is beyond the skills of most clinicians, may sometimes be needed.

In the United States, health care professionals are typically mandated to report suspicion of elder maltreatment to APS or other authorities. The specific circumstances requiring reporting vary, but most states require reporting of self-neglect. The process of reporting maltreatment of older people usually includes describing concerns and identifying the people involved. When APS accepts a case for investigation, an investigator collects information to determine whether the claim can be substantiated and works with the "victim" and, potentially, the "perpetrator" to remedy the situation. This approach may not be applicable in cases of self-neglect, however, when the "victim" and "perpetrator" are the same person.

The boundary between behaviors or circumstances that are unconventional but safe and those that are unsafe and require reporting or restrictive action hasn't been clearly delineated. Is "unsafe" defined by evidence of medical consequences (e.g., emergency department [ED] visits, avoidable hospitalizations) or social consequences (e.g., evictions, bankruptcies)? Or are the risks associated with self-neglect in some people (e.g., those who are cognitively impaired, live alone, and refuse help)

high enough to warrant intervention in the absence of evidence of harm? Intervening on the basis of risk alone would result in labeling numerous older people as selfneglecting. This approach might prevent some tragic outcomes, but many people who would never experience harm related to their behavior would be the subject of APS reports.

Labeling a person as self-neglecting can have substantial repercussions (e.g., loss of trust in clinicians, disruptions in relationships), and the need to make these decisions increases the pressure on clinicians caring for patients with complicated needs. In cases of older adults with unmet needs or potentially concerning behavior, clinicians must determine who is at risk (the patient, other people, or both), the level of risk, and whether the onus to address the risk is on the caregiver or the patient.

a way that balances patient autonomy and safety — which involves assessing the patient's cognitive function, psychological symptoms, and decisional capacity — is critical to ensuring that people in unsafe or potentially unsafe situations are treated ethically and with respect.

Clarification of thresholds regarding self-neglect that could be used to determine when action is warranted might help clinicians navigate difficult decisions. Thresholds must be clear and easy to interpret for clinicians who aren't experts in self-neglect or competency assessment. We propose that patients who are unable to care for themselves and don't have a caregiver who can provide the necessary care be classified into one of three categories: "potential risk of self-neglect," "imminent risk of self-neglect," and "confirmed selfneglect" (see diagram).

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The subsequent course of action may depend on the label used. In nearly every case of potential self-neglect, the process of assessing patients, reporting cases to the designated authorities, and following up is time consuming, can upset patients and family members, and entails substantial strain for clinicians. Addressing concerns in

For example, if a caregiver has done everything possible to provide the patient with needed care, yet the patient repeatedly declines assistance, and there is no immediate safety risk, the patient would be classified as being at "potential risk." People who engage in concerning behavior that poses a substantial safety risk (e.g., unsafely

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operating a vehicle) would be classified as being at "imminent risk." Finally, cases in which people have experienced medical harm (e.g., ED visits precipitated by not taking medications) or social harm (e.g., eviction because of unpaid bills) that can reasonably be linked to lack of self-care would fall under the category of "confirmed self-neglect."

Although additional research would be useful to further clarify thresholds for these categories, this conceptualization may help clinicians confronted with the thorny question of when to involve APS. We recommend actions specific to reporting potential selfneglect; this model shouldn't preclude implementation of other appropriate interventions.² When patients fall under the "potential risk" category, we suggest clinicians monitor for concerning behaviors and safety risks. Clinicians should report cases in the "imminent risk" category when there is a high likelihood of harm to the patient or others. All cases in the "confirmed self-neglect" category should be reported. Clinicians should discuss reporting

with patients and family members and describe APS as an agency that can help improve safety while trying to preserve autonomy and that attempts to use the least restrictive measures possible.

In the case of Ms. G., which would probably qualify as "confirmed self-neglect," APS might implement an approach that involves gradually increasing levels of home care, starting with parttime care at specific hours. APS might also install safety equipment in the home and help establish medication-management protocols, meal-service delivery, and regular wellness checks.

More than 20% of older adults in the United States have mild cognitive impairment, another 10% have dementia,³ and the population of older Americans is rapidly growing.⁴ The number of people at risk for self-neglect is therefore expected to increase substantially in the coming years. Establishing a framework for addressing self-neglect presents an opportunity to move upstream by recognizing opportunities to intervene before harm occurs. This model highlights broader societal questions

about how to weigh the values of autonomy and safety (particularly as they relate to cases in the "imminent risk" category), thresholds for intervention, and the resources required to meet the needs of people identified under this framework.

Disclosure forms provided by the authors are available at NEJM.org.

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This article was published on June 28, 2025, at NEJM.org.

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DOI: 10.1056/NEJMp2501152
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Biologic Drugs and Medicare Price Negotiation

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Biologic drugs have been responsible for an increasing share of Medicare spending in recent years. The Inflation Reduction Act of 2022 authorizes Medicare, for the first time, to negotiate prices directly for costly medications under the Medicare Drug Price Negotiation Program, but the law treats biologic products and small-molecule drugs differently. Biologics are protected from price

negotiation for 4 years longer after approval than small-molecule products, were excluded from being selected for negotiation (under Medicare Part B) during the first 2 years of the program, and may have their selection delayed if a biosimilar product is likely to enter the market in the near future. The Trump administration has committed to continuing the program and announced in March 2025 that

manufacturers of selected drugs had agreed to participate in the second cycle of negotiations. We believe making changes to the program's terms governing biologics covered under Medicare Part B could help address rising drug spending.

Biologic drugs account for 17 of the top 20 drugs by spending in Medicare Part B, which covers clinician-administered drugs.¹ In