Self-Neglect
Clinical Practice Guideline

Overview of the Condition/Disease

Definitions: Self-neglect may involve intentional or non-intentional behaviors, and not infrequently some of both.

Intentional self-neglect occurs when a person who has the capacity to make and carry out decisions regarding self-care and protection freely and knowingly chooses not to attend to their health and/or safety.

Non-intentional self-neglect occurs in individuals where BOTH decisional and executive capacities are so compromised that they have lost the ability to see to some, most, or all of their health and/or safety needs being met, either by themselves and/or with the help of others. Decisional capacity requires the abilities with regard to health and safety needs to (1) communicate choices; (2) understand information relevant to the decision at hand; (3) appreciate the circumstances involved in the decision and the likely consequences of the different possible choices; (4) ability to reason about the situation. (Note: Given the ambiguity of the term "reason," individuals who meets all the criteria for decisional capacity retain the right to make seemingly "unreasonable" choices, as these reflect decisions based on their personal values.) It is important to realize that some individuals, while they meet the criteria for decisional capacity regarding their health and/or safety needs, nonetheless have executive deficits that result in their inability to implement their decisions in the absence of supervision or assistance. This can be observed in persons who "know what to, know how to do it, and may even be able to demonstrate how to do it," but then fail to "follow through," to do what they claim they are capable of doing, unless prompted, supervised, or assisted by others.

It is critical to distinguish between the concepts of "competence" and "capacity." "Competence" is not a medical term, but a legal one, and generally refers to an individual's global abilities. By law persons are presumed to be competent until proven otherwise through a formal review in court. Capacities, by contrast are task-specific—they refer to individual abilities and can be assessed by clinicians. These include the abilities to perform ADLs (activities of daily living such as eating, bathing, ambulating) and IADLs (instrumental activities of daily living such as cooking, cleaning, shopping, using telephone, driving). One of the common challenges in assessing and addressing self-neglect is that it may manifest in different patterns, where members may be intentionally committing or omitting certain actions that place their personal health and safety in jeopardy, while at the same time non-intentionally doing or not doing others. Thus, it is important, as part of comprehensive assessments in cases of self-neglect, to develop a careful inventory of members' specific strengths and weaknesses regarding their capacities to assure their own health and safety.

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A person who engages in self-neglect exhibits one or more of the following:

- Persistent neglect of personal and/or environmental hygiene
- Repeatedly refusing, declining, or simply failing to attend to some/all indicated interventions which could reasonably be expected to maintain or improve quality of life
- Self-endangerment through the commission of unsafe behaviors (e.g., persistent refusal to care for a wound, creating fire hazards in the home, choosing not to eat resulting in dangerous weight loss, wandering outdoors and becoming lost), or the omission of actions needed to preserve one's health and/or safety (e.g., failure to take critical medications as prescribed, losing track of important medical appointments, leaving the stove on unattended)

Risk Factors for self-neglect:

- **Medical Co-Morbidities that are disabling or have the potential, to become so**: Chronic health problems can become progressive and lead to increasingly disabling co-morbidities, and denial, minimization, or unawareness of this happening is common in cases of self-neglect.
- **Mental Health Problems that impair decisional and/or executive capacities:** Mood Disorders, Anxiety Disorders, Personality Disorders, Neurocognitive Disorders (e.g., Delirium, Behavioral and Psychological Symptoms of Dementia) Psychotic Disorders, Other Serious and Persistent Mental Health diagnoses, and Substance Use Disorders
- **Sensory Impairments:** Can lead to lack of awareness of problems, social isolation
- **Physical Limitations**: Decreased mobility limits ability to seek care, maintain the environment, and can increase social isolation
- **Poverty:** Can diminish the ability to obtain and sustain needed nutrition, medications, medical care, transportation, and a safe residence/community
- **Adverse Life Events:** Physical, Financial, and/or Emotional hardships; Traumatic experiences
- **Emotions: Examples include** fear of losing autonomy (control); self-pride in personal independence; strong sense of personal privacy; not wanting to be a burden to caregivers; beliefs that others are more in need than themselves; fear of being targeted/victimized; low self-esteem and feeling unworthy or undeserving
- Poor health literacy: e.g., lack of awareness of the consequences of continuing to smoke cigarettes (i.e., for cardiovascular health as well as lung function); failure to take the full course of an antibiotic medication beyond the point of feeling better

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Best Practice Standards for Prevention and Management

Education: A comprehensive assessment must be completed to identify possible self-neglect in an individual. There are two components to an assessment for self-neglect. The first is to determine the individual's decisional and executive capacities (as described above). The second is to determine the degree of risk for harm to the individual as a result of their behavior or inaction. (General rule: the higher the risks, the higher the standards for meeting decisional and executive capacities.)

Interventions: It's important to ensure the individual experiencing self-neglect is offered opportunities to improve their safety and stability by reducing conditions contributing to the self-neglect. The interventions for managing self-neglect should be implemented based on the cause(s) or reason(s) for the self-neglect. In instances of severe potential harm, imminence of that harm guides choice of interventions (e.g., contacting emergency services when risk is both high and imminent).

Anticipating, Recognizing, and Responding to Symptoms

Seek timely medical attention when current interventions and/or medications are not managing symptoms.

Potential symptoms:

- **Medical Findings**: neglecting chronic medical problems, unexplained lapses in recommended health maintenance activities, lack of personal hygiene/disheveled appearance, infestations (lice, maggots), untreated chronic wounds/ulcers, malnutrition, dehydration, medication non-adherence
- **Psychiatric Findings:**
    - Impaired cognition, often a gradual process which can be challenging to recognize by member and supports- poor memory; executive deficits involving declines in the effectiveness in the abilities to monitor and evaluate the status of one's personal health/safety, to plan and implement (decide, initiate, sustain and follow through on) actions required to maintain health/safety
    - Severe disturbances of mood/motivation- apathy, depression, mania
    - Severe anxiety disorders- e.g., phobias, panic attacks, agoraphobia
    - Psychotic symptoms- e.g., delusions, hallucinations
    - Severe substance use disorders
    - Strong beliefs against and/or unwillingness to engage in discussion of provider's recommendations
- **Function:** Inconsistencies in reported abilities to perform Activities of Daily Living (ADLs) and/or Instrumental ADLs with provider's observations or reports from other caregivers such as family/friends/neighbors

- **Social Networks:** Lack of social network especially if voluntary, estranged or unwilling to communicate with family/friends or other possible supports
- **Environmental squalor:** Home filth, human waste not properly disposed of, pest infestations, inordinate amounts of clutter or numbers of pets (e.g., severe hoarding), non-functioning utilities/appliances, threatened eviction or condemnation by health or fire department

Interventions to manage symptoms: Based off of an individualized comprehensive assessment identified cause(s), using clinical history and observations obtained from both the member and collateral sources of information, along with appropriate screening tools:

- **Medical Findings:** Utilizing principles of motivational interviewing, educate, negotiate, partner with member; may need to engage in trade-offs and sacrifice comprehensive treatment for some measure of safety (forego calcium for osteoporosis in exchange for insulin for diabetes); mobilize home care services, visiting nursing services (VNS)
- **Psychiatric Findings:** Assess and refer to psychiatry/psychology; may need to involve crisis services; further assessment and treatment utilizing outpatient or inpatient resources; Refer for functional assessment by occupational therapy or neuropsychological testing to determine decisional and executive capacities; complete advance directive planning with member and supports
- **Function:** Refer to physical and/or occupational therapy; home safety evaluation; if member refusing/declining assistance, seek assessment of decisional and executive capacities
- **Social Networks:** Seek to identify potential social supports, obtain permission to contact friends/family, help establish support systems (social groups, day centers, church groups, volunteer work, friendly visitors), increase home visits by care team
- **Assessment of Caregivers:** Evaluate appropriateness and effectiveness of family/friends as caregivers, potential for increased risk (psychological, physical, sexual, and/or financial) to member; educate and support caregivers regarding members health and safety needs
- **Environment:** Consider Adult Protective Services, legal services if member is facing eviction, exterminator services, health and/or fire departments (for health and safety inspections)
- **Adult Protective Services:** Refer to Adult Protective Services if the individual's self-neglect is or will likely adversely affect health and/or safety (Note: in Wisconsin, citizens have the right to refuse APS workers entry into their homes.)

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Guidelines and Process for Interdisciplinary Team

The Care Team will assess the factors (as described above) that could place a member at risk for self-neglect at the initial, annual and six-month assessment and as needed when making contact with the member. They will coordinate further OT functional assessment or neurological testing if required for capacity assessments and work with the member and their supports to reduce any risks for developing further self-neglect or further harm from self-neglect. The Care Team will, if necessary, implement a risk management agreement with members who retain both decisional and executive capacities and ensure documentation reflects continued follow-up with member, medical providers, long-term care providers and adult protected services (as applicable).

Cultural Considerations

- In general, ethnic and cultural minority groups have continued to experience a disproportionate burden of disease, injury, premature death, and disability when compared to the white population
- Health disparities can mean lower life expectancy, decreased quality of life, loss of economic opportunities, as well as perceptions of injustice
- Health disparities result in decreased productivity, increased health care costs, and social inequities
- Contributing factors to ethnic and cultural disparities:
    - Mistrust in the health care system (stemming from current and historical mistreatment or neglect)
    - Personal and group experiences of discrimination
    - Varying degrees of health literacy
    - Provider prejudice and unconscious bias
    - Low cultural competency and clinical humility among health care providers
    - Discordance in patient-provider gender, race, and/or ethnic background
    - Under representation of minority health care providers (e.g., only 19% of RNs in the workforce are from racial or ethnic minorities)

All ethnicities and genders are at risk for self-neglect, but research shows some are at higher risk. Please be considerate of members at higher risk and make sure to provide education when necessary.

- Older and/or disabled adults are at significantly higher risk for suffering from self-neglect.
- Studies have revealed higher rates of self-neglect among minorities who live in neighborhoods with elevated crime rates above average and lower than average household incomes.

Quality Assurance Monitoring

Internal file reviews are completed by internal staff to monitor members where care teams report self-neglect. The internal file review monitors their interventions in the member centered care plan and risk reductions to identify any risk for harm the member may have as a result of self-neglect.

References

Haplen, MD, John (2021). Elder abuse, self-neglect, and related phenomena. UptoDate. Retrieved November 1, 2021 from https://www.uptodate.com/contents/elder-abuse-self-neglect-and-related-phenomena?search=pathophysiology%20of%20self-%20neglect&source=search_result&selectedTitle=1~10&usage_type=default&display_rank=1

Halphen, J. M., & Dyer, C. B. (2018). Elder mistreatment: Abuse, neglect, and financial exploitation. In D. J. Sullivan (Ed.), *UpToDate*. Retrieved February 20, 2018 from https://www.uptodate.com/contents/elder-mistreatment-abuse-neglect-and-financial-exploitation?search=self-neglect&source=search_result&selectedTitle=1~8&usage_type=default&display_rank=1

Mataix-Cols D. & Fernandez de la Cruz L. Hoarding disorders in adults. In M Friedman (Ed.) *UpToDate*. Retrieved August 16, 2022, from: *https://www.uptodate.com/contents/hoarding-disorder-in-adults-epidemiology-pathogenesis-clinical-manifestations-course-assessment-and-diagnosis?csi=5c3e9a27-4213-4e2b-8787-c8c9a36067ae&source=contentShare*

Mauk, K. L. (2011). Ethical perspectives on self-neglect among older adults. *Rehabilitation Nursing*, *36*(2), 60-65.

Mosqueda, L., & Dong, X. (2011). Elder Abuse and Self-neglect: "I Don't Care Anything About Going to the Doctor, to Be Honest....". *JAMA*, *306*(5), 532-540.

Naik, A. D., Lai, J. M., Kunik, M. E., & Dyer, C. B. (2008). Assessing capacity in suspected cases of self-neglect. *Geriatrics*, *63*(2), 24.

Pavlou, M. P., & Lachs, M. S. (2008). Self-neglect in older adults: A primer for clinicians. *Journal of General Internal Medicine, 11*, 1841-1846. doi: 10.1007/s11606-008-0717-7

Tress D. Management of the patient with dementia.(2021) In J Givens (Ed.) *UpToDate* Retrieved August 16, 2022, from: *https://www.uptodate.com/contents/management-of-the-patient-with-dementia?csi=903c23ca-3977-4a9b-8d72-d9a3fd32d348&source=contentShare*

Ramey-Klawsnik, Holly (2006). Assessment and Intervention Consideration in Response to Self-neglect Allegations. Victimization of the Elderly and Disabled March/April, 83-84.

Ye, M., Ejaz, F., & Rose, M. (2019). Relationships Between Personal Needs and The Environment: A Study of Abuse and Self-Neglect. *Innovation in Aging*, *3*(Suppl 1), S954. https://doi.org/10.1093/geroni/igz038.3463