POPULATIONS AT RISK

# Self-neglect in Older Adults: a Primer for Clinicians

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Self-neglect in older adults is an increasingly prevalent, poorly understood problem, crossing both the medical and social arenas, with public health implications. Although lacking a standardized definition, self-neglect is characterized by profound inattention to health and hygiene. In light of the aging demographic, physicians of all specialties will increasingly encounter self-neglectors. We outline here practical strategies for the clinician, and suggestions for the researcher. Clinical evaluation should include attention to medical history, cognition, function, social networks, psychiatric screen and environment. The individual's capacity is often questioned, and interventions are case-based. More research is needed in basic epidemiology and risk factors of the problem, so that targeted interventions may be designed and tested. The debate of whether self-neglect is a medical versus societal problem remains unresolved, yet as health sequelae are part of the syndrome, physicians should be part of the solution.

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The 84-year old biochemist with a history of psoriasis, gait instability and irritable bowel syndrome called her doorman once again after "another fall." The doorman or police would help her back in bed. This time the doorman called an ambulance when he noticed she was bleeding. Upon arrival of the ambulance personnel, the patient said "I'm OK." She refused to provide next-of-kin information. They noted that her apartment was extremely dirty, with urine and feces on the floor and bed and that the patient used a bucket for urine. There was spoiled food, rodents and insects, and a large amount of garbage everywhere. She thought the apartment was just "a bit disorganized." She refused transfer to the hospital, but was eventually convinced by the ambulance control center. On exam she was disheveled and malodorous, wearing a pair of broken glasses (with half the frame and a lens missing). Her neurological exam was unremarkable with a normal Mini Mental State Exam, except she walked with the assistance of a decrepit rolling walker. She had several erosive psoriatic lesions, long dystrophic nails, and fungal infections in intertriginous areas; her vital signs and lab studies were normal. She was argumentative throughout her hospital stay. She exhibited a poor understanding of her bowel problems and seemed to lack insight into her behavior. She appeared unaware of the inappropriateness of defecating on the floor when trying to get to the bedside commode, and continued to refuse nursing assistance for transfers. She refused physical therapy evaluation, and refused guidance for correct transfer technique by the occupational therapist. She refused rehabilitation despite significant problems with basic activities of daily living, but eventually accepted some services with her daughter's encouragement, and was discharged home under her daughter's supervision. She returned a week later lethargic with a new cellulitis, and eventually died of septic shock despite resuscitative efforts.

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## INTRODUCTION

In 1975, British physicians writing in *The Lancet* described the curious lifestyle and health-care-seeking behaviors of several of their older patients.[1] These individuals ignored personal hygiene, obvious medical needs, and chose to live in filth and squalor—often in the setting of adequate financial resources. Borrowing the name of the Greek philosopher who himself was dismissive of social norms, the authors coined the term "Diogenes syndrome."

Today, most gerontologists use "self-neglect" to describe this behavior,[2] whether it stems from an underlying medical or psychiatric disorder (e.g., dementia, depression), or the simple unwillingness or inability to seek help for a variety of problems with often straightforward remedies. Of note, the term does not seem widespread in the psychiatric literature, despite occasionally referring to untreated schizophrenia or similar disorders.

We became interested in this topic for two reasons. First, as health services researchers familiar with the epidemiology of disenfranchised older adults, we believe that self-neglect is a growing epidemic that is unfamiliar to both lay and medical audiences. This is unfortunate because the syndrome has profound health and public policy implications for an aging society. Second, as clinicians we believe that physicians of all types will be increasingly called upon to care for these patients, who present a variety of vexing medical, medico-legal, and ethical challenges for which training has not prepared them. Accordingly, in this article we review what is known about the epidemiology of self-neglect, its potential etiologies, and how the clinician can be helpful in the care of such individuals.

## DEFINITIONS

No uniform definition of self-neglect exists.[3] We believe that this is, in part, driven by the dearth of empirical research on

the topic, but also by enormous societal latitude, cultural differences, and individual variability on what constitutes proper attention to health and hygiene. Early papers described the syndrome as "lack of self-care and inattention to personal hygiene, domestic squalor, hoarding, apathy and disinterest for their condition, social withdrawal, and stubborn refusal of help."[1,4] Rathbone-McCuan described self-neglect as "resulting from an individual's difficulty in obtaining, maintaining, and/or managing the necessities of life independently."[5] Adult Protective Service Agencies (APS), the state entities often charged with investigating cases of suspected "self-neglect" use different definitions,[3] but generally report an increase in the prevalence of self-neglect over the past decade[6]. We believe these definitions to be vague, subjective, and not especially useful in clinical practice.

For the purpose of this paper and for clinical practicality, we define self-neglect as outlined in Table 1. This definition was derived after systematic review of the medical literature[2] and roundtable discussions with an interdisciplinary group of experts in the field of gerontology and elder mistreatment (including four geriatricians, two psychiatrists, one psychologist, one epidemiologist, two sociologists, two social workers, one adult educator, and two gerontologists). Although we realize there will be disagreement among readers as to whether this definition is overly inclusive or exclusive, our goal was not to create a validated research instrument. Rather, we wished to create a useful descriptive framework that could foster a dialogue about this poorly understood phenomenon, with the hope of educating physicians and encouraging more research in this area.

## EPIDEMIOLOGY

### Prevalence

The absence of standard definitions precludes reproducible prevalence estimates, but there are data sources that provide at least a window to understand the magnitude of the problem in the United States. One such source is APS agencies, although reporting bias probably underestimates true prevalence. Self-neglect was the most common category of investigated reports (49,809 reports or 26.7%) with >46,000 in older adults according to the 2004 National APS Survey.[6] In a study that linked a well-characterized aging cohort of community-dwelling elders living in New Haven Connecticut to APS records in that state, 153 of 2,812 cohort members were seen by APS for self-neglect over an eleven year follow-up period for a yearly prevalence of 5.4%.[7] The sample was probably biased towards more severe self-neglect cases, which often prompt official referral.

**Table 1. Self-Neglect Definition**

| A self-neglector is a person who exhibits ≥1 of the following: |
|---|
| 1) Persistent inattention to personal hygiene and/or environment |
| 2) Repeated refusal of some/all indicated services which can reasonably be expected to improve quality of life |
| 3) Self-endangerment through the manifestation of unsafe behaviors (e.g., persistent refusal to care for a wound, creating fire-hazards in the home) |

### Etiology and Risk Factors

A growing body of literature has suggested a variety of features associated with self-neglect (Table 2), but this lacks a sound scientific foundation; most papers have either noted the association of these factors with low self-care states for younger populations in observational studies (e.g., alcoholism) and assumed relevance to older populations, or simply proposed an association on theoretical grounds. Two exceptions are dementia (OR=4.24, 95%CI=2.32–9.23) and depression (OR=2.38, 95%CI=1.26–4.48),[8] which have been associated with self-neglect in well-conducted longitudinal studies using self-neglect cases identified by Connecticut APS (same cohort reported in previous paragraph).

Depression is an especially intriguing risk factor for self-neglect for several reasons. First, depression has been shown to be an independent risk factor for a variety of behaviors that might herald self-neglect, ranging from medication non-adherence to dietary indiscretion.[9] Second, recent evidence points to a variant of geriatric depression that includes executive dysfunction (the ability to order and sequence tasks) that is associated with activities of daily living (ADL) impairment out of proportion to the degree of mood disorder.[10] Finally, depression is prevalent but treatable, which raises the hypothesis of a more "remediable" subgroup of self-neglectors who would be important to identify.

Dementia is a highly plausible correlate of self-neglect in that impaired memory and judgment would create an ideal environment for it to occur; dementia is prevalent in older adults and patients with dementia invariably develop progressive inability to self-care. However, as a practical matter, self-neglect in patients with dementia should probably be considered a different entity from the vantage of both "diagnosis" and treatment approach. The care of such patients is probably more straightforward and homogeneous than self-neglectors with normal cognition (although there are no studies using extensive neuropsychological assessments to test clinical impressions of "intact cognition" described in self-neglectors). They will likely require an assessment of capacity as it wanes, and may need interventions such as guardianship to improve their circumstances. Patients who self-neglect with normal cognition are probably a far more heterogeneous population and more difficult to assist.

Although the above definition does not distinguish between cognitively impaired and intact self-neglectors, in this paper we repeatedly call the reader's attention to this important bifurcation, as we believe subsequent definitional work in this field should distinguish between the two.

## CLINICAL EVALUATION

The cornerstone of proper evaluation of the older self-neglector is multidisciplinary geriatric assessment, wherein medical, cognitive, psychosocial, functional and environmental factors are evaluated in a comprehensive team approach mostly to create a safety net around the individual while addressing remediable problems. The irony is that most self-neglectors would not submit to such an exhaustive evaluation voluntarily. Thus, while physicians may occasionally see such patients in ambulatory practice, they are far more likely to be encountered in situations where serious medical or social sequelae of

Table 2. Proposed Risk Factors and Correlates of Self-Neglect in Older Adults

| Feature | Comment |
|---|---|
| Medical co-morbidity | Opportunity to self-neglect, denial, chronic problems are progressive and lead to more co-morbidity (e.g., hypertension leading to cardiovascular, renal disease, stroke and/or loss of vision) |
| Dementia | Dementia may cause memory loss, loss of executive function, impaired judgment, and disrupt a variety of intellectual spheres needed to maintain capacity for self-care. Dementia related delusions and paranoia may cause patients to stop eating, or shrink their social network if provocative behaviors alienate friends, as well as refuse professional help offered |
| Depression | Elements of depression such as feelings of low self-esteem, poor self-worth, psychomotor retardation, lack of insight, anhedonia, lack of motivation and energy to maintain self-care are conducive to self-neglectful behaviors. A subset of depressed older people develop executive dysfunction (the inability to plan, order, and execute goal oriented behavior), and these individuals have a high prevalence of activities of daily living impairment[10] |
| Alcoholism | Alcoholism in younger individuals is associated with poor self-care behaviors. Consequences may include malnutrition, dehydration, anemia, unintended injuries, dementia |
| Anxiety disorders and phobias | Agoraphobia may preclude individuals from venturing out to seek medical care. Patients may have anxiety or phobias about specific treatments or settings (e.g., magnetic resonance imaging scans, dentists) that can cause them to forestall or avoid care altogether |
| Schizophrenia and delusional disorders | Disorganization, poor insight and psychosis may preclude the individual from seeking and/or accepting help |
| Obsessive-compulsive disorder | Repetitive behaviors of poor or harmful self-care often associated with hoarding behaviors may endanger the individual and/or the surrounding community (e.g. fire hazards, resultant infestations, animal hoarding) |
| Personality disorders and lifelong personality traits | The individual may be suspicious, mistrustful, avoidant or paranoid, which may limit the patient's social network leading to isolation and depression, and may compromise the doctor-patient relationship |
| Other mental illness | Loss of the older adult caregiver may unmask lack of capacity for self-care in the adult impaired child |
| Metabolic and other organic disorders that can influence cognition and behaviors | Delirium may be provoked by such problems as diabetic ketoacidosis, hypercalcemia, infections, and hypoxia. In many cases delirium never completely resolves, but assumes a chronic state with impaired judgment and decreased capacity of the individual for self-care decisions |
| Sensory impairments | Decreased vision and hearing may increase social isolation, and impair the ability to recognize that the environment or personal state may be amiss. They may also lead to disorientation, depression, unsteady gait and traumatic falls |
| Physical impairments | Decreased mobility from any medical condition (e.g., arthritis, congestive heart failure, chronic obstructive pulmonary disease) limits ability to seek care, and/or maintain the environment. They tend to force the individual into a vicious cycle of isolation, often due to both loss of support systems and unwillingness to accept loss of independence |
| Social isolation | Decreased social network, separation, divorce or being widowed, living alone, friends dying, bereavement, shame for current social situation, self-ageist attitude (negative stereotypes internalized), fear of a progressive/ever-changing technological society, leading to seclusion "me vs. them" attitude, perhaps leading to hoarding as a way to build "physical walls" to shield from society around them. Poor social networks lead to disability and affect recovery from acute illness[14] |
| Low education | Health illiteracy, uninformed lifestyle choices |
| Poverty | Little or no medication coverage insurance for older adults, healthy diets are expensive |
| Adverse life events | Physical, financial, or emotional hardship (including bereavement) may compromise ability for self-care |
| Pride in independence | Fear of losing independence or privacy, or being targeted/victimized |

self-neglecting behaviors have made contact with the health care system unavoidable. Examples include non-elective hospitalization (such as a hip fracture), as a medical consultant during involuntary psychiatric hospitalization, as a physician-expert in the setting of guardianship proceedings, or in the course of making a home visit at the request of family, a state agency, or local social service program.

Physicians who encounter these individuals in ambulatory practice are likely to be overwhelmed by the multiple medical and social problems they harbor. The task is made additionally daunting because no team is typically available to assist in such outpatient settings. Thus, the presentation of the self-neglecting patient to the hospital provides a rare but crucial opportunity to make a relatively expeditious assessment with the help of other professionals.

Irrespective of setting, we offer here several tools to assist the general practitioner in recognizing, evaluating, and treating self-neglect. In addition to the typical history and physical exam, we urge primary care providers to pay particular attention to the following areas: 1) medical history, 2) cognitive assessment, 3) basic and instrumental ADLs, 4) extent of social networks, 5) depression screening and other psychiatric history, 6) environment. Table 3 outlines several red flags that may suggest probable self-neglect. The medical history should look at the "trajectory" of these behaviors using as many sources as possible, and a non-judgmental approach. If self-neglecting behaviors are of acute onset then the probability of an underlying medical problem as culprit (e.g., stroke, delirium, medications) becomes much higher. Any and all sources of information should be used in garnering history about the patient; interviews with family, neighbors, and the person's ad hoc social network (e.g., local merchants, landlord) often provide a fascinating history into the "life-course" of the person.

The complete medical and psychiatric history may need to be obtained piecemeal over time. Similarly information about any impairment in basic and instrumental ADLs should be corroborated, as self-neglectors typically hide, underestimate, or deny their limitations. A home visit, if allowed by the patient, is crucial in revealing safety and health hazards that may otherwise go unnoticed. At every stage of the patient's assessment it is

Table 3. Clinician's Guide to Red Flags of Possible Self-Neglect

| Focus | RED flag |
|---|---|
| Medical findings | Consciously neglecting chronic medical problems (e.g., refusing diabetic medication) |
| | Unexplained lapses in recommended health maintenance activities |
| | Lack of personal hygiene, disheveled appearance |
| | Infestations (e.g., lice, maggots) |
| | Untreated chronic wounds/ulcers |
| | Long fingernails/toenails (including onychomychosis/griffosis) |
| Cognition | Impaired cognition |
| Function | Possible discordance in reported abilities to perform basic/instrumental activities of daily living with provider's observations or reports from family/friends |
| | Refusing needed assistive devices |
| Social networks | Lack of social network (family/friends) especially if voluntary e.g., estranged or unwilling to communicate |
| Psychiatric findings | Positive screen for depression |
| | Psychotic symptoms |
| | Strong beliefs against, and/or unwillingness to engage in open discussion of provider's recommendations |
| | Substance abuse |
| Environment | Report of home infestations (e.g., mice, insects) |
| | Report of clutter in the home |
| | Report of non-functioning utilities/appliances |
| | If Home Visit: obvious infestations, clutter/hoarding, blocked exits, fire-hazards, evidence of rotten food, malodors, multiple animals, degree of environmental hygiene, non-functioning utilities/appliances |
| | Threatened eviction |

important for the clinician to ask about reasons behind particular behaviors. Religious or cultural beliefs may influence behaviors. Alternatively behaviors may indicate a lack of capacity and serve as the basis for interventions.

## INTERVENTIONS

There are no specific interventions or intervention trials to date for self-neglect. Risk factors are still largely unknown and more basic epidemiologic research is needed so that eventually targeted interventions may be designed for the remediable causes. The goal of any intervention would be to reduce co-morbidity from neglected chronic illnesses, maximize functionality and improve quality of life. Based on current knowledge the clinician is, therefore, faced with behavioral modification and "negotiation" challenges while caring for the recalcitrant patient. The management of self-neglectors can be one of the most trying experiences in medicine. Patients are typically inaccessible until profoundly ill. Patient refusal of interventions—especially for highly effective ones—can be exasperating for physicians and others who have selected careers in the "helping professions." Involvement with the legal system (e.g., guardianship, eviction) is foreign to many practitioners and taxing of their time. And while physician advocacy for society's most vulnerable members is in the finest tradition of medicine, the target of advocacy in these cases "does not want to be helped."

We propose an algorithm in Table 4 for the assessment and treatment of self-neglect. We target the common and remediable problematic areas identified in Table 3. Such interventions may improve safety, quality of life and mortality. Resistance to interventions, however, is frequent. Almost invariably then, treatment hinges on the critical issue of capacity. Patients lacking capacity who are endangering themselves or others will likely need some form of temporary or permanent guardianship. Patients whose self-neglect is deemed remediable may require involuntary treatment including hospitalization. The physician's role here may not only be as treater, but also in providing evidence of incapacity in legal proceedings. The role of physicians in guardianship process has been described elsewhere.[11]

For the self-neglector who retains capacity, he/she should be made aware that help is available in the future should there be a change in preference. Advanced directives should be aggressively sought, without judgment as to the nature of those preferences. A paradox of self-neglectors is that without advanced directives, these patients will receive all manner of resuscitative efforts when they present without communicative ability; how ironic that they would be the least likely to request or receive such "high technology" medical care prior to losing capacity.

## DISCUSSION

Elder self-neglect carries significant morbidity (hazard ratio for nursing-home placement = 5.23, 95%CI=4.1–6.7)[12] and mortality (OR=1.7, 95%CI=1.2–2.5).[13] It is the most common referral to APS for older adults according to the 2004 National APS Survey.[6] In view of the growing aging demographic it is increasingly important to answer the multitude of research questions remaining in this area.

One crucial area of research is to determine the prevalence of underlying medical and psychiatric diagnoses, the degree to which they contribute to self-neglecting behavior, and the extent to which medical interventions can improve such behavior. Another compelling research agenda at the nexus of bioethics and health services research concerns the prevalence of advanced care planning in these individuals, and the economic and non-economic costs of implementing aggressive resuscitation efforts and end-of-life care when, predictably, self-neglectors medically decompensate and require heroic intervention. Table 5 outlines some of the major gaps in the current self-neglect literature which research needs to address first. It is by no means exhaustive and although demonstrates the dearth of existing knowledge, it hopefully inspires researchers to delve into this complex topic.

**Table 4. Assessment and Treatment of the Self-Neglector**

| Focus | Finding | Assessment | Treatment |
|---|---|---|---|
| Medical findings | Neglecting chronic medical problems<br>Lapses in health maintenance activities | Ask why | Educate, negotiate, partner with patient—may need to sacrifice comprehensive treatment for safety (e.g., forgo calcium for osteoporosis in exchange for insulin for diabetes) |
| | Lack of hygiene, Infestations | Refer to homecare agency | Homecare services |
| | Untreated wounds | Refer to visiting nurse agency | Visiting nurse to assist with wound care treatments |
| | Long toenails | Refer to podiatry | Regular podiatric care (Note: for long fingernails—depending on severity—may need professional attention beyond soaking nails prior to trimming) |
| Cognition | Impaired cognition | Refer for neuropsychological testing | 1) According to findings of assessment |
| | | Capacity determination | 2) Further psychiatric evaluation may be indicated<br>3) If dementia, then treat accordingly<br>4) Important to identify social network and obtain advanced directives<br>5) Periodically determine capacity for problematic behaviors |
| Function | Problem in ≥1 basic or instrumental activities of daily living | Refer to physical and/or occupational therapy | 1) May need periodic treatments or rehabilitation<br>2) May need home safety evaluation for equipment (e.g., raised toilet seat)<br>3) Refer to social service agency which may offer volunteer services for shopping, transportation, money management, etc. |
| | Refusing assistive devices | Capacity determination | If lacks capacity, refer for neuropsychological testing and/or psychiatric evaluation |
| Social networks | Lack of social network | Refer to social work | 1) Aggressively seek to identify social network<br>2) Obtain permission to contact friends/family<br>3) Obtain advanced directives<br>4) Help establish support system (e.g., social groups, senior center, adult day care, church group, volunteer work) |
| Psychiatric findings | Depressive symptoms | Assess depressive symptomatology using standardized scale (e.g., PHQ-9, GDS, etc) or DSM-IV-TR criteria | Treat appropriately and/or refer to psychiatry/psychology |
| | Other psychiatric findings (psychotic symptoms, suspicion of personality disorder, substance abuse) | Evaluate for safety (suicidal or homicidal ideation) | 1) Refer to psychiatry for further evaluation<br>2) May need to call mobile crisis center depending on urgency of findings<br>3) May need inpatient or outpatient rehab |
| Environment | Clutter, hoarding, infestations, hazards, threatened eviction | Refer to social service agency and/or Adult Protective Services (especially if in a state with mandatory reporting laws) | 1) May need cleaning services (often mobile crisis units aid with associated patient anxiety)<br>2) Exterminator services<br>3) May need legal services if faced with threat of eviction |
| | If behavior poses public health hazard | Patient with capacity | May need to involve law enforcement authorities |

**Table 5. Gaps in the Current Self-Neglect Literature**

| Gaps in self-neglect literature |
|---|
| Prevalence of medical conditions |
| Prevalence of psychiatric conditions |
| Accurate prevalence of elder self-neglect |
| Risk factors for self-neglect |
| Economic implications on various levels |
| Health outcomes of each definitional criterion of self-neglect (e.g., is neglecting personal hygiene equivalent to consequences of service refusal?) |
| Collaborative work between the research and the practice community for more practical and readily applicable solutions |
| Extensive neuropsychiatric testing of self-neglectors |
| Investigation of the life trajectory and personal opinions of self-neglectors |

Discussions of self-neglect invariable evoke debates about the wisdom of characterizing the syndrome as a medical entity as opposed to a societal problem outside the purview of medicine. While proponents of libertarianism and unimpeded autonomy would likely recoil at the notion of a "disease-based" approach to self-neglect, medical and psychiatric conditions probably underlie most cases. The medical model is, therefore, appropriate, as physicians will be increasingly called upon to provide medical care to these individuals when neglected health conditions result in clinical extremis. As with many conditions prevalent in older adults, the proper management requires expertise that extends beyond medicine but requires physician familiarity with both the syndrome and available resources that must be coordinated.

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