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Elder Self-Neglect and Dementia: Challenges for Community Based Teams

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Abstract
Elders with dementia are significantly more likely to neglect their own needs, and determining the role of cognitive impairment is a key factor in creating successful interventions for change. Community based care teams, be they clinic based, or from home health, are similarly confronted with the challenge of how to support independence while promoting wellness and safety. Through careful analysis of the multi-factorial nature of self-neglect, teams can create care systems that honour autonomy and prevent placement. Creativity, flexibility, and acceptance of the "dignity of risk" allow care providers to make an impact while supporting aging in place. Reflecting on recent patients will allow a close intimate consideration of elders, who self-neglect and the risks and benefits of intervention.

Introduction:
Self-neglect has been defined as The inability intentional or non-intentional to maintain socially and culturally accepted standards of self-care. These authors consider that a person may self-neglect either intentionally or due to a lack of ability. However, a number of other institutions, such as the National Center on Elder Abuse determine self-neglect as nonintentional. The objective of this overview is to describe and update on self-neglect.
In particular, this overview focuses on the predisposing factors and consequences of the syndrome. We want to provide information to help general practitioners identify elderly people who are at risk of self-neglect. Finally the management and future need to research the syndrome are discussed.

This overview is based on a literature search, performed in the PubMed database using the terms self-neglect squalor syndrome or Diogenes syndrome. The limits for the search were English language and the age of 65 years or older.

Prevalence and Incidence:
The exact prevalence of self-neglect in community-based aged populations is not known. This is due to the difficulty in exploring self-neglect in unselected populations. Individuals who neglect themselves do not have contact with social and health care services until they suffer from the severe and often urgent social or medical consequences of self-neglect such as infection, dehydration, malnutrition, hip fracture, sores and delirium. In a population based cohort of the Chicago Health and Aging Project with 9318 participants aged over 65 years, 16.6% of participants were reported as self-neglecting during the 12-year.

Follow up. The mean age of the self-neglecters was 74 years, and 66% of these were women. In the subset of the same cohort, the prevalence differed between Caucasian and black older adults 5.3% versus 21.7%, respectively. A linkage of an unselected cohort of elderly people in New Haven Connecticut, with records from Adult Protective Services in order to indentify self-neglect cases, yielded a self-neglect incidence of 5.4% during an 11-year follow-up. There are no studies on the prevalence or incidence of self-neglect in European countries.

Predisposing Factors:
Cognitive impairment is the most important predisposing factor for self-neglect in the elderly population. In an aged cohort, individuals with dementia had a four-fold risk of self-neglect (OR: 4.24; 95% CI: 2.32–9.23) during nine years of follow-up . If both dementia and depression were present, the risk was 8.6 times higher than that of non-demented and non-depressed people.

Pre-morbid personality and psychiatric disease predispose to self-neglect. Depression is commonly associated with self-neglect, and may also be a consequence of this syndrome. Depression is often associated with cognitive impairment, and may be an early manifestation of dementia years before the diagnosis. Depression more than doubles the risk of self-neglect (OR: 2.38; 95% CI: 1.26–4.48). Depression was found in 51% of older people with self-neglect compared to 28% in those without self-neglect. Depressive self-neglecters have more untreated medical conditions than the self-neglecters without depression (56% versus 21%). In addition, other psychiatric disorders, often untreated, are common among the elderly with self-neglect.

Alcohol and substance abuse may also result in self-neglecting behaviour with the result of severe concomitant medical problems, malnutrition, poverty and social isolation. In the cross-sectional study of Halliday et al., alcohol abuse was present in 27% of self-neglecters.

A number of other factors have also been found to be associated with self-neglect. Old age, living alone, low income, hip fracture and a history of stroke predict self-neglect during the follow-up of nine years. In addition, male gender was a risk factor when the adjustment with age and many other variables was made. Self-neglect is associated with low physical function, chronic physical illness and impairment in instrumental activities of daily life.

Low levels of social networking and social engagement are related to an increased risk of self-neglect. Many older people who neglect themselves live in an isolated environment without appropriate social support or health care services. In the observational study of Burnett et al., 41% of elderly people who had self-neglected themselves lived without a spouse, compared to 11% of matched controls. In addition, visits by children, neighbours and friends to self-neglecters were more infrequent. Altogether, 95% of self-neglecters receive only moderate or low social support. It is not known, however, whether poor social networking is a cause or consequence of self-neglect. It has also been suggested that self-neglect is attributable to a poor socioeconomic situation and insufficient public support rather than to individual risk factors.

Risk Factors:

Self-neglect results from complex interactions between medical, psychological, and social risk factors. In terms of medical and psychological issues, the factors that are currently under the greatest degree of study are cognitive impairment and depressive disorders. Numerous researchers point to dementia as a risk factor, although the possible failure of executive function is also currently a focus of study. One of the risk factors for which we currently have the most data is the reduction in social resources. Research studies demonstrate that self-neglecting elders reduce their participation in social activities and have a reduced informal social support network.

Consequences:

Self-neglect is an independent risk factor for early mortality among the aged. The one-year mortality after diagnosing self-neglect was six-fold, and the long-term mortality was almost twice as high compared to elderly people who had not self-neglected. Self-neglect was associated with increased mortality risk from cardiovascular, pulmonary, neuropsychiatric, endocrine, metabolic and neoplastic diseases. In another prospective cohort with older adults, the nine-year mortality of the self-neglecters was almost twice (OR: 1.7; 95% CI: 1.2–2.5) compared to other members of the cohort. Causal pathways and mechanisms of death are unclear.

Self-neglect is associated with poor health and social well-being and dependency. It can lead to low food intake, weight loss, frailty, multiple nutritional deficiencies, vitamin D deficiency, low physical function, osteoporosis, falls and fractures and untreated pain. Emergency visits and acute hospitalization are common. In addition to the medical consequences, self-neglect involves a number of social, ethical and legal problems. Self-neglecters fail to maintain their personal and environmental care and their personal safety is jeopardized due to an unsafe environment and lack of medical care. Inability to take care of financial issues worsens the economic and social situation.

Clinical Indicators:

It is likely that self-neglect is largely under diagnosed due to the inability and unwillingness of sufferers to seek help. Diagnosing self-neglect is easy on a home visit, but often difficult at a medical appointment or during hospital treatment, particularly if a caregiver is not available. Poor personal hygiene, abnormal behaviour, forgetting appointment times, untreated medical problems, inappropriate use of medication, malnutrition, bruises and bedsores and noncompliance may indicate self-neglect. Hair is unclean and nails are uncut and men may not shave for long periods. Adequate heating, electricity, running water and even toilet facilities may be lacking in the residence. Taxes and bills may not have been paid for months. Concomitant psychiatric disorder, cognitive impairment or alcohol abuse may also raise suspicion of self-neglect.

There are no validated and reliable diagnostic criteria for self-neglect. Consortium for Research in Elder Self-neglect of Texas (CREST) has developed the Self-neglect Severity Scale, which was validated in a pilot study. The reliability of the scale was adequate, but the sensitivity and specificity remained below conventional acceptable ranges. Pavlou and Lachs have presented the criteria for the screening of potential self-neglect as follows: A self-neglecter is a person who exhibits one or more of the following:

Persistent inattention to personal hygiene and/or environment

Repeated refusal of some or even all specific services, which can reasonably be expected to improve the quality of life

Self-endangerment through the manifestation of unsafe behaviours

Any of these findings in primary care could lead to the detailed assessment of health and life situation of the elderly person performed by a general practitioner and home care service.

Conclusion:

There is no sufficient scientific evidence to support the benefits of early intervention in self-neglect. Controlled studies are needed, especially to show whether early diagnosis followed by increased social support and tailored health care services have an effect on the outcome.