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Elder Self-Neglect: Medical Emergency or Marker of Extreme Vulnerability?

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To address the vulnerability that often accompanies aging, a social contract was established with older Americans in the 1960s through legislation leading to the creation of the Social Security and Medicare programs. This contract was augmented in 1975 through passage of Title XX of the Social Security Act, which required states to develop and maintain protective service agencies for senior citizens. In most states, these agencies are the first responders to reports of elder abuse, including physical abuse, neglect and financial exploitation. The most common reason for referral to adult protective services, however, is self-neglect, an ill-defined syndrome characterized by the inability to meet one's basic needs to an extent that it poses a threat to personal health and safety (1,2). The absence of a caregiver distinguishes self-neglect from neglect, which is the most common subtype of elder abuse (3).

In this issue of *JAMA*, Dong and colleagues (4) evaluate the mortality related to self-neglect and abuse in a large biracial cohort of community-living persons aged 65 years or older who were followed for a median of 6.9 years. Confirming prior work (5), the number of reported cases of self-neglect dwarfed that of abuse by a ratio of nearly 14 to 1. While both self-neglect and abuse were independently associated with mortality, the short-term affect of self-neglect was particularly pronounced, with a nearly 6-fold elevation in the risk of death within 1 year. Such elevations in risk are usually reserved for acute and highly morbid medical conditions such as myocardial infarction, stroke, or hip fracture, and suggest that a report of self-neglect should be considered a medical emergency, warranting immediate referral for diagnosis and treatment.

Alternatively, some older persons reported for self-neglect may be at the end of their life. Supporting this supposition, the median time to death for cancer, the prototypical terminal condition, was only 3.5 months. While self-neglect could have led to advanced cancers being diagnosed only after referral to the social services agency, it is more likely, given the short survival period, that the diagnosis of cancer predated the referral, and it is even possible that the cancer led to the self-neglecting behaviors. Whether the cause of death was cancer or another condition, this chicken-egg dilemma cannot be adequately addressed by the data available in this well-designed epidemiologic study. Information on medical conditions and other relevant factors such as cognitive status and physical function was obtained during comprehensive assessments that were completed a median of 19 months before the report of self-neglect. Prior work has shown that older persons experience high rates of illnesses or injuries leading to hospitalization or restricted activity, over intervals shorter than 19 months (6), and that these intervening events commonly precipitate significant declines in functional status (7). Hence, the health and functional status documented in the preceding comprehensive assessment may not accurately reflect a

participant's status at the time of self-neglect referral. Supporting this possibility, Dyer et al. found that the prevalence of physical and cognitive impairments and poor-to-fair self-reported health was high in a large sample of older persons with self-neglect who were referred by adult protective services for comprehensive geriatric assessment (8). Consequently, the authors' findings that the mortality risks associated with self-neglect and elder abuse were not restricted to persons with the lowest levels of cognitive or physical function must be interpreted cautiously.

Whether considered a medical emergency, a manifestation of a terminal condition, or simply an indicator of extreme vulnerability, self-neglect poses significant challenges to the health care system and social safety net. The number of cases of self-neglect has been increasing (3) and will likely continue to increase with the graying of the baby boom generation. Accelerating this trend, the number of informal caregivers has been decreasing, as evidenced by the marked reduction in the the oldest old support ratio, which denotes the number of people aged 50 to 74 years who are potentially available to care for one person aged 85 years or older. This value, which was as high as 30.9 in 1970, is projected to further fall from 9.9 in 2010 to 4.1 in 2050 (9). Of considerable concern, despite an increasing demand, recent budget cuts due to the deepening recession are forcing protective service agencies in some states to lay off caseworkers (10).

Given the high short-term mortality risk attributable to self-neglect, caseworkers must be particularly adept at triaging affected individuals and implementing a care plan. One tool, used by the social service agencies in the current study, is a 15-item scale that assesses self-neglect severity (11). Short-term mortality was particularly high among persons with scores greater than 30, denoting severe self-neglect. Ideally, the caseworker could refer high-risk individuals back to their personal physician, but self-neglect is often characterized by social isolation and, despite the availability of Medicare, many individuals may not have an ongoing relationship with a personal physician (1). The current study provides no information about the receipt of health care services or other interventions.

In the absence of a personal physician, referral for a geriatric assessment may be warranted. Individuals who are acutely ill or at imminent risk may need to be hospitalized, while others who are at the end of life may benefit from hospice services. During the course of the assessment, particular attention should be focused on ascertaining the presence of dementia (including impairments in executive function), psychiatric disorders, and substance abuse since each can have pronounced deleterious affects on decision-making capacity. Individuals with self-neglect who lack decision-making capacity (12) and refuse help from social agencies and family may be unsafe to remain at home (13). In such cases, when a legally designated durable power of attorney or close family member is not available, referral to the courts for appointment of a legal guardian should be pursued so that important decisions can be made (14).

Although differences in analytic strategies preclude a direct comparison, the mortality risk associated with self-neglect appears to be much higher in the current study than that in the only prior population-based study (5). The most obvious difference between the two study populations is race, with a much larger percentage of blacks (63% versus less than 18%) in the current study. Surprisingly, however, while reports of self-neglect in the current study were four times more likely in blacks than whites (23% versus 5.5%), the mortality risk associated with self-neglect was significantly lower in blacks. A similar, although less striking phenomenon was observed for gender. Women were more likely than men to be reported for self-neglect (18% versus 14%), but were less likely to die. The reasons for these racial and gender differences are uncertain. One possibility is that the threshold for referral to the social services agencies was lower for blacks and women, respectively, but the

severity of self-neglect did not differ according to race or gender. Alternatively, there may be racial or gender differences in the conditions leading to self-neglect or in the subsequent management of self-neglect after referral to the social services agencies.

The mortality related to self-neglect and abuse could be interpreted as a failure of society and the health care system to adequately protect the most vulnerable older adults. To better address the complex needs of this burgeoning population, a stronger geriatric work force will be needed, as highlighted in a recent Institute of Medicine report (15). While awaiting evidence-based answers to the myriad of unanswered questions regarding the epidemiology and management of self-neglect and abuse (1,16), we should act to renew our social contract with older Americans by supporting and expanding model programs for these potentially devastating disorders (8,17).

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