ELDER SELF-NEGLECT: IMPLICATIONS FOR HEALTH CARE PROFESSIONALS

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Abstract

Elder self-neglect refers to the behaviour of an elderly person that threatens his or her own health and safety. Despite the adverse health outcomes associated with self-neglect, the majority of cases go unnoticed by health care professionals. This article discusses the epidemiology of self-neglect, associated factors, and its consequences. Even though there are significant gaps in research, enough information is known to guide clinical practice. This article presents the practical approaches a health professional can take when a reasonable suspicion of elder self-neglect arises. Public health and interdisciplinary team approaches are needed to manage what will be a growing problem as the number of older adults around the world increases.

Résumé

La négligence de soi chez une personne âgée représente un comportement qui met en péril sa santé et sa sécurité. Malgré ses effets délétères sur la santé de la personne âgée, la majorité des cas de négligence ne sont pas identifiés par les professionnels de la santé. Cet article discute de l'épidémiologie, des facteurs associés, ainsi que des conséquences de la négligence de soi. Malgré les lacunes dues au manque de données en recherche dans ce domaine, il y a suffisamment de données scientifiques pour guider la pratique clinique. Cet article présente des approches pratiques qui peuvent être adoptées en cas suspicion clinique de négligence de soi. Il y a un besoin d'approches interdisciplinaires et en santé publique afin de permettre la prise en charge de cette condition, qui augmentera en fréquence avec le vieillissement mondial de la population.

Definition of Elder Self-Neglect

Elder abuse, sometimes called elder mistreatment or elder maltreatment, is a pervasive public health issue and is associated with adverse health outcomes. Among all cases of elder abuse reported to social services agencies, elder self-neglect is the most common and crosses all demographic and socioeconomic strata of the aging population. The National Center on Elder Abuse defines self-neglect as "the behavior of an elderly person that threatens his/her own health and safety. Self-neglect generally manifests itself in an older person as a refusal or failure to provide himself/herself with adequate food, water, clothing, shelter, personal hygiene, medication (when indicated), and safety precautions."[1] In 2004, the United States spent nearly US$500 million on social services agencies to serve and protect older adults who are abused or neglected by others or themselves. Little research has been conducted on self-neglect, and most studies to date are small, cross-sectional, and limited by sampling techniques and definitional issues.[2]

Box 1. Definition of Self-Neglect

Self-neglect is the behaviour of an elderly person that threatens his or her own health and safety. Self-neglect generally manifests itself in an older person as a refusal or failure to provide him- or herself with adequate food, water, clothing, shelter, personal hygiene, medication (when indicated), and safety precautions.

Significance

Scope of the Problem

Studies to estimate the scope of self-neglect have been based on data that are derived from reports made to Adult Protective Services (APS). These studies suggest that self-neglect is on the rise and

is more common than all of the other forms of elder abuse combined. Recent studies in a large population-based study indicate that the prevalence of elder self-neglect is about 9%.[3] In addition, among old adults with lower levels of socioeconomic status ($US15,000/year) and cognitive impairment and physical disabilities, prevalence could be as high as 15%. However, no population-based epidemiological study has systematically examined the incidence of self-neglect or the potential change in self-neglecting behaviours over time.

Risk Factors

Available evidence suggests that those over age 75 years, African Americans, and those with lower socioeconomic status are at higher risk for self-neglect.[4] In addition, evidence suggests that lower socioeconomic status is associated with greater severity of self-neglect in community-dwelling populations. Several cross-sectional studies have found that cognitive impairment and physical disability are associated with an increased risk for self-neglect, even after considering socio-demographic and socio-economic statuses.[5–7] Recent studies suggest that older adults with higher levels of psychological distress and lower levels of social relations are more likely to be reported to APS for self-neglect.[6]

Few longitudinal studies have examined the factors associated with self-neglect. One study of 2,812 older adults in the Established Populations for Epidemiologic Studies of the Elderly (EPESE) cohort found that greater cognitive impairment and depressive symptoms predict self-neglect reports to APS.[8] A study of 5,519 older adults from the Chicago Health and Aging Project (CHAP) demonstrated that a decline in physical function (both observed physical performance testing and self-reported) and executive function predicted the presence and severity of self-neglect.[9,10] However, it is also possible that self-neglecting behaviours may exacerbate the cognitive and physical functions, and temporal relationships and causal mechanisms require further exploration.

Consequences of Self-Neglect

Despite major gaps in our current knowledge about the consequences associated with self-neglect, available evidence suggests that they are associated with significant adverse health outcomes. One cohort found that self-neglect was associated with an increased risk for nursing home placement[11] and all-cause mortality.[12] Similarly, a study of 9,318 older adults found that self-neglect was associated with a higher mortality rate, particularly during the first year of being identified for self-neglect.[13–15] In addition, self-neglect is associated with a 15-fold increased risk for cancer related mortality and 10-fold increase in nutritional- and endocrine-related mortality. Moreover, research from the same cohort suggest that Black compared with White older adults with self-neglect had substantially higher all-cause mortality risk and that this elevated mortality differential is sustained over time.[14]

Self-neglect is also associated with increased utilization of health care services. Dong et al. found in the CHAP cohort that older adults who self-neglect used emergency services at a rate that was three times greater than that for those without self-neglect. Even after controlling for extensive confounding factors, the significant association remains.[16] In addition, self-neglect is associated with increased rate of hospitalization and longer lengths of hospital stay.[17] Moreover, a recent study suggests that those who self-neglect use hospice services more frequently and that they have a shorter time between admission and death.[18] Despite the need for further research on the consequences of self-neglect, evidence thus far suggests that self-neglect is associated with significant adverse health outcomes.

Management Principles

Role of the Health Care Professional

The primary care physicians are well situated to screen for elder self-neglect in its early stages. Phenotypes of self-neglect typically include personal hygiene, environmental hazard, and dangerous lifestyle choices.[19,20] There are two scales that have been psychometrically tested to examine the phenomenon of self-neglect – namely, the Chicago Self-Neglect Scale and the Texas Self-Neglect Severity Scale – both of which require an in-home and in-person visit.[3,19] During a routine primary care physician office visit, answers to questions about how older adults manage their daily lives can suggest predisposing issues that will eventually impair the patients' ability to live independently. Minor difficulties in handling these activities of daily living may be associated with present and future self-neglect, which may evolve and could progress in severity over time. Assessments of patients' functional and cognitive statuses are important adjuncts to understanding the predisposing and precipitating risk factors associated with elder self-neglect. In addition, those patients who screen positive for psychosocial distress could also be potentially screened for elder self-neglect.

Our recent understanding shows that self-neglect often correlates with the health care system use. Increased screening and treatment should be instituted in the emergency departments and hospital settings, especially for those who frequently visit the health care setting despite adequate care and management plans. Discharge planning and home health services could play pivotal roles in identifying potentially dangerous environments and lifestyle choices that could jeopardize the safety and well-being of older adults in the community. Early detection and interventions, such as leveraging effective treatment of actual underlying issues, providing community-based services, and appropriately involving family, may help delay or prevent self-neglecting behaviours. Indicators of possible self-neglect should lead to a report to APS, the ombudsman, or local police. It is important for health care professionals to know their own country's and state's/province's definitions of self-neglect and mandatory reporting requirements.

Reporting

In the United States, almost all states have mandatory reporting laws that require health care professionals to report a reasonable suspicion of elder abuse cases, including self-neglect. APS is charged with taking a report and investigating alleged self-neglect if the older adults reside in the community. A long-term care ombudsman agency investigates alleged incidents that occur in licensed facilities such as skilled nursing facilities. However, APS is not readily available in most part of Canada, and health care providers should pay special attention to the legal and adult protective issues within their jurisdictions. In addition, there is significant differences in the Canadian versus US health care system and potential differential access to primary care physicians, which in turn

Box 2. Responsibilities of Health Care Professionals

There are differences in US and Canadian social services and legal services in dealing with the issues of elder self-neglect.
Health care providers should pay attention to the legal and adult protective services issues within their jurisdiction in Canada.

might affect the ability to diagnose or the outcomes for the self-neglect cases.

According to the 2000 Survey of State APS, the most recent data available, health care professionals were responsible for 11.1% of elder abuse complaints or reports. Specifically, physicians made 1.0% of the reports. A survey of APS workers in 43 states found that of 17 occupational groups, physicians were rated in the least-helpful category for detecting abuse and neglect. The reasons cited by physicians for not reporting included subtlety of signs, victim denial, and lack of knowledge about reporting procedures. Other reasons described by primary care physicians included concern about losing physician-patient rapport, doubts about the impact of an APS intervention on a patient's perceived quality of life, and perceived contradictions between mandatory reporting and the health care provider's ability to act in the patient's best interests. Despite these concerns, most health care providers in the United States are mandated reporters. Failure to report may lead to legal consequences ranging from monetary penalties to jail sentences. A compassionate clinician's explanation of the need to make a report and the desire to help improve a dangerous situation can help the APS worker have a more successful visit.

The scope and delivery of services provided by APS agencies vary due to differences in state laws, how enforcing laws are interpreted, and levels of funding and interest in different areas within the state. APS authority is limited. Irrespective of location, APS aims to provide self-neglecting older adults with coordinated interdisciplinary care that encompasses social and health systems. This is done with an underlying philosophy that promotes a client's rights to autonomy and self-determination, maintains a family unit whenever possible, and provides recommendations for the least restrictive living situation. The APS worker must presume the client has decision-making capacity and must accept the client's choices until the client is determined by a health care provider or the legal system to lack capacity.

Decision-Making Capacity

One of the most difficult dilemmas involves this: under what types of situations does the medical community and society at large have a responsibility to override an adult person's wishes? For health care professionals, this issue is typically framed in terms of decision-making capacity, something that clinicians assess on a regular basis in both formal and informal ways.[21] The presence or lack of capacity is often a determining factor in what the health care professionals, community, and society need to do next. However, capacity is not often completely present or completely absent. It is a gradient relationship between the issues in question and an older adult's ability to make these decisions. For complicated health issues, there is greater need to require higher levels of decisional capacity. At the same time, for simple issues, even an adult with cognitive impairment could have decisional capacity. Health care providers are often forced to take a grey area and make it black or white for purposes of guiding next steps such as guardianship/conservatorship. Commonly used brief screening tests such as the MMSE are inadequate for determining capacity except at the extreme scores. Tests useful in assessing decision-making capacity are the Aid to Capacity Evaluation, the Hopkins Competency Assessment Test, and Understanding Treatment and Disclosure.

Role of Interdisciplinary Teams

The proliferation of interdisciplinary teams in the field of self-neglect despite a dearth of data regarding cost-effectiveness is an indicator of the complexity of the problem. Such teams are usually composed of primary care providers, social workers, social services, legal professionals, ethicists, mental health professionals, community leaders, and residents. However, before such a team meets to discuss a case, an in-home visit should be conducted; this would greatly assist the team in the assessment, evaluation, and intervention strategies for a case of self-neglect. A survey of the APS workers who made referrals to a team indicated that the team was helpful in confirming the abuse, documenting impaired capacity, reviewing medications and medical conditions, facilitating the conservatorship process, persuading the client or family to take action, and supporting the need for law enforcement involvement. Other studies have used mixed quantitative and qualitative measures, and have found that an elder abuse forensic centre team consisting of APS and other community-based workers, medical professionals, and criminal justice professionals (police and district attorney) improved the efficiency and effectiveness of handling suspected elder abuse cases. Navarro et al. used a logic model to provide a framework for describing an elder abuse forensic center; meeting participants rated the team as highly effective.[22] While interdisciplinary teams may be an example of "action over evidence," the team members' belief that these meetings are highly effective implies the utility of this mechanism for handling elder mistreatment; it deserves further study. At the present time, however, there is no institutionalized funding mechanism to support these services.

Key Points

- *Elder self-neglect is a pervasive public health issue, and prevalence is estimated to be around 9%.*
- *Cognitive impairment, physical disability, and psychosocial distress are associated with increased risk for self-neglect.*
- *Self-neglect is associated with morbidity, premature mortality, and increased health services utilization.*
- *Physicians should consider screening for and treating cases of self-neglect in health care settings, as well as making determinations of decision-making capacity in older adults.*
- *Interdisciplinary teams are critically needed to treat and prevent cases of elder self-neglect.*

Conclusion

There have been many opportunities for health care professionals to intervene with cases of self-neglect through the health care system. While data are lacking, it is fair to surmise that maximizing function and linking older adults to rehabilitation, community programs, and/or social services may help prevent worsening self-neglect. The complexities of elder self-neglect require the coordination of medical, social, and legal professionals as well as the broader community to balance the duty to protect with the duty to respect civil liberties.[23] How self-neglect relates to other types of elder abuse is just beginning to be understood. Future longitudinal studies are critically needed to inform practice and policy to protect this vulnerable population.

Acknowledgements

The authors wish to thank the front-line workers addressing the issues of elder abuse and neglect and protecting this extremely vulnerable population. This work was supported by National Institute on Aging grant (R01 AG042318, R01 MD006173, R01 AG11101 & RC4 AG039085), Paul B. Beeson Award in Aging (K23 AG030944), The Starr Foundation, John A. Hartford Foundation, and The Atlantic Philanthropies.

This article was peer reviewed.
Conflict of interest: None declared.

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