Self-neglect and Resistance to Intervention: Ethical Challenges for Clinicians

Alexia M. Torke, MD, MS[1,2,3,4] *and Greg A. Sachs, MD*[1,2,4]

[1]Indiana University Center for Aging Research, Indianapolis, IN, USA; [2]Regenstrief Institute, Inc., Indianapolis, IN, USA; [3]Fairbanks Center for Medical Ethics, Indianapolis, IN, USA; [4]Division of General Internal Medicine and Geriatrics, Department of Medicine, Indiana University School of Medicine, Indianapolis, IN, USA.

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The recent IOM report Retooling the Aging Workforce[1] draws attention to the urgent need for all health care providers to develop greater expertise in geriatric medicine in order to care for the nation's growing population of older adults. General internists will play an essential role in that care, and therefore must gain competence in the recognition and treatment of geriatric syndromes. In addition to syndromes that have been well characterized, such as falls and incontinence, there may be additional conditions that have been less well described but that are equally important. In this issue of the Journal, Pavlou and Lachs describe such a clinical entity: self-neglect.[2] The authors point out that self-neglect is an important problem for medical professionals because it has medical causes and leads to negative health consequences. Although the prevalence may be high in older adults and the causes may be treatable in an important number of cases (for example when caused by depression), self-neglect has been studied very little. There is a need for empirical data to guide medical practice. The authors have made an important contribution by drawing our attention to the issue of self-neglect. They also provide a useful clinical approach to such patients, based on the limited evidence base that is currently available on this topic. Finally, they outline a research agenda to better define self-neglect, augment the evidence base for this condition, and identify effective treatments.

As practicing clinicians who care for a population of frail, older adults, this paper speaks to our clinical experience. However, the authors do not fully address our discomfort when treating patients who self-neglect but are resistant to interventions. Although there is little empirical evidence that addresses decision making for these patients, we provide a framework developed from the ethics literature for addressing patients with self-neglect who resist interventions. We note that this framework may be helpful to general internists in other settings too, such as a in the care of patients with both serious mental illness and complex medical problems.

Patients who resist medical interventions are often troubling to physicians because they challenge our ability to meet one of the fundamental goals of medicine: to act for the good of the patient.[3,4] This goal has traditionally been justified by the principle of beneficence o`r best interests. More recently, others have noted that ethical obligations may also arise from our sense of caring for others and a desire to maintain relationships.[5] In the medical setting, an ethic of caring may provide an equally strong justification for taking responsibility for patients' needs.[6] Under most circumstances, we assume that our patients will act in their own best interests and that we can support them in their efforts. Clinicians may face great moral distress when they witness a patient making choices that seem to be harmful or dangerous. Allowing a patient to neglect his or her own fundamental needs without intervening may be a violation of our obligation to care for the patient. Yet some patients who self-neglect will be highly resistant to intervention that may improve their health and safety. Why is it such a struggle to intervene in the life of a self-neglecting patient? We believe this is because of U.S. society's strong emphasis on individual liberty.

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PATIENT PREFERENCES AND DECISION MAKING CAPACITY

American society, perhaps more than any other, has long placed a high value on self-determination. In many instances, individuals are permitted to make lifestyle choices that are unusual or eccentric, as long as they are not violating laws or infringing on the rights of others. The authors rightly point out that our society tolerates wide variations in acceptable levels of behavior, including personal health and hygiene. Additionally, we allow a great deal of latitude in the type of justification individuals must give for their own actions. Many persons give reasons for their choices that would not meet the philosopher's strict definition of an autonomous act — one that is consistent with that person's own motivations and values.[7] In our society, we err on the side of personal freedom in many cases. Current American medical practice is suspicious of paternalism or overriding a patient's preferences for his or her own good.[3]

The authors correctly point out that the first ethical issue in a case of self-neglect is determining whether the patient has decision making capacity. Although this may identify some patients who are clearly unable to make their own decisions, the issue of self-neglect challenges the boundaries of decision making capacity. Is it possible to give adequate justifications for living in squalor or ignoring one's basic needs? It may be reasonable to state that a failure to provide for one's basic human needs provides enough evidence that a person lacks capacity. A related question is whether self-neglect should be handled differently when it is part of a life-long pattern of behavior as opposed to a recent change. Some have argued

that behavior consistent with one's previous life choices should be respected, because it is authentic or a reflection of who the person is.[8] However, a change in behavior may be an indication of a new and possibly treatable medical diagnosis, such as depression or subacute or chronic delirium. Should suspicion for an underlying medical cause justify a higher level of intervention?

The authors point out that there is a subset of patients who self-neglect but have intact cognition based on formal testing. It is difficult to determine if such patients lack decision making capacity. There are empirical and theoretical arguments that cognitive function and decision making capacity are separate, distinct concepts.[9] Although they almost always overlap at the extremes (for example, patients with severe impairments in cognition always lack decision making capacity), they may not be concordant when impairments in either domain are less severe.[10,11] For example, it would be reasonable to conclude that the patient described in the article lacks decision making capacity despite her normal Mini Mental State Exam, because she lacked appreciation of the consequences of her behavior to her own health.

However, even if we determine that the patient in this case lacks the capacity to make decisions about her living environment, the decision of how to intervene remains difficult due to the practical constraints of providing for a patient's best interests. Patients who resist intervention pose a second key ethical issue: how to determine what is best for the patient.

PRACTICAL CONSIDERATIONS AND BEST INTERESTS

Establishing a safe living environment for an older adult who self-neglects may be challenging if the patient resists. Patients who are placed in a new living environment may be able to leave, or may be disruptive to other residents. Even if the person appears to have poor judgment, living in an environment of the patient's choosing may in some cases be preferable, for example, to a locked dementia unit in a nursing home. In other words, even if clinicians determine that the individual lacks the insight to make decisions about their living environment, it may not be in the person's best interest to be institutionalized or placed in any other highly restrictive environment. Studies have found that many people state they would rather die than live in a nursing home.[12] The point at which a patient—even one with mild to moderate dementia—should be forced to move from independent living to a nursing home setting is not always clear.

Additionally, the fragmented U.S. health care system provides a patchwork of social services to older adults that vary widely by geographic location. The nature and extent of resources available to help older adults live independently in the community may have an impact on the likelihood of institutionalization. Variations in nursing home quality may impact whether or not living in a nursing home is in the best interests of the patient, even compared to a less than ideal home setting. Health care services for older adults should be broadly defined to include informal care and community based resources. Improvement in all these types of care is needed to address the needs of our aging population.[1]

In some cases, patients who self-neglect will lack a clear surrogate decision maker, such as a legally designated durable power of attorney or a close family member. Physicians must also consider who should make a determination of best interests for such "unbefriended" older adults. In some cases, it may be necessary to petition the courts for establishment of a legal guardian. If more urgent decisions are needed, health care providers may need to act based on their own assessment of the patient's interests. Ethics consultation services may provide additional guidance in such cases. In all cases, health care providers, legal guardians and other surrogate decision makers should seek to reach consensus on the best course of action for the patient.[13]

Many complex cases of self-neglect will reach a good outcome by negotiation with the patient and by an effort to reverse treatable medical causes. However, patients who resist intervention will continue to provide important ethical and practical challenges for clinicians. We provide a 2-step framework for addressing these challenges. The first step is to determine whether the patient has decision making capacity. In some cases, a lack of insight about the self-neglecting behavior may provide adequate evidence that the patient cannot make decisions regarding their living environment. If the patient lacks capacity, the second step involves determining what interventions are in the patient's best interests. Physicians, surrogate decision makers and other health care providers must work together to determine whether a proposed intervention would truly leave the person better off than their current circumstances.

Corresponding Author: *Alexia M. Torke, MD, MS; Indiana University Center for Aging Research, 410 W. 10th Street, HITS Suite 2000, Indianapolis, IN 46202, USA (e-mail: atorke@iupui.edu).*

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