



Ethical Perspectives on Self-Neglect Among Older Adults

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KEY WORDS

autonomy
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Self-neglect is a serious and growing problem among older adults. A 2004 survey from Adult Protective Services (APS) showed that adults age 60 or older were named in 85,000 reports of self-neglect from 21 states (Naik, Lai, Kunik, & Dyer, 2008; Teaster, Dugar, Mendiondo, Abner, & Cecil, 2006). Although rehabilitation nurses are obligated to uphold the autonomy of older adults and strengthen their independence, dilemmas result when people's poor health behaviors put them or others at risk for negative consequences. When making decisions about nursing actions related to self-neglecting elderly people, the basic principles of autonomy, beneficence, nonmaleficence, and capacity must be considered. The purpose of this article is to discuss major ethical perspectives related to self-neglect among older adults.

From their earliest education, nurses are taught to uphold the autonomy, or self-determination, of their patients. This is a basic tenet of the American Nurses Association (ANA) *Code of Ethics for Nurses with Interpretive Statements* (2001), which states "a fundamental principle that underlies all nursing practice is respect for the inherent worth, dignity, and human rights of every individual" (p. 7). But what if the patient's decisions are unhealthy or cause harm to him or herself or others? Are there situations in which the nurse's obligation to support autonomy might be overshadowed by the ethical principles of beneficence (to do good) or nonmaleficence (to do no harm)? The issue of self-neglect presents such a dilemma. The purpose of this article is to discuss major ethical perspectives related to self-neglect among older adults.

Self-neglect among older adults is a serious and growing problem in the United States. A 2004 survey of adults age 60 and older showed that Adult Protective Services (APS) received nearly 85,000 reports of self-neglect from the 21 states that provided this information by age group (Naik, Lai, Kunik, & Dyer, 2008; Teaster, Dugar, Mendiondo, Abner, & Cecil, 2006). Because older adults who self-neglect tend to be socially isolated, it is likely that this number is grossly understated. These APS statistics represent less than half of the states in the United States, so the true number of older adults who self-neglect could be staggering.

With the growth of the older adult population, more emphasis has been placed on strengthening the autonomy of older adults and empowering them to remain independent in decision making for as long as possible. But when does the ethical obligation to respect an older adult's autonomy conflict with the ethical principle of doing no harm or promoting good? Consider the following case.

Case Example

Mrs. Lindquist was an 83-year-old female with no significant medical history and no living family members. She lived independently at home alone until she fell in her basement while doing laundry; she lay on the floor for more than 48 hours until she was found by some neighbors. After being treated in the intensive care unit for severe dehydration, multiple contusions, and a fractured wrist, she was transferred to the inpatient rehabilitation unit to undergo therapy and regain her strength. During discharge planning, Mrs. Lindquist had no recollection of her fall, nor why it might have occurred. In an interview with the social worker, she denied ever having fallen. A physician noted on the chart that she had mild dementia but could still be discharged to home. Mrs. Lindquist did poorly on a 3-item recall test, but scored a 28 on a later mini-mental status exam. Her short-term memory seemed to be the most significant problem. She refused home health services at first, stating she was fine and could manage at home by herself with a little help from her friends. After some coaxing from her friends, Mrs. Lindquist signed papers for follow-up home therapy and companion services on a limited basis.

The day after discharge, the first nurse to visit found Mrs. Lindquist on the floor in her bedroom where she had fallen again and could not get up. She did not have any apparent injury. She seemed unaware that her clothes were soiled with urine and feces. There was no food in the house, although it was tidy and neat, except for some fruit flies in the kitchen on some spoiled candy. She said she had not eaten all day. Friends were to come in each evening to help with meals and check on her at night. The discharge planner recommended 24-hour-a-day care for at least 2 weeks until Mrs. Lindquist was able to regain more

range of motion in her wrist. Mrs. Lindquist refused to allow people in her home for more than a few hours in the morning because she didn't think she needed help and didn't want to pay for services, despite having the financial resources.

One week after discharge, her physical status had improved, but she was still at significant risk for falls due to an unsteady gait. Two home health agencies refused to provide services after evaluation because they felt she was in a dangerous home environment without 24-hour-a-day supervision due to her fall history and dementia. Mrs. Lindquist would not allow any other agencies to enter her home, maintaining that she was fine living alone. Within 10 days after discharge from the rehabilitation unit, Mrs. Lindquist was living independently again without any home health services, relying on the kindness of neighbors to do her shopping and other chores. At 3 weeks postdischarge, she had not been out of her home at all and was totally dependent on one neighbor for help, but was talking about driving her car again. She never completed the physician-ordered physical and occupational therapies to help with regaining range of motion in her wrist and improving her balance. Her memory continued to deteriorate and, at times, she became belligerent and irate with others when they suggested that she needed help. She wore soiled, tattered clothing, yet continued to refuse healthcare assistance, saying she didn't need any help. Although she had personal financial resources, she chose not to purchase new clothing for herself or replace completely worn out household items such as towels and bed linens. Mrs. Lindquist was able to feed and dress herself, but she did not bathe regularly or pay attention to her personal hygiene. Whether or not she ate food that was provided by her friends was questionable, and she appeared to have lost a small amount of weight in the 3 weeks postdischarge from the rehabilitation unit in the hospital, although she was not emaciated. She refused services such as Meals on Wheels and allowed only a few neighbors who were willing to assist with grocery shopping and home maintenance into her home.

In a situation such as this, the older adult has not been deemed incompetent. It is assumed that she has the capacity to make her own decisions with regard to self-care, finances, and living arrangements. Mrs. Lindquist was indeed able to make many reasonable decisions on her own, such as what food she wanted from the grocery store or when she would go to bed at night, but made many other decisions that contradicted the advice of all medical professionals involved in her case. Considering her diagnosis of early dementia, her lack of attention to personal hygiene, nutrition, and safety were red flags of the syndrome of self-neglect. Self-neglect as a geriatric syndrome includes

its "often multifactorial etiology, its clear independent association with increased mortality, and the fact that two other geriatric syndromes (cognitive impairment and depression) are risk factors for self-neglect" (Pavlou & Lachs, 2006, p. 831). Although Mrs. Lindquist's home was tidy because the neighbors had cleaned it for her, she had poor personal hygiene and negative health behaviors that were uncharacteristic for her prior to her fall. She was strongly independent and placed a high value on remaining so.

What if an older adult such as Mrs. Lindquist makes a conscious choice to live in a self-neglectful manner when services are available that are not cost prohibitive to the individual's situation? Or what if the person has early dementia, as in Mrs. Lindquist's case, and chooses to refuse support services? Where does the patient's right to autonomy end and the ethical obligation of the nurse to do no harm or to do good begin? How do the answers to these questions influence nursing actions? To explore some possible solutions, we must first identify what is meant by self-neglect.

Defining Self-Neglect

Self-neglect is "the inability to provide for oneself the goods or services to meet basic needs" (Dyer, Goodwin, Pickens-Pace, Burnett, & Kelly, 2007). Self-neglect is associated with functional decline and poor nutrition (Reyes-Ortiz, 2006). Significant predictor variables of self-neglect were found to include perception of fewer social resources, poor performance on the mini-mental state examination (MMSE), and a diagnosis of chronic obstructive pulmonary disease (COPD; Tierney et al., 2004). Self-neglect has been associated with problems of dementia, depression, diabetes, psychiatric illness, cerebrovascular disease, and nutritional deficiency that lead to executive dysfunction and either a lack of capacity for self-care or an impairment in ability to perform activities of daily living (ADLs) and instrumental activities of daily living (IADLs). When such impairments are combined with inadequate support services, self-neglect is often the result (Dyer et al.).

Gibbons, Lauder, and Ludwick (2006) defined *self-neglect* as "the inability (intentional or unintentional) to maintain a socially and culturally accepted standard of self-care with the potential for serious consequences to the health and well-being of the self-neglected and perhaps even to their community" (p. 16). They reviewed the concept of self-neglect in the literature and summarized risk factors that included advanced age, social isolation or poor social support, chronic medical conditions, acute hospitalizations or emergency room visits, and malnutrition or dehydration. The authors suggest the following diagnostic test criteria be used by healthcare providers to

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identify self-neglect: "...inadequate personal hygiene (or environmental hygiene) or at least two of the following: lack of follow-up or missed appointments for health problems, escalation of health problems to unmanageable levels possibly requiring emergency interventions, inadequate preventative practice (diet, exercise, smoking cessation), medication or treatment mismanagement despite a clear understanding of the rationale for regimen recommendations, and a lack of follow-through with preventative or diagnostic testing related to health conditions" (Gibbons, Lauder, & Ludwick, p. 15). The case study discussed earlier had each of the risk factors listed and met the test criteria for self-neglect in personal hygiene, poor diet, and lack of follow-up with home health care and therapies.

Ethical Principles Related to the Right to Self-Neglect

The major ethical principles that interact with an older adult's right to self-neglect are autonomy and capacity of the person, and beneficence and nonmaleficence of the healthcare provider. Each of these principles will be discussed.

Autonomy

Autonomy is self-governance, independent decision making, and freedom of choice without the constraint of others. Beauchamp and Childress (2001) state that respect for autonomy "is a professional obligation. Autonomous choice is a right, not a duty of patients" (p. 63). The *ANA Code of Ethics for Nurses* (2001) reflects these same ideals, stating that "respect not just for the specific decision but also for the patients' method of decision making is consistent with the principle of autonomy" (p. 9). Nurses are expected to be sensitive to the differences that might be seen among older adults regarding decision-making processes that may be different from their own.

Rehabilitation nurses have a professional obligation to place a high value on supporting the patient's autonomy. Vulnerable older adults are considered at high risk for losing their autonomy for various reasons, including family members stepping in to make decisions for a competent parent, healthcare providers' lack of sensitivity to the needs of older adults, or the lack of societal awareness of normal changes during aging that might make an older adult appear less competent than he or she truly is. The trend toward fostering the autonomy of older adults to maintain independence for as long as possible is a good one. However, in cases of self-neglect, it could delay needed intervention as healthcare professionals attempt to respect autonomy above all other principles. Certainly a balance is needed and may be found in considering the concepts of beneficence and nonmaleficence.

Beneficence and Nonmaleficence

A general guiding principle for overriding an older adult's rights to refuse treatment or make decisions that could negatively affect their health is to prevent harm, either to the older adult or to others (Bandman & Bandman, 2002). The ethical principle of *beneficence* "refers to a moral obligation to act for the benefit of others" (Beauchamp & Childress, 2001, p. 166). This involves protecting the rights of people, preventing harm, removing conditions that could cause harm, helping the vulnerable, and rescuing those in danger. *Nonmaleficence* is the obligation not to harm others or to do no harm. It is a more passive principle than beneficence, which actively seeks to promote good. Together, both principles provide a strong rationale for action in cases of self-neglect among older adults.

For example, a nurse could report a person's self-neglect to APS if he or she deemed the threat of harm to the person was serious enough that his or her actions were needed to prevent harm. In this way, the nurse may be using beneficence—actively promoting good—in trying to ensure his or her patient's best interest.

Nurses may base their interventions related to beneficence and nonmaleficence on the knowledge that self-neglect can have serious consequences for the older adult. Naik, Burnett, Pickens-Pace, and Dyer (2008) used a cross-sectional matched pairs design to examine 100 community-living adults reported to APS for self-neglect and 100 adults from a community geriatric clinic. Study results indicated that self-neglect was associated with increased morbidity and mortality. In another study, rates of nursing home placement from self-neglect were 69.2% (Lachs, Williams, O'Brien, & Pillemer, 2002).

Although there will be certain circumstances that unquestionably mandate reporting to APS, there are many situations when an older person may be marginally able to continue to live alone or chooses as a competent person to live a life of self-neglect. Nurses must carefully weigh the decision to report suspected self-neglect to APS, and several important issues should be considered. Self-neglect consequences if health professionals intervene could mean forced removal of the person to a facility that is unfamiliar and undesired and institutionalization or state guardianship. Rehabilitation nurses must ask themselves whether the consequences would be in the best interest of the patient. For example, a competent older adult may prefer to live in his or her apartment in social isolation and neglect medical care by never leaving the home because of social phobias, yet if he or she has a neighbor who helps with grocery shopping and housekeeping and a home care nurse to periodically check on him or her, he or she is neglecting himself,

but not causing harm to others. Forcing such a person to leave his or her own home and go to a long-term care facility may result in more psychological harm than physical good. Careful consideration is needed.

However, if an older adult is neglecting his or her own health and living in squalor, it can also affect the surrounding neighborhood. Report of rodent infestation and garbage pile-ups have caused some neighbors to report the self-neglecting older adult to protect their own homes and families. If competent, do we allow the self-neglecting person to be left alone or forcibly intervene to protect him or her or the neighbors? Naik, Lai, Kunik, and Dyer (2008) quoted clinical ethicist Linda Farber-Post as saying "honoring the wishes of a person with capacity demonstrates respect for the individual. Honoring the wishes of a person without capacity is a form of abandonment. The distinction, insofar as it can be reliably made, is critical" (p. 26). It is often assumed that the person who lives in a socially unacceptable manner must not have capacity. This person would not be able to exercise autonomy because his or her incapacitated state would make it impossible to express his or her true wishes, and no one with capacity would wish to live in such conditions, or so it is postulated. The problem then becomes the determination of capacity.

Capacity

Capacity is a term that is often used interchangeably with *competence*. However, the courts are the ultimate authority when determining *competence*, and capacity assessments, such as those done by a qualified mental health professional, may provide information about a person's competence. In contrast, *capacity* may have several dimensions, including decisional, personal care, self-care and self-protection, and executive capacity, depending on which author is consulted (Hazelton, Sterns, & Chisholm, 2003; Naik, Lai, et al., 2008). One key to identifying self-neglect "involves determining whether the individual can both make and implement decisions regarding personal needs, health, and safety (i.e., does the patient possess the capacity for self-care and self-protection)" (Naik, Lai, et al., p. 26).

There may be a variety of dimensions of capacity in which an older adult may be able to make some decisions but not others. Competence can fluctuate, according to some experts.

In dementia, there can be a differential impairment of recall memory while the personality, values, and substantial long-term memory remain intact, as does implicit memory for recent events. People with dementia are vulnerable to being negatively positioned, thereby unfairly undermining their rights to make decisions about aspects of their lives (Sabat,

2005). It is possible that individuals can retain some significant decision-making power, albeit usually not regarding health care, even with advancing dementia. The diagnosis of dementia is not itself a criterion for incapacity (Defanti et al, 2007; Gevers, 2006; Woods & Pratt, 2005).

Mrs. Lindquist's case provides an example of a person giving clear answers during cognitive testing, yet failing to remember to eat or follow through with healthcare appointments that are obviously in her best interest. Is the older person merely asserting the right to choose, or are underlying cognitive problems variant enough to display themselves at certain times and not others? Hazelton and colleges (2003) stated that the principles of autonomy and beneficence "may appear to be in conflict in cases involving personal care capacity assessments. In theory, these discrepancies are addressed by the fact that the patient who lacks insight into his or her deficits is not truly able to act autonomously" (p. 131). As previously discussed, in cases of older adults who lack capacity to the point of harming themselves or others, the nurse may be compelled to make a decision to act in favor of beneficence to facilitate the most favorable long-term outcome for the patient.

When determining a person's capacity for decision making, there should be a focus on interdisciplinary team interventions, maintaining an ethical foundation, acknowledging cultural and gender differences, and emphasizing valid and reliable measures of capacity. Dick (2006) states that "nurses need to recognize that the self-neglect of personal and environmental health needs may not be pathological, but instead may be rooted in cultural beliefs and family coping patterns" (p. 13). The professional judgment of the person conducting the evaluation should examine the older adult's ability to make decisions about health and lifestyle. Although there are a number of tools that assist with cognitive assessment, a cognitive capacity screening done in conjunction with the MMSE may provide higher sensitivity than either test alone (Xu, Meyer, Thornby, Chowdhury, & Quach, 2002). Thus, cultural considerations related to lifestyle and environmental patterns should be explored thoroughly during the capacity evaluation. Gender differences also seem to exist in the literature. Menne and Whitlatch's (2007) research suggested that older males with depression and more advanced dementia tend to report less decision-making involvement than females and those with milder dementia.

Nursing Implications

Rehabilitation nurses truly must strive to balance protection of the older adult's autonomy with protection of his or her health and well-being. In doing so,

Key Practice Points

1. Self-neglect is a serious and growing problem among older adults.
2. Although rehabilitation nurses are obligated to uphold the autonomy of older persons and strengthen their independence, dilemmas result when people's poor health behaviors put them or others at risk for negative consequences.
3. When making decisions about nursing actions related to self-neglecting elderly people, the basic principles of autonomy, beneficence, nonmaleficence, and capacity must be considered.
4. In cases that involve making decisions related to capacity, an interdisciplinary team of professionals should be consulted and decisions should be made that are in the ultimate best interest of the older adult.

however, nurses must take care not to impose their own beliefs about what type of living environment or decisions are socially acceptable and consciously strive to find the "right balance between individual autonomy and social control through legislative intervention" (Lauder, Davidson, Anderson, & Barclay, 2005, p. 47).

Most sources agree, however, that in circumstances in which an older adult does not have the capacity to make decisions due to cognitive limitations, a surrogate decision maker may be needed. The ANA *Code of Ethics for Nurses* (2001) states "in situations in which the patient lacks the capacity to make a decision, a designated surrogate decision maker should be consulted" (p. 8). This person must act in the best interest of the older adult and understand what the patient's wishes might have been. Many area councils on aging provide guardianship services where a group of qualified individuals act as surrogate decision makers for older adults.

Although the final determination of competence is not within the scope of practice of the rehabilitation nurse, there are some practical suggestions that may help rehabilitation nurses assess the decision-making capacity in older adults and, subsequently, know when follow-up related to mental health is indicated. A comprehensive assessment should include complete background information obtained during the history and physical on admission. Information from the initial assessment may provide insight into the patient's past decision-making patterns or habits. For example, older adults who lived during years of great economic depression or recession may have adapted a lifestyle of thriftiness. Decisions that might be considered by

others as self-neglectful could be a reflection of that person's desire to save money and resources in the event of future economic downturn. Likewise, if the client is from a culture unfamiliar to the rehabilitation team, the patient should be questioned about his or her beliefs and norms. If possible, the team can confirm traditional practices with other members of that culture to help distinguish between culturally acceptable norms and true impairment in decision-making capacity. Rehabilitation nurses should thoroughly explore the personal history of the person whose capacity for decision making is in question and invite the entire interdisciplinary team to share background information of cultural or historical significance that could impact the evaluation of capacity.

The rehabilitation nurse can also perform screenings for several problems and share the results at the team meetings. Nurses can screen for general mental health status, as well as several specific conditions that would influence decision-making capacity. A general screening for cognitive function should be performed. Assessment tools such as the MMSE can provide clues to cognitive impairment, but the MMSE is no longer in print and may be difficult to obtain. The Mini-Cog is currently the preferred tool for quick differentiation between delirium and dementia. It takes only 3 minutes to administer and consists of test components that are not influenced by language, ethnicity, or educational level (Doerflinger, 2007).

The rehabilitation nurse should also rule out causes for impaired decision making that may be temporary or treatable, such as depression or delirium. Persons with chronic illness and disability are especially susceptible to conditions that place them at risk for depression and delirium. The geriatric depression scale (GDS) is a reliable and valid tool that can be used in community, home, acute care, rehabilitation, or long-term care settings to assist with the assessment of depression, even in patients with some dementia. The short form consists of 15 questions, and the long form has 30 questions. The short form is more appropriate for older adults in rehabilitation because it takes 5-7 minutes to complete (Kurлович & Greenberg, 2007). The confusion assessment method (CAM) provides a valid and reliable tool to examine the common signs of delirium, including onset, inattention, disorganized thinking, and level of consciousness (Waszynski, 2007). Rehabilitation nurses can access these and many other free screening tools at the John A. Hartford Institute for Geriatric Nursing's website: <http://consultgerim.org/resources>. Finally, it is important that a psychological evaluation by a qualified mental health professional be ordered if basic screenings suggest a problem.

In summary, there are many aspects to the issue of self-neglect among older adults. It is a complex

phenomenon with many ethical pitfalls, potential causes, and solutions. Nurses should strive to uphold the older adult's autonomy as much as possible, but when an elderly person self-neglects, the nurse may be compelled to make a decision that overrides the person's autonomy to prevent harm to him or her or others. Rehabilitation nurses should conduct a careful and thorough assessment to provide information to other team members. In many instances of self-neglect, the ethical obligations of beneficence and non-maleficence may take precedence over the autonomy of the person to self-neglect. In cases that involve making decisions related to capacity, an interdisciplinary team of professionals should be consulted, and the decisions that are made should ultimately be in the best interest of the older adult.

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