

Self-Neglect and the Elderly: A Multidisciplinary Exploration

“. . . [We] need to start over and quit seeing it as a safety-versus-freedom issue. It's more an issue of are we going to try to heal and restore people, or are we going to maintain that it's up to individuals to get what help they need, and (let them) deal with whatever has happened to them in their lifetimes on their own” (Loree Cook-Daniels, Amer. Soc. of Adult Abuse Professionals and Survivors).

This multi-year proposal is designed to develop practice guidelines and training materials for addressing self-neglect that are based on and multidisciplinary analysis of the ethical, medical, and service issues relevant to the growing problem of self-neglect. This effort is the first of its kind nationally and responds to legislation (HB 4676) in Illinois that includes self-neglect in the elder abuse statutes.

Introduction

For many years, service providers and other professionals have sought to address abuse and neglect of the elderly. More recently, we have focused on what might be called self-neglect—the older person who lives in an apartment or house so crowded with “things” that there is no pathway to the door; the 85 year old woman who rarely takes her medications or the man whose refrigerator is empty or filled with moldy food, and whose cupboards are bare. The problem might be an apartment reeking of cat urine or maggots on open wounds. Sometimes the person has Alzheimer’s disease or another form of dementia; at other times he or she appears to have a mental illness; often the person is thought to be highly “eccentric.” If neglect is identified and the person accepts assistance and there are services in the community that can meet the need in ways that are acceptable to the older person, then there are no insoluble problems. But in the absence of these conditions, we lack a clear sense of what actions are acceptable and which ones are not. Such encounters often trigger wrenching practical and ethical questions--What do I do? How do I do it? What do I have the resources to support? What weight ought to be given to indications of mental illness? Who defines risk and how might that definition differ according to who is doing the defining (e.g., a social worker, a nurse, a daughter, an 84 year-old woman)? How might we think about short-term and long-term autonomy?

When an older person appears to be suffering from a dementia or AD, though the appropriate responses may seem less conflictual, ethical and practical concerns are equally relevant. Important questions include: How much decisional capacity remains and in what areas? How much should we consider the expressed wishes of the individual even when they seem incongruous with what appears to be immediate needs? How do we honor the individual’s lifelong preferences and choices at the same time that we recognize changed conditions?

Given questions such as these and others, care providers are often torn between their wish to respect the rights of the person and their compassionate regard for what appears to be needless suffering. Self-neglect elicits compassion, frustration, and even anger (why

doesn't the person see what is good for her), familiar symptoms of moral distress. Because we are in certain professional roles, in large part for the very reason that we care about people who are or appear to be vulnerable, this kind of emotion is unsettling and suggests that further exploration is necessary. The absence of sustained discussion about these moral uncertainties leaves us with few ways to imagine actions that we can justify, other than walking away. Thus, self-neglect challenges very familiar and long-accepted ways of thinking, while at the same time it leaves us feeling very uneasy and even fearful that serious—but perhaps avoidable—harm may occur.

The following scenario illustrates the difficulties of finding solutions when the older adult resists those who offer assistance.

A caseworker at the local Care Coordination Unit (CCU) receives a call from a neighbor, who is concerned because she has not seen Mrs. Smith in more than a week. Alerted by the same neighbor, Mrs. Smith's son calls from Texas and reports that his mother "doesn't sound right." He asks that someone check up on her. Deirdre, an experienced case manager, makes a visit, and while Mrs. Smith welcomes Deirdre into the house and is willing to talk, she insists that she is fine and doesn't need anything. In the kitchen, Deirdre finds a sink filled with unwashed dishes and the odor of rotting garbage. She looks in the refrigerator, and finds only an old container of milk, the "use by" date three weeks ago, some slices of moldy cheese and a few eggs. They talk for awhile, but Mrs. Smith continues to insist that she doesn't need anything. Deirdre returns a week or so later and continues her conversation with Mrs. Smith, whose cognition seems somewhat questionable, though no clearly identifiable signs of dementia are noted. Mrs. Smith tells Deirdre that she thinks her medications are making her sick so she doesn't take them; she mentions that she has blacked out a few times. When Deirdre asks to see the medication bottles, Mrs. Smith gets very angry and insists that she has thrown them all out. She then tells Deirdre that "this conversation is over."

Madelyn Iris 4/24/06 2:52 PM

Comment: I added this about demtnia since that is a focus for FY 06 and I think we should emphasize that its not always obvious

In ideal circumstances, the CCU or another entity would have the time and resources to make several follow-up visits to Mrs. Smith in order to develop a relationship with her and build trust, with the hope that Mrs. Smith might then accept services that can improve her quality of life, protect her long term autonomy, and help her avoid becoming even more physically impaired because of her poor diet and inattention to her medications. In less than ideal circumstances, Deirdre might make one more visit and, if Mrs. Smith continues to refuse help, close the case on the grounds of client self-determination. At present, however, a heavy case load and limited resources leave the caseworker few options. Since Mrs. Smith is adamant about not wanting help, Deirdre has no legal authority to take any other action, and in today's thinking it is uncertain if she has any moral responsibilities since the question of self-neglect has fallen almost exclusively under the rubric of self-determination. And so Mrs. Smith continues to live in her small house with no assistance.

Situations like that of Mrs. Smith are familiar to anyone who spends time working with older people in the community. It is also emerging as a concern among family members, neighbors, clergy and many other people who see what may be described as self-neglecting behaviors among colleagues at work, the person down the street, a member of their congregation, or someone they once saw regularly at the grocery store. Yet, self-neglect has received little attention in the research or practice literature in contrast to the more familiar abuse or neglect perpetrated by another person. The reasons for this are not entirely clear but we can make some assumptions that are generated by broadly held values in American society. Freedom from interference so we can live as we choose is a leitmotif in the U.S. It is further assumed that all adults are autonomous and have the skills and experiences that permit them to make choices without outside interference. In the helping professions, such as social work, interference is negatively labeled paternalism. Hence, we would seemingly have no moral obligation to care for others, or even to take them into account as we make decisions about our own lives, unless our own behavior exposes them to explicit and immediate dangers such as fire.

Madelyn Iris 4/24/06 2:52 PM
Comment: I deleted this sentence in order to shorten the proposal but if that's not a goal, then it can be left in.

Yet, there is a contrary view. Molly Rees Gavin, the President and CEO of Connecticut Community Care, Inc, one of the largest and oldest care management agencies in the U.S., put it this way, “professional social workers and nurses abdicate the highest level of professionalism at the altar of self-determination” (personal communication, 10/22/05). With heavy case loads, staff turnover, and limited resources in publicly funded programs, checking an older person with decisional capacity who refuses services “off the list” is one less person to worry about (personal communication Steve Barlam, Live at Home, 10/22/05).

Thus, situations like that of Mrs. Smith raise a variety of ethical and practical problems. Is she “self-neglecting”? How do we decide? If so, what, if any responsibilities do we have for her? What other less obvious values, in addition to self-determination and “best interests,” must we protect? If we must choose among competing values, such as self-determination and “doing good” how do we make this choice? Does self-determination always override other values such as compassion, protection of the vulnerable, and the notion that a good society must relieve “unnecessary suffering?” How ought we operate in the gray zone when a person is competent but suffers from mental illness and engages in seemingly self-destructive behaviors? What actions can we ethically justify and, of those, which are pragmatically possible? What practices will help us work toward “fixing” a situation that seem unnecessary difficult? How do other situations similar to that of Mrs. Smith’s, but also distinctive, help us to think about other actions? If someone like Mrs. Smith, who may be eligible for the Community Care Program, but who appears to be neglecting her own health, well-being and safety refuses any intervention, does society, as represented by the case management agency or the elder abuse unit cease to have any obligations to the client? Are we, as community care providers, relying too strongly on one value to the exclusion of others? Where does choice end and self-neglect begin? What practices can respond to our core values? How can the CCP – or private case management services--translate these ideas into practice? Why do we think of self-neglect for those who are over 60 but not for younger people? Does it make a difference if a person has always been this way or if it is new behavior? How can we direct people

in the community, who contact us with their concerns and their offers of assistance?
What can we learn from other states?

Other questions are raised when we think about conceptual or definitional issues: What concepts and specific actions constitute self-neglect? How is decisional capacity to be defined in suspected cases of self-neglect? What weight ought to be given to clear indications of mental illness? What are the different meanings that can be associated with the idea of risk? Who defines risk and how might that definition differ according to who is doing the defining (e.g., a social worker, a nurse, a daughter, an 84 year-old woman)? How might we think about short-term and long-term autonomy?

The Project

This project will operate over the course of three fiscal years. The project will be overseen by a four member management team (see descriptions of this team below), who will meet at least monthly to track progress.

The intent is to stimulate statewide participation in data collection and analysis, the development of practice guidelines, and a core training curriculum. An Advisory Committee will be established that will include community-based providers, ethicists, attorneys, older people, family members, and representatives from the Illinois Department on Aging. The Consortium's membership includes geriatricians, a geriatric psychiatrist, several social workers, an ethicist, social science researchers, a geriatric educator, aging network representatives, and an attorney (see membership list attached). From this foundation, we will develop multidisciplinary practice guidelines that can be incorporated into training for health and/or social service providers who will have responsibilities first for investigating possible cases of self-neglect and then working with clients. A subcommittee that includes case managers and other CCU staff will work with the Advisory Committee to develop case examples around which this project will be built. These cases will be constructed from the situations that case managers and physicians who see older patients encounter.

Madelyn Iris 4/24/06 2:52 PM

Comment: What about investigations of self neglect?

Overall project goals are:

1. To develop an ethically rich understanding of how we might honor both our obligations to and our respect for the rights of the older person who appears to be self neglecting.
2. To have in place a tested instrument that will assess risk for self neglect and be available for use by health, social service and other providers, to trigger further assessment.
3. To provide to the Steering Committee that HB 4676 will establish draft practice guidelines that address legal, ethical and practical concerns
4. To develop a training curriculum that reflects current best practice knowledge of self neglect.

Activities: Year One (all the following subject to revision)

1. Review and, as necessary, modify the structural components of the project.
 - a) Assess current membership of the Consortium to assure that the representation reflects the disciplines needed to assure a comprehensive analysis of the issue; invite new members if appropriate
 - b) This newly constituted group will serve as the project Advisory Committee
 - c) Continue existing subcommittees such as legislative, ethics/legal, data collection, clinical interventions, training, and evaluation, to support the Committee's work and add, as necessary
2. Revise the data collection instrument recently developed by the Data Collection Subcommittee, based on feedback from the CCUs and Elder Abuse staff who will use the instrument between May 15 and June 15 2006.
3. Complete a draft plan to implement a statewide data collection process from an expanded group of organizations and agencies.
4. Establish field sites for focus groups that will, in FY' 07, engage in multidisciplinary case analysis, the foundation for developing the state-wide intervention system for self neglect; initiate recruitment of participants.
5. Explore a variety of situational issues that can lead to self neglect; in particular, the presence of dementia, Alzheimer's Disease, and mental illness, and determine methodologies for addressing these.
6. Based on Consortium research currently underway to develop a "ground-up" understanding of the behaviors/concepts that are identified with self-neglect; combine this with a review of the limited, peer-reviewed gerontological, medical, social work, nursing and other relevant literature on self-neglect, and the definitions used by states in order to recommend additions and/or modifications to the definition in HB 4676.
7. Complete the risk assessment instrument now being developed by Council for Jewish Elderly and the University of Illinois School of Public Health

Madelyn Iris 4/24/06 2:52 PM

Comment: Add a few words about what the focus groups are for

Martha Holstein 4/24/06 2:52 PM

Comment: I know this is very watered down but I want to respond to Lois's apparent resistance to the definitional parts of our original proposal.

Activities: Year Two

1. Work collaboratively with the Data Subcommittee (established at the Self-Neglect Summit) to continue gathering quantitative and qualitative information that provides demographic and descriptive information about individual cases that come to the attention of the CCUs, the AAAs and/or the Elder Abuse units; compile incident reports and garner descriptive information, through a content analysis, about individuals who come to their attention.
2. Gather relevant information on the significance of mental health problems and the presence of dementia, and what such problems might mean for ethical decision-making.
3. Identify values that ought to be included in any analysis of possible cases of self-neglect.
 - a) Work with Subcommittee on Law and Ethics to identify action-guiding values that are relevant for addressing identified cases of self-neglect.
 - b) Review the ethics literature on autonomy, vulnerability, and decisional capacity

- c) Interview ethicists, health and social service professionals
 - d) Meet with older people and family members
4. Conduct multidisciplinary analyses of cases in statewide focus groups that have been identified using the information obtained in #s 1-3.
 5. Based on this multidisciplinary analysis of cases, develop a values framework for addressing situations of apparent self-neglect
 6. Identify best practices adopted by other states and locales to address identified cases of self-neglect. Summarize findings and disseminate to the Advisory Committee for review.
 7. Incorporate the risk assessment instrument (see under FY '06) into statewide practice on a trial basis, to test its validity and establish protocols for use.
 8. Incorporating all of the above, develop practice guidelines and draft a training program.
 9. Draft a plan for demonstration projects on self-neglect using different practice models.

Activities Year Three

1. Complete practice guidelines and identify the resources needed to implement these guidelines.
 - a) Test these pathways with a minimum of 3 groups who had not participated in the process, including an interim session at the 2006 Governor's Conference on Aging
 - b) Return to the working group for feedback and decision-making about these pathways
 - c) Finalize the recommended practice pathways
 - d) Determine the resources necessary to implement these pathways

2. Design a comprehensive training program, a video or other tool such as a DVD, an easy to use informational booklet, materials; distribute to churches, synagogues and other religious institutions, and other written materials suitable for different audiences. Test training materials in a minimum of two sites; make revisions as appropriate
 - a) The curriculum will:
 - i. Define Self Neglect
 - ii. Assess capacity
 - iii. Highlight mental health issues
 - iv. Identify ethical and legal issues and means of dealing with conflicts
 - v. Recommend practice pathways for addressing self-neglect
3. Launch demonstration projects that implement the practice guidelines with appropriate data collection and monitoring strategies
4. Conduct a capstone conference that presents findings to health, social service and legal providers throughout the state.
5. Implement statewide training program.

6. Disseminate materials through articles and presentations at conferences in Illinois and in other states.
7. Recommend structure and composition of a multidisciplinary team to address self-neglect issues; include developing a model for service delivery within a fee for service [mental health] system to work with older people who have behavioral problems
8. On the basis of this model, design a system-wide response for Illinois, identifying where it should be housed, who should be involved, instruments that will be used, resources necessary; with legislative committee, determine if any additional legislation is required; if so, seek sponsor and draft legislation, etc.
9. Conduct a capstone conference to present the results of this project and to launch the training program.
 - a). Plan program, choose date and location; confirm speakers
 - b) Publicize program
 - c). Select and train small group facilitators
 - d). Convene conference
 - e). Prepare report of the conference
10. Prepare other papers and dissemination materials
11. Conduct statewide training

Staffing and Organizational Efforts