

Between a Rock and a Hard Place: Balancing Safety and Independence with the Frail Elderly

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Mrs. White is an 83-year-old widow who lives alone in a small one-bedroom apartment. Until recently, her only ailments were minor arthritis and high blood pressure, but a year ago she fell on the sidewalk and broke her hip. After hospitalization and a short stay in rehab, she returned home. Following this event she became eligible for 15 hours per week of assistance from a home care aide and monthly visits from a nurse.

Mrs. White's apartment is cluttered with old furniture, piles of newspapers, and boxes of books that belonged to her late husband. She also has two cats whose feeding dishes are scattered about. There is no air conditioning and in the summer she manages with just one fan. The neighborhood where she lives has gone through significant changes and is no longer very safe. Mrs. White goes to the small grocery store at the end of her block about once a week, and spends the rest of her time in her apartment sitting, looking out the window and petting her cats.

The home care provider assigned to her finds Mrs. White very pleasant, but is concerned about coming into this

neighborhood and is frustrated by Mrs. White's refusal to get rid of some of the "junk" as she sees it. The caregiver has also expressed concern that Mrs. White's nephew, who shows up now and then, is taking money from her.

During her monthly visits, the nurse suggests to Mrs. White that they increase her hours of assistance. The nurse also introduces the possibility of moving to assisted living. Mrs. White rejects both of these suggestions, saying she likes her privacy and intends to stay in her apartment for the rest of her life.ⁱ

Introduction

Elderly women, such as Mrs. White, are ubiquitous. She is our mother, grandmother, aunt, or the woman next door. In their own ways, these elderly women and men are working hard to give purpose and a predictability to a life that has been filled with loss – loss of loved ones, loss of standing in the community, loss of the identity that is connected to their work, and perhaps most challenging, loss of health and physical independence.

In this article, I will explore one of the thorniest issues that families, health care providers, and society must address when considering the elderly, especially those elderly who are cognitively able, but

physically impaired. Common ethical wisdom argues that the wishes of the elderly person should be respected and supported; and yet, there is frequently legitimate concern on the part of family, caregivers, and the community for the elderly person's physical well-being as well. It is a difficult dance to balance these two values--maintaining independence and ensuring safety--in the process of honoring the goals of the elderly. As a result the default position often chosen by family and caregivers is to choose safety for the elder over the desire for independence.

Autonomy and the Frail Elderly

Autonomy, as traditionally viewed in secular bioethics, is defined as the ability to make decisions for one's self without coercion or undue influence.ⁱⁱ It is a deeply-held Western value and a foundational principle of health care ethics. Autonomy is conceptually divided into "agency," the freedom to choose among options, and "action," the freedom to carry out the chosen course of action. As Arthur Caplan puts it "... it is a common presumption concerning autonomy—that individuals are the best judges of what is in their interest."ⁱⁱⁱ He goes on to say "...when the [decisional] capacity for autonomy is present, it must be respected and enhanced."^{iv} Within health care, providers are required to give the patient all necessary information in order to make an informed choice about the health care they will receive. Even when the patient is a very elderly person,

it is assumed, at least in theory, that if the person has agency or decisional capacity, she will be able to make her own health care decisions.^v

In actuality, the frail, elderly patient's decisional capacity often comes under scrutiny. Most frequently, it is questioned if and when the patient is not in agreement with recommendations made by the health care providers. There are also other legitimate reasons for questioning a person's ability to make these decisions. If she is determined to be cognitively unable to make decisions that are in her best interest, a surrogate is asked to make decisions for her. But what of the patient who is elderly and who clearly has agency, but due to physical frailty or illness, may not have the ability to act on her decisions? The frail elderly patient, who has decisional capacity but lacks what Bart Collopy calls "executorial capacity," presents one of the greatest challenges to health care providers, regardless of whether she is the recipient of home care, is a patient in acute care, or is a resident in a long term care facility.^{vi}

Problems with Autonomy

Many have argued that the commonly held definition of autonomy does not really work within the complexities of elder care. George Agich has suggested that the definition of autonomy that is held as the standard works with decisions in which clear alternatives exist and the weighing of benefits and burdens of each choice is appropriate. However, Agich

contends that many decisions routinely made by all of us are of an ordinary kind. Agich refers to this reality as “actual” autonomy.^{vii} Actual autonomy is about the concrete reality of the one who is choosing. It is not just a matter of hypothetical choice, but is manifested by the habits and disposition of the individual in an automatic way, without the critical reflection normally associated with what he refers to as “ideal” autonomy.^{viii} Agich believes that the vast majority of decisions made are of the “actual” autonomy sort, so he argues that consideration of decisions about the elderly person’s day-in and day-out living should be focused on this type of autonomy. Agich believes that choices offered and decisions made should reflect who the elderly person is and what she values most. The reflection of the elder’s priorities and values will ensure recognition of the elder’s actual autonomy or agency. Agich is particularly interested in the long-term care setting where ordinary or actual decisions are made on a daily basis, but considerations of actual autonomy may be useful in working with elderly patients or clients regardless of the setting. Appreciation of who the elderly person is as an individual with a particular history and set of values, as well as a voice, should translate to virtually any setting. Social workers and nurse case managers who work in home care often worry about how to help patients or clients maintain their executional autonomy in order stay in their own homes. Thus, they engage both types of autonomy – if the choice is about whether or not to move to long-

term care, this is the kind of decision-making that calls for “ideal” autonomy. If, however, the concern is about getting groceries to the client, then it would be more of a decision requiring “actual” autonomy.

In acute care, the medical model wherein the patient is presented with appropriate options for treatment, including the benefits and risks of each, remains the existing paradigm. Since most decisions made in the acute setting have clear choices, the weighing of the benefits and burdens of the options is required. So concerns about Agich’s “actual” autonomy aren’t recognized here as relevant except when the topic is discharge planning, a process that often becomes very challenging for the elderly patient, family, and caregivers. Although there may be significant either/or decisions to make, the decisional patient who is now more frail than before she was hospitalized is trying to figure out if she will be able to go back to the life she knew. She may be very focused on those everyday decisions she has always made and whether she will be able to continue to do so. The biggest challenge of discharge planning is that it forces decision-making not only for right now, but for the future as well. Because the patient is discharged so much sooner than before, the ability to accurately predict her future functional ability is extremely difficult and the concern or fear of the frail, decisional patient is that decisions will be made for her that will inhibit or dramatically change her everyday life.

In each of these settings, if the elderly person has decisional capacity but her executional capacity is questionable, there is tension regarding her safety versus her independence. Whether the patient is being discharged home with home care or transferring to a long-term care facility, either for short stay for more rehabilitation or perhaps permanently, issues of physical safety tend to trump legitimate concerns about the patient's independence and autonomous decision-making.

Challenging the Inclination to Safety

Historically, social workers and nurses who serve elderly clients in their own homes have been among the strongest advocates for client autonomy. These health care professionals focus on making sure that clients have the services needed to maintain their current, and generally preferred, living situation. However, their professional commitment of respect for autonomy often conflicts with their duty of beneficence. In practical terms, the conflict between maintaining an elderly client in her home and ensuring the client's safety is often precarious. The client's family's concerns, as well as those of the home care agency, community and state accrediting and funding agencies, and their own need to be responsible, often put the social worker or case manager in an untenable position.^{ix} Bart Collopy cautions that too often with elderly clients "...social aberrations may be construed as mental aberrations, physical frailty as cognitive frailty, and

periodic lapses in function as proof of permanent incapacity."^x In other words, professionals and family members, no matter how caring, may misinterpret the elder's quirks or frailty as cognitive dysfunction or inability to physically function independently and, because of safety concerns, override the elderly person's right to make choices about her own life. Yet, society does have an expectation that those who case manage the frail elderly in their homes will balance client self-determination against family and community pressures to ensure safety as well as their own professional and legal requirements to "...promote the client's well-being and protection from harm".^{xi} The drum beat for safety over independence, which comes from multiple quarters, often forces case managers to acknowledge the inevitability of nursing home placement and abandon efforts to keep the elderly client in their own home.^{xii}

Some of the most extensive and creative work on the safety vs. independence balancing act has been done by those focused on the nursing home environment. Bart Collopy has argued that standard bioethical discourse frames this dilemma in terms of conflict between autonomy and beneficence. Although this paradigm of decision-making may be useful in the acute setting, Collopy claims that it is not very helpful in the long-term care environment where decisions made shape the ongoing lives of residents.^{xiii}

Collopy has challenged the belief that the balancing that goes on between independence and safety portrays these two values as polar opposites. He argues that within long term care, "...safety ought to be understood within the context of other values. In itself, it provides an extremely limited ethical framework."^{xiv} Collopy also claims that an ethically accurate view of safety (especially when considering the frail, decisional elder) requires a consideration that goes beyond generalities to the particular situation. In other words, to know how much harm might come to a resident is important when deciding to consider if there is sufficient advantage to being safe from the harm. By this account, he argues that safety offers little *generalized* ethical guidance. Risks need to be weighed in terms of benefits and burdens or harms. As a goal, safety must be measured against other goals, taking into account the elderly person's weighing of risks and benefits, and *potential* harms should be gauged by "...solid predictors, not worse case theory."^{xv} Collopy concludes that physical safety is not an absolute that must trump all other values. It is only one among numerous values, and its import should depend on the amount of risk and the weight of other values, including the elder's willingness to bear the burden of risk in light of some goal or conflicting value. In other words, might an elderly person need to take a safety risk in order to maintain or shore up her sense of self that has been deeply threatened by a sense of displacement or progressive disability? Collopy goes on to suggest that if the

definition of safety is enlarged to include psychosocial safety, there might be greater appreciation for what sustains Mrs. White in her apartment.^{xvi}

Collopy also challenges the common definition of independence and suggests a wider view. For an elderly person, independence may be seen as simply staying out of a nursing home. This narrow definition places independence at a site (home) rather than as a consideration of a wide number of choices that are made in the course of daily living. In fact, this narrow definition of independence becomes one of "avoiding the nursing home but struggling on in the community with lean possibilities and limited options."^{xvii} When one becomes old and frail, there may still be a strong desire to be independent, even if it causes the elderly person to push the limits of safety. Collopy believes this may be because the person, such as Mrs. White, wishes to remain in a home she has known for a long time, with familiar people or pets, furniture and clothing, to have the ability to eat when she wants, or bathe and get up when she chooses. These familiar beings, things and choices about daily routines are what compel her to hang on to them, and they in fact create a different kind of safety. Viewing independence through this lens allows for the recognition that these kinds of preferences could translate into the decision-making she is able to make, perhaps even in the long-term care environment. Collopy acknowledges that the challenge is to help the long-term care facilities allow residents to have as much of

this kind of independence as possible, because it will hopefully give them some of the psychological safety they had when they lived in their own home. Thus, Collopy seems to suggest that, rather than relying on abstract concepts of autonomy and beneficence, our operative notions of independence and safety of the frail elderly should depend, in part, upon what the elder judges to constitute independence or safety.

The Problematic Acute Care Model

Unfortunately, the acute care setting has been the least successful in navigating the challenge of honoring the elderly patient's wishes while still being mindful of the concerns for her safety. In spite of careful attention to giving a patient with decisional capacity the opportunity to make numerous other decisions regarding her care while she has been hospitalized, at the point of discharge planning this same patient is often overlooked in the decision-making process. Frequently, the physician makes a pronouncement that the patient is not safe and therefore cannot go home. Physical and occupational therapy concur and family members are informed that they must choose a facility since the patient will be discharged in two days. In reality, the physician may not have seen the patient out of bed; frequently, due to increasing case loads, physical and occupational therapists might not actually do a physical assessment of the patient, but instead rely on information in the chart and on the patient's demographics, to help them

make a determination of patient needs; and the social worker or discharge planner has forty-eight hours to have everything in place for the patient's discharge. Often in this process, there has been little time given to doing a true assessment of the patient's needs and goals. Admittedly, some of these shortcuts or efficiencies are a result of changes in Medicare payment structures, resulting in shorter lengths of stay and the frequent expectation that the elderly patient will spend some time on a Medicare unit in a long-term care facility anyway. Regardless of the reason, the patient's frequent lack of real input into the process is concerning, and may have consequences for the patient that go far beyond the expectations of the medical caregivers who have decided and implemented this course of action.

It is well recognized that there are many who have interests in where and how the elderly person lives, what help she might need, what services are available, and how much it will cost. In fact, few decisions are made in the health care setting that so significantly impact the interests of so many people as do decisions about discharge. Hence, determining the appropriate decision maker in discharge situations is an important issue. Questions of physical safety are always of major concern to the health care providers and to family; whether the decisional patient should be able to make a risky decision is also a dilemma for both family and providers. Even the most caring of families, who want very much to honor the patient's desire to maintain her

independence, have limits in terms of time commitments and financial obligations to the elderly person. John Arras addresses these conflicting interests. He argues that the traditional model of patient-centered ethical decision-making does not adequately take into account other interests, especially when considering discharge needs.^{xviii} If an elderly patient is adamant about returning home but is assuming that her daughter, who is a single mother and works full-time, will be available on an as-needed basis, Arras wonders if the needs of that daughter should not count just as much and maybe even outweigh her mother's wishes. Just as frequently, the elderly patient may refuse offered assistance in home, especially if it is from an agency, rather than a family member.

Towards Negotiation

Many in the field of geriatrics, as well as medical ethics, have suggested that the most equitable way to resolve challenging issues with the elderly person is some version of shared decision-making with input from the elderly person, family members, and other caregivers involved in the elder's care. The following case illustrates one version of shared decision-making.

Mrs. Moran is an 88-year-old widow who lives in a second story walkup apartment, her home for over twenty-five years. Mrs. Moran has congestive heart failure and has been hospitalized for almost a week. Her acute episode has resolved and she has

received physical and occupational therapy. The therapists are confident she will be able to manage at home, but have great concerns about the stairs. A family meeting is suggested and the patient agrees. Mrs. Moran has six children, all successful professionals. Most live in the same community as their mother and are very attentive to her. They, too, have been very concerned about the stairs and address this issue in the family meeting. Initially, she brushes off their concern saying that this is her decision and someday she will walk down the stairs to get the mail and not be able to get back up and maybe she will have a heart attack right at the bottom of the stairs. She says this matter-of-factly, but her children are not in agreement and express their worries. One son offers to buy her a condo in the elevator building directly across the street from her apartment, but Mrs. Moran refuses. After more discussion there is agreement that Mrs. Moran should go home, but she would get a medical alert button to wear and will not go downstairs without one of her children being present. Since someone visits virtually every day, Mrs. Moran reluctantly agrees.

This narrative illustrates what Harry Moody refers to as "negotiated consent."^{xix} He believes that a process in which all those with a vested interest in the outcome have an opportunity to present their opinions and that there is dispersed authority for decision-making so that no one person, including the elderly patient holds a trump card. In Mrs. Moran's

case, she was able to state her desire to return home and her family expressed their concerns for her safety, but they were able to come to a compromise that worked for everyone. Of course, such a process is not always managed this smoothly. Many families have much more difficulty expressing conflicting views, and coming to a resolution. What was most significant about this process was that Mrs. Moran was able to state her wishes, which were heard and honored by her children. Her children expressed their legitimate concerns, and they were able to work out a solution that respected Mrs. Moran's need for independence, but independence that was somewhat modified in order to accommodate her children's worries about her safety.

Given the patient-centered model in acute care that leaves decision making to the physician and the decisional patient, there are those who feel such a process of negotiated consent might be paternalistic and even coercive. Some years ago, Nancy Dubler participated in a study of the discharge process with elderly patients and the results included: first, a decisionally-capable patient must be given the available discharge options to consider; second, a decisionally-capable elderly patient "...has the right to assume personal risks even if those risks may place them in a situation of potential harm. The choice of risks does not negate the presumption that the patient is decisionally capable."^{xx} However, the results also acknowledge that caregivers must discuss with the decisionally-capable patient the discharge

alternative considered in the patient's best medical interest and that is realistic given family and community supports.^{xxi} Currently, if the family and elderly person are in conflict regarding choices the elderly person is making, the prevailing wisdom seems to favor some version of negotiation.

Families should, and frequently do, have much to say about an elderly family member's living situation and care needs. Families are often stretched emotionally, physically, and financially to assist their family member with her needs and may respond in many ways to the elderly person's desire to maintain her independence. Families such as Mrs. Moran's are able to support her desire to stay in her apartment. They have numerous caregivers to assist her and the financial resources to make sure she has everything she needs to ensure her safety. Moreover, Mrs. Moran honored her children's concerns with her willingness to accommodate them with the medical alert button and limiting her independent trips to the first floor. However, the reality in many cases is that the family member or members do not or cannot support the elderly person's desire to maintain the current living situation. Thus, in spite of the elderly person's ability to make a strong case for what she would like, the realities of family resources may not support it.

Nevertheless, it is most important that the decisional patient be a participant in conversations regarding her situation. If

the case manager or the physician in the hospital believes that the elderly person cannot safely manage at home, or needs more care to do so, what is essential is not what the final decision is, but that she is a participant in the planning and decisions made about her future state.^{xxii} The elderly patient or resident who has no family members, or those she has live too far away to be involved in her life on a regular basis, still needs to be informed of the choices and the rationale for them, and participate in the decisions made about her care. As Collopy points out, safety may be the ultimate goal for family and especially professional caregivers, whether they be social workers or case managers in the community, caregivers in long-term care facilities, or physicians, therapists, nurses, or social workers in the acute setting. However, the frail, elderly person who has decisional ability or “agency” still has the right to weigh the choices based on her assessment of safety as a goal and its relationship to her other goals. She can argue for her position and negotiate if she is able, but her goals and wishes should be known and seriously considered.

Conclusion

Long-term care has been most successful at honoring the elder’s wishes. Yet, as Agich admits, the decisions made there are generally of a more ordinary kind.^{xxiii} Nonetheless, residents are certainly able to push the limits in all sorts of ways in these settings. As more long-term care facilities move toward flexibility, allowing residents

the opportunity to have a say in all sorts of daily decisions, the elderly person with decisional capacity is encouraged to execute her agency as much as she is able.

For the elder who is determined to stay in her own home no matter what, the home care providers should heed Collopy’s caution about making safety the ultimate goal. However, as he points out, the ongoing conversation between caregiver and elderly person should include weighing the reality of limitations on her independence that exist for her by staying in her home. Like Mrs. Moran, who turned down the offer to live in an elevator building that would allow her more physical independence, there is no certainty that this argument will carry much weight. Yet with fewer funds and resources available within communities, if financial or caregiving assistance from the community is needed, staying independent in one’s home may become less realistic for the frail, but decisional elderly person.

Acute care settings must do a better job of engaging the elderly patient. Too many assumptions are made about the patient and these assumptions often have a strong influence on decisions that are made for the patient as opposed to with the patient. Using a narrative approach from the day the patient arrives, would help physicians and staff have a better understanding of who this patient is, what she values, and how she has functioned prior to her hospitalization. When this happens, conversations regarding the patient’s plans

are more likely to include the patient, be less paternalistic, and more respectful of her wishes.

NOTES

ⁱ Collopy, Bart J., "Safety and Independence: Rethinking Some Basic Concepts in Long-Term Care," in Laurence B. McCullough and Nancy L. Wilson (eds.), *Long-Term Care Decisions, Ethical and Conceptual Dimensions* (Baltimore: The Johns Hopkins University Press, 1995), p. 138.

ⁱⁱ Beauchamp, Tom L. and James F. Childress, *Principles of Biomedical Ethics* (New York: Oxford University Press, sixth edition, 2009), pp. 99-148.

ⁱⁱⁱ Caplan, Arthur L., "The Morality of the Mundane, Ethical Issues Arising in the Daily Lives of Nursing Home Residents," in Kane, Rosalie and Arthur Caplan (eds.), *Everyday Ethics, Resolving Dilemmas in Nursing Home Life* (New York: Springer Publishing Company, 1990), pp. 44-45.

^{iv} *Ibid.*, 44.

^v Throughout this article, the elderly person will be referred to as "she". This is because statistically, when speaking of a frail, elderly person, who lives alone or in a long term care, that person is seven times more likely to be L.

^{vi} Collopy, op. cit., p. 147. Collopy spells out the difficulties of assessing decisional capacity in the very elderly. He says that for many elderly, decisional capacity is "often a varied and shifting reality...it can be present in certain areas of choice and behavior but absent in others."

^{vii} Agich, George J., "Actual Autonomy and Long-Term Care Decision-Making," in McCullough and Wilson (eds.), *Long-Term Care Decisions, Ethical and Conceptual Dimensions*, pp. 114-116. Agich has developed a framework for discussing autonomy and the elderly person. He says that there are two kinds of decision-making that the elderly person may experience in health care, especially long-term care. The first kind he calls *nodal decision-making*. These are decisions made where there are clear alternatives and where weighing the benefits and burdens is relevant. Agich argues that this type of decision puts the elderly person at risk of coercion because of disparities of power. These decisions are more often made in the acute setting than in long-term

care. The other type of decision is "*interstitial decision making*". These are the everyday decisions that need to be made regardless of the setting. They are less dramatic and cause less conflict than nodal decisions. Agich says these are usually "...not even experienced as matters of explicit decision, but rather simply as habitual ways of acting and interacting. Agich believes that this is the kind of decision-making that many elderly want so badly to maintain.

^{viii} *Ibid.*, 120-121

^{ix} Wetle, Terrie, "Ethical Issues and Value Conflicts Facing Case Managers of Frail Elderly People Living at Home," in McCullough and Wilson (eds.), op. cit., p. 74.

^x Collopy, Bart J., "The Burden of Beneficence," in Rosalie Kane and Arthur Caplan (eds.), *Ethical Conflicts in the Management of Home Care: The Case Manager's Dilemma* (New York: Springer Publishing Co., 1993), pp. 93-100.

^{xi} Wetle, op. cit., p.75.

^{xii} *Ibid.*, p. 76.

^{xiii} Collopy, "Safety and Independence: Rethinking Some Basic Concepts in Long-Term Care," p. 138.

^{xiv} *Ibid.*, p. 141.

^{xv} *Ibid.*, p. 142.

^{xvi} *Ibid.*

^{xvii} *Ibid.*, p. 145.

^{xviii} Arras, John D. *Long-Term Care Decisions, Ethical and Conceptual Dimensions*, pp. 200-201.

^{xix} Moody, Harry R., *Ethics in an Aging Society* (Baltimore: Johns Hopkins University Press, 1992), p. 163.

^{xx} Dubler, Nancy Neveloff, "Improving the Discharge Planning Process: Distinguishing Between Coercion and Choice," *The Gerontologist* 28, Supplement, 1988: p.79.

^{xxi} *Ibid.*, p. 80.

^{xxii} Moody, op. cit., pp. 92-93.

^{xxiii} Agich, op. cit., pp. 114-116.