

Preface

In virtually all the developed countries of the Western world, people are living longer and reproducing less. At the same time, costs for the care of the elderly and infirm continue to rise dramatically. Given these facts, it should come as no surprise that we are experiencing an ever-increasing concern with questions relating to the proper care and treatment of the aged. What responsibilities do societies have to their aging citizens? What duties, if any, do grown children owe their parents? What markers should we use to determine one's status as "elderly"? Does treatment of pain in aged patients present special medical and/or moral problems? How can the competing claims of autonomy and optimal medical care be reconciled for elderly persons who require assisted living? When, if ever, should severely demented patients be included in nontherapeutic clinical trials? These questions, and others of similar interest to those concerned with the proper treatment of the aged, are discussed in depth in the articles included in this text.

The essays in this volume of *Biomedical Ethics Reviews* fall loosely into two broad categories. The first four articles—those contributed by Sheila M. Neysmith, Allyson Robichaud, Jennifer Jackson, and Susan McCarthy—raise general questions concerning the propriety of Western society's current mechanisms for dealing with and treating elderly citizens. The remaining four articles—those by Simon Woods and Max Elstein, Marshall B. Kapp, Claudia Mills, and Sarah Clark Miller—grapple with problems that arise for medical personnel and family members who provide care for elderly persons.

Care of the Aged is the twentieth annual volume of *Biomedical Ethics Reviews*, a series of texts designed to review and update the literature on issues of central importance in bioethics today. For the convenience of our readers, each article in every volume of our series is prefaced by a short abstract describing that article's content. Each volume in the series is organized around a central theme; the theme for the next volume of *Biomedical Ethics Reviews* will be *Stem Cell Research*. We hope our readers will find this volume of *Biomedical*

Ethics Reviews to be both enjoyable and informative, and that they will look forward with anticipation to the publication of *Stem Cell Research*.

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Abstract

Aged persons often suffer deprivation and unhappiness, as a direct result of how they are cared for—or, rather, not cared for. Various attitudes held about aged persons can be shown to play a role in these ethical blunders. Aged persons often become as dependent as children, yet we fail to meet their needs as we would those of children. If we imagine treating children as we sometimes treat aged persons, it quickly becomes clear that there are problems with the way some care for aged persons is conducted. This has to do with, for example, our notions of obligation and conceptions of reasonable cost-saving measures. The needs of aged persons bow to the needs of institutions caring for them. Without adequate or trained staff, residents must endure indignities and discomfort. Although cognitive decline is often part of the aging process, rather than finding ways to respectfully accommodate it, aged persons are restrained, talked down to, or ignored. There is much discussion concerning the rationing of care for aged persons as their number continues to increase. Prominent among such discussions is the notion that in order to ensure that there are enough resources to care for younger persons, care for aged persons, especially life-extending care, must be restricted. Reasonable and sound arguments can be made in favor of rationing care without including age as a determinative factor. Our ideas about who should get care, what that care should be like, how much they should get, and who should pay for it result more from attitudes toward, than facts about, aged persons.

Disrespecting Our Elders

Attitudes and Practices of Care(lessness)

Allyson Robichaud

In this chapter I want to discuss some of the ethical problems raised by the way we care for aged persons—I will use the terminology “aged persons” in order to avoid language that “. . .verbally reduces persons to a single characteristic.”¹ I will contend that the attitudes we hold concerning aged persons are at least partly responsible for why some aspects of care are far worse than they ought to be. The views we have of dependent persons impacts on both the form and amount of care available. We need to acknowledge these attitudes in order to begin to change them and reform the way care currently takes place. I have carved out four areas in which to highlight attitudes and their attendant problems. By looking at some of the practices of and ideas about the care of aged persons, attitudes consistent with these practices and

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ideas can be examined for legitimacy. Along the way, I make some suggestions for changes consistent with shifts in attitude, which, if adopted, would result in better care of aged persons.

Comparison of Aged Persons with Other Dependent Persons

There is complete symmetry between children and many aged persons insofar as both are dependent on others for their care and well-being. Without such care, neither will thrive. This symmetry, which ought to be crucial to our thinking about care for aged persons, is often ignored. We tend to keep our focus on the asymmetries and, in so doing, find justification for our approach to their care. However, some of these asymmetries are the result of attitudes about and perceptions of aged persons, not strictly matters of fact, and so ought to be subject to critical scrutiny. It will be useful to clarify the asymmetries and attitudes in an effort to locate the reasons for some of the ethical problems raised in association with care of the aged.

We are prepared to care fully for children, by ourselves, in our homes, for extended periods of time. In fact, many currently care in this way for dependent handicapped children (or permanently injured young adults) for their entire lives, which can be long. Indeed, it is far less likely these days for parents to institutionalize handicapped children, as was the norm in the past—attitudes have shifted. Many no longer view these individuals simply as an endless burden, but as persons who can add wonderful dimensions of interest and pleasure to the lives of those around them. Caring for them, much as with nonhandicapped children, though difficult, is rewarding.²

If there exists a willingness to care for dependent children, even dependent, disabled, never-to-be-autonomous children, closely and scrupulously, why is this not true for dependent aged persons? Practically speaking, children, unlike aged persons, are

smaller and so physically easier to handle for things like, changing diapers, moving, and so forth. Although some accommodations must be made when there are children in a home—so-called “baby-proofing”—one need not worry about installing bathrooms on ground floors or ramps for stairs because one can easily carry a child over obstacles. Caring for dependent adults may require extensive adjustments; however, it is not clear that such adjustments would be more expensive or disruptive than those we readily make for children. Dependent aged persons are likely to have some assets and possessions; children come to us with nothing. Children will eventually (most likely) become independent and no longer require high levels of care. Most children learn to walk, use the toilet, feed and dress themselves, and so on. For a significant number of years after they have mastered these tasks they continue to require support of various kinds, but such support, for most of them, becomes increasingly unnecessary.

For aged persons, the process is reversed. Although intense dependency is likely to last no longer than the dependency of a child, death, not independence, is what is anticipated. When the needs of aged persons become most like those of very dependent children, many are placed in long-term-care facilities. Typically, people reside in long-term-care facilities for 1–5 yr.³ Although some aged persons choose to be cared for in an institution so as not to burden other family members, many others do not go willingly—like the obstreperous kids sent to boarding school or boot camp.

As people age, they first become unable to perform activities known as the instrumental activities of daily living (IADLs), such as cooking, shopping, and using the telephone. If they deteriorate further, they then become unable to perform the activities of daily living (ADLs), like eating, dressing, and bathing (ref. 4, p. 3). Those who suffer increasing debility usually live on their own; their families are grown and they have their own homes. These days, extended families often live far apart from one another or at least far enough apart to make daily visits either onerous or impossible. The good news is, when aged persons

reach the point where they need assistance with IADLs or even ADLs, many families rise to the occasion and cobble together some way of caring for them that does not involve institutionalizing them. “[In] 1990 . . . 78% of the 7.3 million people over 65 who needed long-term-care lived in the community.”⁵ Still, roughly one-quarter or “. . . more than 1.6 million people lived in nursing homes; about 50,000 were scattered in other kinds of institutional accommodations.”⁶ Over one and a half million people living in institutions is a lot of people and the bad news is, because of the way such institutions are generally set up, those living in them often do not have what many would consider a good quality of life. If one survives to age 65, he or she will have a 25% chance of living in a long-term-care facility at some point.⁷ Many of us will, in the future, be faced with just such a fate. This alone ought to motivate us to think more carefully about the kind of life those in long-term-care are forced to lead.

More effort is put into the care required by children than into that required by aged persons. For example, families with young children whose parents both work can be placed in day care or attend school, where they are entertained or stimulated until picked up by their parent(s) or guardian(s) and brought home again. Socially, we have made arrangements for the care and nurturing of children (not that it is perfect by any means), but there are few such mechanisms in place for aged persons, especially those requiring the same care as children (i.e., they cannot live alone but do not require either nursing care or around the clock surveillance).⁸

Parents are responsible for bringing their children into existence. The same is, of course, untrue of one’s parents. As children, we expect our parents to give to us, to support us; we do not see ourselves relating to our own parents as their caregivers. Even as adults, we expect our parents to be supportive and helpful, not the other way round. Something seems wrong if they begin to depend and lean on us. Likewise, parents are often unable to put themselves under the care of their children. There is a way in

which sons and daughters remain forever children in their parents' eyes. Notice, for example, how people will say, "I have two children," even when those "children" are in their 50s.

One's relationship with his or her parent(s) as an adult usually differs from the childhood relationship. As one's parents age, perhaps the only similarity to the earlier relationship is that one member in the relationship is in a position of dependency. As a child, one is only vaguely aware of the joys of independence from any sort of authority or care until fairly late in the game. For someone who has aged into dependency, such is not the case. When decisions must be made, aged persons not unreasonably want, and should have, a say in the process. When their desires clash with those of their children, it might not be clear whose desires should be realized, whose needs should override. By the time aged persons need extensive care, their sons and daughters have lives of their own, often children of their own. They are older and more fully realize just how intense the commitment, disruptions, and personal sacrifices necessary to care for dependent persons can be.

Barring extreme circumstances, parents have a moral obligation to care for their children themselves. There is no symmetry here with respect to one's obligations toward one's parents. (Although this is not true in all cultures.) Although it is easy to argue in favor of a moral obligation to ensure one's parents are cared for, arguing there is a moral obligation to care for them oneself is much harder. Indeed, caring for one's parents oneself is now seen as a supererogatory act, morally praiseworthy but not required. Typically, actions that would require too great a personal sacrifice, like giving up one's place on a lifeboat, cannot be morally required, although will be morally admired. However, some would argue that in the case of one's own children, there are special duties entailed above and beyond any one might have toward other relatives or total strangers. In which case, the sacrifices one makes for one's children, even at great cost to oneself, are seen as morally required, not supererogatory. Perhaps, it is this line of thinking that gives rise to the idea that children are not

morally required to make great sacrifices to care for parents. Indeed, parents, even aged parents, as a result of the moral obligation they have toward their children, are expected to make sacrifices for their children, not the reverse. It is not that aged persons have lived their lives and so should let the next generation have full opportunity to do so. Rather, aged parents have a moral obligation not to burden their children as a result of the special duties they have toward them.

This asymmetry of obligation is mirrored in the law. Parents are legally obligated to provide for their children. One is not, however, legally obligated to provide for one's parents. Even if one's parents are or become destitute, one is not legally required to provide support. Here again, one could argue that in this circumstance, children might have a moral obligation to provide financial support. What may account for this absence in the law is the notion that one's parents are adults, so responsible for their own poverty. Because they are responsible, it is not unreasonable (or even unethical) to leave them to pay the price for their actions. Unlike children who have little control over their lives, and certainly no financial control, one's adult parents presumably did and do. Also, there is a strong sense that people are financially liable for things they choose to undertake, like having children or spending rather than saving for retirement.

In a culture as pro-natalist as ours, many individuals plan for and choose to have children. Although I think people are often both surprised and overwhelmed by the amount of care and supervision children require, they willingly undertake it for the sake of their children's welfare. Children grow up to live independent lives that reflect back on their parents, for good or for ill. Life with them is mostly forward looking. There is great anticipation surrounding children. Parents are anxious about their arrival, what they will look like, be like. Watching and helping children achieve some success in life brings enjoyment to the lives of most parents. Aging persons do not have the same trajectory; the goals and milestones are far different. These are not always looked for-

ward to with pleasurable anticipation—unfortunately, it may often be with dread. There is little sense of becoming with aged persons. In such a goal- and achievement-oriented society, the lives of aged persons can appear rather discouraging. This may account for our not ensuring that aged persons have interesting and stimulating lives, insofar as they are able.

Caring for aged persons, as with children, is predominately done by women. This is true whether the persons being cared for are members of one's own family or strangers. Caregiving tasks are typically thought to be women's work. Because a lot of the care required by dependent persons does not require highly skilled labor, such labor is typically not financially well rewarded.⁹ Unfortunately, the paid care of children is exactly like the paid care of aged persons in this respect. A lot of care for dependent persons also occurs without any financial remuneration: "Three out of four unpaid caregivers to the elderly are women, usually wives, daughters, and daughters-in-law."¹⁰ Therefore, women in society absorb the costs of caring for dependent persons, to a large extent. It is telling that care for dependent persons is not seen as worth paying much, if anything, for. Much more is paid to look after and manage money, for example.

There are also some interesting differences between aged men and women who are dependent on others for their care. Most importantly, the majority of aged persons are women, many of whom are not particularly wealthy—especially women of color. Most of the residents in long-term-care facilities are women, more than 75%.¹¹ In general, aged men tend to suffer illnesses requiring hospitalization, which is mostly covered by Medicare; aged women however, tend to suffer from chronic illnesses, like arthritis. The home care required to cope with these chronic problems is not covered, so daily living for these individuals is much harder than it ought to be—both for the women and for those who are likely to be unpaid caretakers.¹²

That women live longer than men probably says little about social attitudes toward them. This may, however, not be true for

how life goes for dependent aged persons. In a culture oriented toward youth and males, it is interesting to wonder how this affects the treatment of aged persons, especially women. Isolated as they are from society, by design or infirmity, we are not very often called upon to reflect on the kinds of lives these people lead.

Institutional Needs Versus Resident/Patient Needs

As Mary, my grandfather's wife of 30 years, edged toward her 85th birthday, she began to decline mentally. Although my grandfather was younger, he was not well physically, thus incapable of the sort of constant monitoring Mary began to require. Mary's children and my grandfather decided it would be best for all concerned if she were placed in a long-term-care facility close enough for him to visit daily. The move went reasonably smoothly, although Mary did not fully appreciate her loss of mental function and so could not be made to understand why she was no longer living with her husband. Thus, she began the all too common begging to be taken home, which was very hard on everyone.

As time went on, Mary's mental decline continued, and she became frailer as well. At this point, she was forced to spend more time either seated in a wheelchair or in bed. Because she was no longer reliably able to get to the toilet herself, she began to have the occasional accident. As is most often the case, the institution caring for her did not have the staff that would be required to toilet all of its residents, so Mary was put into a diaper. It took some time for her to become accustomed to soiling herself. She would call for help because she needed to go to the toilet, only to be told she was in diapers and so had no need to use it. Even though her mental abilities were much in decline, Mary would still have been able to manage to use a toilet if only she could have been aided in doing so. Her precipitous decline in using the toilet was a function of understaffing, not declining

abilities. Being forced to soil herself and then have others to clean her had a deleterious effect on her self-respect, even in her failing mental state. Jecker notes, "In the case of the disabled elderly person, an insidious process can be set in motion whereby events that are within one's power are viewed as response independent or 'beyond one's control.'" ¹³

This is a familiar downward spiral. For those who are aged (or handicapped), the less they do, the less they are then able to do. Dependency increases, leading to further decline in ability. In fact, it has been shown that all of the help aged persons receive in long-term-care facilities can actually decrease their ability to do things for themselves. ¹⁴ Given how slowly aged persons perform tasks, as with children, it is hard to resist the urge just to save time and do things for them. With children, we might have more patience because we want children to benefit from the practice of doing tasks themselves. The same is true for aged persons; that is, they benefit from being active and performing as many tasks for themselves as possible. However, time is often in short supply, especially in institutions where the number of residents each staff person must attend to is large.

When I heard this story about Mary, I could only imagine how often it must be repeated in long-term-care facilities. The ethos of institutional care, which comes about, in part, as the result of attitudes toward the residents, takes over and the comfort and needs of the residents are then sacrificed for it. Unless residents spend an unconscionable amount of time in soiled diapers, I am not sure that keeping them in diapers saves either time or money. The costs of the diapers and the time required for cleaning and changing residents are not insignificant. The only way diapers could be efficient is if residents are left to soil them multiple times. This would not only save the time spent taking them to the toilet, it would offset the time needed for cleaning and changing. Sitting in soiled diapers can only be uncomfortable, even for those whose mental status has deteriorated. We would not hesitate to censure parents who, because inept or bad, do not properly care

for children in diapers. As a grown adult whose mental status is not compromised, such a fate does not bear thinking about. It may be that changing diapers is just easier, but given the consequences for the residents of prolonged diaper use, what is easiest for the staff should perhaps count for less. Requiring assistance with the toilet can also be burdensome unless it is attended to with some vigilance on the part of others. Being forced to monitor one's liquids so as not to be caught short or having to sit for extended periods in need of a trip to the toilet makes for less than pleasurable days. Sitting overlong on a commode waiting to be helped off is equally unpleasant.

While thinking of my grandfather's wife, I had the fanciful notion¹⁵ of employing extra workers, preferably strong ones, who would take turns doing less desirable tasks, like taking residents to the toilet on a schedule, and more desirable jobs, like aiding in exercise and recreational activities. Exercise and recreation are things residents must also often forgo for want of aid to accomplish them and/or the means to finance the aid required. However, in order for such a program to exist, more money would be required, and the view seems to be that too much is being spent already.

I had noticed a variation of this same problem once in the geriatric unit of a hospital. The patients, many of whom suffered from dementia, leaving them agitated and/or confused, had to listen to the constant chattering of the intercom speaker in their rooms. Although the intercom system was no doubt a boon to those who needed to quickly and conveniently convey a message to people working on the floor—without actually leaving their position at the front desk—the constant disruption struck me as, at best, annoying, and at worst, frightening. It also seemed unfair for each room (including empty rooms) to be inundated with this noise when the person sought via the intercom could only be in one room.

It is ironic that the institution meant to serve the needs of its residents should instead suborn them. This is often done through strict adherence to rules and regulations.

Chronically understaffed and faced with patients who are unable to make decisions for themselves or whose choices make management difficult, such facilities develop ways to improve efficiency. A common response is to make a large number of rules about what patients should do—in other words to routinize care.¹⁶

In some instances this is perfectly sensible, for example, meal times need to be relatively constant to make food delivery feasible. If a particular resident is not typically an early riser, it does not seem unreasonable to allow her remain in bed. It would be easy enough to make minor provisions for such individuals, like having a toaster and bread available. However, the tendency in these situations is to force the resident to conform to the schedule or rules rather than making allowances and so tolerate some disruption in routine. There will, of course, be a point at which such individual preferences cannot be accommodated—a resident's desire to play his TV very loudly late at night for example. Nonetheless, more latitude should easily be possible.

Such accommodations as are possible need to be implemented if we are to come at all close to treating those in long-term-care facilities as the individuals they in fact are. In a society that prides itself on respecting and fostering individuality, treating a person as one from a set of identical objects—one of the aged persons—should be repugnant to us.

In old age in the nursing home, . . . people are expected to . . . homogenize their individual traits and eccentricities to a remarkable extent in order to fit into a bureaucratically defined behavioral norm.¹⁷

Long-term-care facilities are often modeled on the acute hospital setting and so have little character. This is not overly burdensome in the case of most hospital stays, as they are relatively short. Although there are requirements that must be met to

satisfy health and safety regulations, bland hospital-like rooms with no personality, all equally interchangeable apart from their view and distance from the nursing station, make a facility as inviting as a dentist's office, yet this is what some must call "home." Add to this inflexible rules that overly regulate behavior and compromise comfort and "home" is hardly what comes to mind.

Problems with Autonomy

Some aged persons remain mentally sharp until their death; although the body may not be able to oblige, cognition remains optimal. However, very often as people begin to decline physically, they also begin to decline mentally. As noted earlier, aged persons increasingly need more and more assistance with IADLs and ADLs. The need for such assistance increases dramatically once people begin to decline cognitively. Indeed, once the decline is significant, such persons cannot safely be left alone. Not only is it possible for them to harm themselves (e.g., by forgetting to turn off the stove), many are on medication regimens they can no longer faithfully follow.

Much as children are more or less autonomous, so it goes with adults in later years. It is probably useful to think of autonomy as a continuum rather than as either totally present or absent. Cognitive function is not usually lost all at once, but gradually; nor are those in decline uniformly impaired. Even those who are quite impaired can have moments of relative lucidity; thus, autonomy waxes and wanes. At times, they are competent and thus fully autonomous. At others, confusion annuls autonomy. Care needs to be taken not to treat all persons as if incompetent, and when incompetent, to try to remember to treat them at least as one might an incompetent child (i.e., with kindness and understanding).

Although it makes sense to maintain a parentalist attitude toward individuals who are profoundly dependent for their continued safety and welfare, it is much harder to justify doing so

with persons who are not so compromised. At times, aged but intact persons are not treated as one would other competent adults. In such instances, it seems we are pulled by the symmetry of aged persons to children, but to no good end. A health care professional might fail to address the patient, addressing his daughter instead, or speak to him as if he were dull-witted or as unsophisticated as a child. Worse still, problems resulting from medication are sometimes wrongly assumed to be the result of cognitive impairment simply because the person troubled is aged. Otherwise intact and autonomous individuals are then left to suffer (e.g., confused thinking or even hallucinations) because they are not taken off the offending medication.

Once the physical restrictions of debility begin, one's freedoms necessarily contract. Most of the desires aged persons wish to satisfy now depend on there being someone available to help realize them. Added to this is the difficulty of negotiating between their desires and the desires of others, including their children. Some of the time, not being able to act on one's desires will have only trivial consequences—the television channel will not be changed. Other times, the consequences are life altering. Suppose that it is my desire to stay in my own home, surrounded by my beloved possessions. Moving me someplace else, even if for my own safety, abrogates my autonomy. At earlier stages in my life, I would have been allowed to decide to do things that risked my safety and security. There is something about the way we view aged persons that accounts for the relative ease with which we override their wishes. This may be because we make the assumption that cognitive decline is the cause for decisions involving risk rather than idiosyncratic whimsy or sound judgment—which is what we are likely to assume about someone younger. The desire to do something entailing risk is grounds enough to generate the belief that the person must not be thinking clearly. This is not to say that a given person might not be wrong-headed in her thinking, but it ought not be assumed that she cannot think clearly simply because she is an aged person.

People who suffer from dementia or Alzheimer's disease are often unable to care for themselves or about themselves. They are the ones for whom maximal care is necessary—care beyond what any one individual could possibly provide. While ambulatory and unguarded, they are often a danger to themselves and can even pose a danger to others. These are the persons who must be under constant surveillance, living in locked facilities. They are also the aged persons most likely to be diapered and restrained.

As was noted earlier, long-term-care facilities require residents to give up much of their freedom (not to mention possessions), sometimes for no reason other than to follow an institutional rule. One of the rules that seems to me close to a form of physical torture is the rule many institutions have about not getting back into bed during the day. This may be done to keep people from being too inactive—a benefit to the residents—but it may also be to keep the beds neat or to try to ensure that there is not so much comfortable napping that residents are then up during the night. Laird, a self-described survivor of a long-term-care facility, eloquently details how terrible it is to be forced to sit in a chair for hours with no hope of relief, until an aid decides that it is time to help her back into bed.¹⁸ Whenever I have visited long-term-care facilities, I am bothered by the sight of residents who are rolled up against a wall in the hallway, tied into their chairs, heads lolling at uncomfortable angles as they drift in and out of sleep. I always worry about there being an inordinate number of stiff necks—a very unpleasant condition. I am similarly bothered when I see parents dragging about children who clearly need to be somewhere sleeping comfortably.

Of course, it is not nearly as hard to see the uncomfortable chair-sleepers as it is those who are trying desperately to loosen their bonds, begging passersby for help. The use of restraints to restrict the freedom of some residents seems medieval in character. Safety is often the reason given to justify employing restraints; however, restraints are just as likely to be used in the “maintenance of order, efficient task completion, and the enforcement of

rules.”¹⁹ Imagine our reaction to finding out that the local day-care center for children routinely tied up the 2-yr-olds to keep them from falling or to give the staff a chance to have a coffee break or clean up the toys. Two-year-olds cannot competently choose to risk their own safety by possibly falling, yet we allow them to do so while taking all the precautions we can to ensure they will not cause themselves great harm. The benefits of being free outweigh the possible risk of harm. There is no reason we should not do likewise for aged persons.

Some of those whose dementia is severe cannot comprehend that or how their movements are being restricted. For others, the restraints take on a sinister quality: “He used to sit, restrained in his geri-chair and talk on an imaginary telephone. He would say things like, ‘Help! Is this the police? You’ve got to come and rescue me. They’re holding me prisoner here.’”²⁰ Even for the most severely demented, restricting the ability to move one’s body is to restrict one of the few pleasures left to such persons. The use of restraints is an awful experience for most residents, especially when they are first restrained.²¹ In other countries, residents of long-term-care facilities are managed without the use of restraints.²² This practice seems, at best, a poorly thought out means to “protect” residents—at worst, the unethical treatment of human beings. That we think it appropriate to fetter aged persons is indicative of a lack of respect for them as persons. Unfortunately, the practice is self-reinforcing.

It seems axiomatic that nursing home staffs will have trouble respecting the autonomy of residents while they continue the general practice of tying residents up, confining them to Geri-chairs, and the like.²³

Rationing Care

As the numbers of aged persons continue to rise, the costs associated with caring for them rise. This has generated a discussion of

the possible need to engage in health care rationing. As should be clear from the preceding sections, care for the aged in long-term-care facilities and elsewhere is already rationed in the sense that there are not enough paid workers available to provide optimal care.

Much has been written on the subject of rationing other forms of health care for the aged. Callahan has predicted that we will face dire consequences within the next decade without some kind of containment of the health care money spent on aged persons.²⁴ He is well known for his views on the need to find ways to reduce spending health care dollars on extending the lives of aged persons. Callahan's argument in favor of rationing health care to the aged is based on the idea that everyone is only owed whatever aid is required to help them reach what he refers to as a natural life-span. Beyond that span, only comfort care should be made available, not life-extending interventions.²⁵ In this way, he argues, there will be adequate resources available so everyone will have an equal opportunity to reach such a span. Although some bioethicists, like Daniels²⁶ and Veach²⁷ have argued that Callahan's notion of a natural life-span is problematic, they have not argued against the idea of rationing. They also argue in favor of reducing spending on aged persons in order to keep health care costs from skyrocketing out of control, compromising the availability of care for younger individuals. In fact, Veach claims to be "convinced that not all procedures should be provided and that age is a morally legitimate basis for setting the limits. . . ."²⁸

The arguments made in favor of rationing are sophisticated, not mere appeals to lives not worth extending because nonproductive and/or nearly over. I do wonder, however, if some of these attitudes linger in the background. Such discussions may perhaps not be so much about financial cost or justice, fairness, and prudence as they are about who and what we value. Kilner points out that Americans spend \$3 billion annually on potato chips, making the idea that there is not enough money to care for aged persons seem less than sincere.²⁹ He also notes,

Health care costs are increasing due to a variety of factors, many of which have no special connection to elderly persons. Why are older people singled out as a group to bear the brunt of cutbacks in life-saving care?³⁰

It is the case that infirmity increases with age, as does frailty. Older people generally do not tolerate surgery as well as younger individuals. If we look at outcomes, a young person is more likely to survive a complicated surgery and do better in the long run than an aged person. However, what we should be focused on here is the likelihood of doing well and survival for everyone being considered, not the age of the individual. It is neither unfair nor unreasonable to limit resources such that we only support those procedures with a high likelihood of success. Such a limitation will not be based on age but on an individual's ability to benefit. A very ill and frail octogenarian is unlikely to survive a liver transplant. If she is then denied the opportunity to receive an organ, it is not because she is an octogenarian but because she is ill and frail and thus, unlikely to survive the insult of transplant surgery. We ought to think the same way were she a very ill and frail 40-year-old. A transplant team might decide to provide a transplant for a very sick but hardy younger person on the ground that because hardy there is a good chance he will survive—survive to discharge, not just survive the surgery. We are not, in this case, rationing liver transplants on the basis of age and/or the amount of un-lived life-span remaining, but rather on the basis of likelihood of success. Livers being scarce, we are disinclined to “waste” them. As Wicclair notes in arguing against age-based rationing, “From the perspective of the likelihood of benefit, then, overall health status is a more appropriate criterion for the relevant *groups* or *classes* than age.”³¹ To refuse treatment on the basis of age alone is agist and is, therefore, as unacceptable as a criterion for rationing as sexist or racist criteria would be.

I think an argument can be made for rationing some forms of life-extending medical care for aged persons, like dialysis for the

seriously demented, for example. However, I would likewise be willing to ration dialysis for severely developmentally disabled children as well. Here, the rationale for limiting care has to do with the undue burden such care imposes on each. It is impossible for such individuals to maintain the kind of voluntary compliance necessary for a successful dialysis regimen, including all the dietary and liquid restrictions required. They will be mostly unable to understand what is happening to them and why. In order to assure safety during dialysis sessions, the use of maximal restraint would be necessary. These limitations would further burden and already burdensome life, drastically reducing what small pleasures remained. Age is not being used as the means to decide the allocation of resources; the condition of the individual is and should be.³² For such patients, an argument in favor of limiting other sorts of care can also be made on the basis of undue burden to the person, not cost to the system.³³ Frankly, if more decisions of this sort were properly made and hospice rather than acute hospital care provided for aged (and other) persons who are dying, spending would be greatly reduced. Better yet, suffering at the end of life would be reduced, both for those dying and their families.³⁴

Some of the pressures generated by rising costs could perhaps be better dealt with by reshaping our attitude toward the way health care for aged (and other) persons is funded. Optimally, there ought to be a system that allows universal access to decent health care (and long-term care) in the United States. Because this is not now the case, rationing currently exists in the form of millions of persons having no or inadequate access to health care.

Presently, there is no means test of wealth or income; thus, aged persons who could afford to pay more toward their health care do not. I will make a number of suggestions to try to get at the reason for resistance to the idea that those who could afford to pay a larger portion for their care should do so, enabling others to have access to some or better care.

First, there is the idea that everyone is responsible to save money to support themselves later in life and those who manage to

amass ample amounts of money ought not to have to pay when those who are profligate will pay nothing. Were it true that those who cannot afford to pay much of anything toward their health care in later life cannot as the result of being spendthrifts, this argument might have some weight. However, I suspect this is true in very few cases. Many of those who cannot afford to help pay for such care are unfairly lumped in with the true profligates. Opportunities allowing for the kind of saving needed to provide sufficient resources in later years simply do not exist for everyone.

Second, people believe because they have already paid into the system through taxation, they ought now to reap the benefits previously paid for. Given the rising cost of care, most people do not come close to paying in advance even a small portion of the costs associated with their care through taxation of wages.

Finally, there is the idea that people ought not to be forced to spend their wealth on health care, and so leave nothing in the way of an inheritance. This has always appeared to me an odd idea because it means inheritance is then subsidized by the rest of society. Subsidizing health care for those who need aid is a laudable goal for society. Subsidizing the passage of wealth from one generation to the next, especially when not everyone has access to even minimal care, is unfair, if not unreasonable.

Such a system would not demand that one spend all of his or her wealth on care, which frequently occurs in the case of long-term care. If everyone who could afford to contribute something toward the cost of care were to do so (and I would include everyone in this scheme, not just aged persons) and a sliding scale used so even the not-well-off would pay a small fee, what each person would be required to contribute would not be a hardship for any one of them. It would operate much in the way health insurance plans operate where a copayment is required. This sort of system allows everyone to participate in a more expensive plan. If health care is getting more and more expensive, partly as a result of increased numbers of people requiring more care, then everyone contributing into the system would mean everyone who needs care could benefit from it.

This is not to say that if everyone using the system just chips in a little to help pay for it, no rationing would be necessary. Even if the government were to provide universal health care, rationing is still likely to be required. However, having aged persons—or the poor—bear most of the burdens of rationing is unsupportable.

Conclusion

I have argued for the idea that underlying attitudes have a greater impact on the way care of the aged takes place than the reasons often given. It is generally not simply a matter of doing what is best while managing costs. I have pointed out a number of things we do in caring for aged persons that we would consider unethical or cruel were they to be done with children. Clearly, the salient feature of dependence is not the only thing determinative of care. We seem not to have the same respect for some aged persons that we have for others. We seem to feel fewer obligations to provide optimal care for them than for children. Such attitudes toward aged persons result in unethical practices. The idea that advanced age renders one somehow undeserving of optimal care is unsupportable. As the population of aged persons continues to grow, the possibility of cumulative harm is staggering.

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Notes and References

¹Kilner, J. F. (1996) Why now? The growing interest in limiting the lifesaving health care resources available to elderly people, in

- Choosing Who's to Live: Ethics and Aging*, Walters, J. W., ed., University of Illinois Press, Chicago, p. 121.
- ²Bérubé, M. (1998) *Life As We Know It: A Father, a Family, and an Exceptional Child*, Vintage, New York, p. 27.
- ³Kane, R. A. (1990) Everyday life in nursing homes: "the way things are," in *Everyday Ethics: Resolving Dilemmas in Nursing Home Life*, Kane, R. A. and Caplan, A., eds., Springer, New York, p. 7.
- ⁴Kane, R. A., Kane, R. L., and Ladd, R. C. (1998) *The Heart of Long-Term Care*, Oxford University Press, New York, p. 3.
- ⁵Ibid., p. 17.
- ⁶Ibid., p. 17.
- ⁷Ibid., p. 5.
- ⁸There are some monies available for limited amounts of respite care, and this is usually for those who are caring for developmentally disabled children. Respite for those who care for aged persons is usually done on a volunteer basis.
- ⁹Aroskar, M. A., Urv-Wong, E. K., and Kane, R. A. (1990) Building an effective caregiving staff: transforming the nursing services, in *Everyday Ethics: Resolving Dilemmas in Nursing Home Life*. Kane, R. A. and Caplan, A., eds., Springer, New York, pp. 274–277.
- ¹⁰Jecker, N. S. (1996) Caring for the disabled elderly: the economics and ethics of financing long-term care, in *Choosing Who's to Live: Ethics and Aging*, Walters, J.W., ed. University of Illinois Press, Chicago, p. 83.
- ¹¹Kane, *Everyday Ethics*, p. 9.
- ¹²Kane, Op. cit., pp. 75–76.
- ¹³Ibid., p. 80.
- ¹⁴Ibid., p. 87.
- ¹⁵I also think it would be wonderful for all long-term-care facilities to have animals living in, cared for by residents and staff. Plants, works of art, and more personal belongs would go a long way to making the atmosphere more congenial.
- ¹⁶Lidz, C. W., Fischer, L., and Arnold, R. M. (1992) *The Erosion of Autonomy in Long-Term Care*. Oxford University Press, New York, p. 104.
- ¹⁷Foldes, S. S. (1990) Life in an institution : a sociological and anthropological view, in *Everyday Ethics: Resolving Dilemmas in Nursing Home Life*, Kane, R. A. and Caplan, A. L., eds., Springer, New York, p. 23.

- ¹⁸Laird, C. (1979) *Limbo: A Memoir About Life in a Nursing Home by a Survivor*, Chandler & Sharp, Novato, CA.
- ¹⁹Lidz., *Erosion of Autonomy*, p. 167.
- ²⁰Ibid., p. 163
- ²¹Ibid., pp. 160–161.
- ²²Kane, *Everyday Ethics*, p. 287.
- ²³Ibid., p. 287.
- ²⁴Callahan, D. (1993) Intolerable necessity: limiting health care for the elderly, in *Facing Limits: Ethics and Health Care for the Elderly*, Winslow, G. R. and Walters, J. W., eds., Westview, Boulder, CO, p. 4.
- ²⁵Callahan, D. (1987) *Setting Limits: Medical Goals in an Aging Society*, Simon and Schuster, New York.
- ²⁶Daniels, N. (1988) *Am I My Parents' Keeper? An Essay on Justice Between the Young and the Old*, Oxford University Press, New York.
- ²⁷Veach, R. M. (1993) How age should matter: justice as a basis for limiting care to the elderly, in *Facing Limits: Ethics and Health Care for the Elderly*. Winslow, G. R. and Walters, J. W., eds., Westview, Boulder, CO, pp. 211–229.
- ²⁸Ibid., p. 227.
- ²⁹Kilner, *Choosing Who's to Live*, p. 123.
- ³⁰Ibid., p. 123.
- ³¹Wicclair, M. R. (1993) *Ethics and the Elderly*, Oxford University Press, New York, p. 86.
- ³²I also think that when making resource-allocation decisions, if limits are placed on certain treatments, the limits must apply to everyone not just those who cannot afford to pay for them.
- ³³See, for example, Post, S. (2000) Key issues in the ethics of dementia care. *Neurol. Clin.* **18(4)**, 1011–1022.
- ³⁴Wilkinson, A. M. and Lynn, J. (2001) The end of life, in *Handbook of Aging and the Social Sciences*, 5th ed., Binstock, R. H. and, George, L., eds., Academic, San Diego, CA, p. 456.