Long-Term Care of the Aged: Ethical Dilemmas and Solutions

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This article identifies the need to rethink beliefs and assumptions about the bioethics of long-term care of elderly people. An unconventional way of conceptualizing autonomy is explored that may help occupational therapists support and maintain the independence of older frail and dependent persons. In addition, the partnership model of bioethics is introduced—that is, an ethical framework that makes partners of family members in health care decisions affecting the older adult.

Changes in Medical Technology and Demographics

Since the 1950s, there have been dramatic changes in both the growth and the use of life-sustaining medical technology. These include renal dialysis, nutritional support and hydration, mechanical ventilation to induce necessary inflation and deflation of the lungs, a variety of technologies that restore the heart rate and blood flow following respiratory or cardiac arrest, and a massive array of antibiotics used to cure or control many types of infections (Office of Technology Assessment, 1987). The widespread use of these medical technologies has changed the landscape of biomedical ethics. New landmarks are being sought to help preserve the rights of individuals, to understand the process of living and dying, and to answer demands to distribute limited resources (Center for Biomedical Ethics, 1989; Office of Technology Assessment, 1987).

Well-publicized Census Bureau estimates indicate phenomenal growth in both the number and proportion...
of the population 65 years of age and older. These projections have major implications for the nation's health, social, and economic institutions (Guilford, 1988). As though the Bureau's figures were not significant enough, a National Institute on Aging (1988) report has stated that certain of the Bureau's estimates of older adult population growth are off by as much as 50%. For example, this report maintains that there will be 23.5 million Americans 85 years of age and older by the year 2040, rather than the 12 million projected by the Census Bureau, and that there will be 86.8 million Americans 65 years of age and older rather than the Census Bureau estimate of 66.8 million.

Although the dramatic aging of our population may well present the single most important challenge to the future of our society (Baker, 1988), aging alone does not challenge the older patient's autonomy or create special ethical dilemmas for health care professionals. Rather, it is the associated needs of elderly people that pose challenges to society. For example, we know now that "the incidence and the prevalence of all types of chronic illness are positively correlated with increasing age, and rise to particularly high levels in the population over sixty-five" (Jennings, Callahan, & Caplan, 1988, p. 5). As Scanlon (1988) has shown, 13% of people 65 to 69 years of age need some kind of long-term care. Even more significant, 55% of those 85 years of age and older require some form of assistance.

**Autonomy. The Cornerstone of Current Biomedical Ethics**

Autonomy is one of the ethical issues that applies directly to both frail and dependent older people receiving long-term care and those who care for them. Patient autonomy is a relatively new concept in bioethical thinking (Center for Biomedical Ethics, 1989). Over the past 25 years, however, the concept of patient autonomy has developed into what Jennings et al. (1988) called "the autonomy paradigm" (p. 8)—an ethical framework that health care professionals, ethicists, and policymakers will use to make moral and fair health care policy decisions in the future. The autonomy paradigm embodies the concepts of personal autonomy, medical authority, disease as an enemy, and the notion that the patient and physician work together in a temporary relationship to combat the illness.

Although these principles are gaining acceptance by many as the cornerstone of biomedical ethics, "within long term care few ethical issues prove more problematic than those involving personal autonomy" (Collopy, 1988, p. 10). As many ethicists point out (Agich, 1990; Collopy, 1988; Collopy, Dubler, & Zuckerman, 1990; Crabtree, in press; Hardwig, 1990; Jennings et al., 1988), the autonomy paradigm as currently constructed is not well suited for understanding the distinctly different chronic care issues of the aging, many of which are only indirectly related to health. To consider the unique ethical dilemmas that often arise out of providing long-term care services to older adults, we will examine this popular body of ethical thinking more closely.

According to Jennings et al. (1988), three interrelated models form the foundation of most current bioethical thinking: the medical model of illness, the contractual model of medical care, and the model of the individual as a rational, unique person who is free to choose and act in his or her best interest.

Of these overlapping concepts, the medical model of illness assumes medicine's ability to successfully cure the patient of an acute illness or compensate for any residual loss from that illness. The medical model of illness attempts to reduce a disease to its most basic elements and relationships in order to understand and influence them (Kielhofner & Burke, 1983). The contractual model of health care casts the provider in the role of an authority on health and casts the patient as one who voluntarily submits to this authority to regain his or her health. The temporary nature of acute illness and the brief loss of personal autonomy, according to this model, make collaboration with health care professionals on a short-term basis acceptable, particularly since both parties in this situation have the goal of curing the disease and restoring the patient to health (Jennings et al., 1988). The third component of the autonomy paradigm assumes that the rational individual's self-determination and self-interest exist before the need for medical help and that the person, of his or her free will, chooses to use available medical services as he or she sees fit (Jennings et al., 1988).

**The Autonomy Paradigm Challenged**

For at least three reasons, the autonomy paradigm is poorly suited to guide occupational therapists' decisions regarding older adults who require long-term care. First, popular notions of autonomy, including the autonomy paradigm, are typically conceived in terms of legal or political abstractions such as freedom from tyranny and oppression by others (Agich, 1990). This concept of autonomy inadequately describes the realities of aging, human frailty, and "dependence as a nonaccidental feature of the human condition" (Agich, 1990, p. 12). Second, the current concepts associated with the autonomy paradigm are inexorably linked to the medical model, which conceives of aging as a medical problem and focuses on the etiology, treatment, and management of disease while overlooking the nonmedical issues associated with long-term care and the elderly (e.g., social problems, housing, transportation, family needs) (Estes & Binney, 1989). Finally, this modern autonomy paradigm does not take into account the remarkable differences between acute and chronic care. For example, the older adult needs to continue to find meaning and purpose in life in spite of chronic illnesses and deficits. Older adults with
chronic health problems cannot place independence, let alone their lives, on hold while health care professionals take care of them.

The temporal differences between acute and chronic illnesses are major. The person with an acute illness may have temporarily abrogated his or her autonomy to the health care professional but will recover within a reasonable period of time and no longer require the services of health care providers. By comparison, the long-term nature of a chronic illness means that the illness may require intermittent medical intervention for decades; it thus offers ongoing challenges to the older adult's autonomy. The level of family involvement in acute care tends to be minimal. In the case of a chronic disease, the family probably performs many of the dependent older person's activities of daily living (e.g., dressing, bathing, cooking, shopping, banking) and may make life-and-death decisions for the older family member. Last, successful chronic care requires the active participation of the older client; many treatments in acute care medicine do not (Lo, 1990).

The long-term nature of older people's deficits, the high degree of family involvement in care and services, the need for the older adult to be an active participant in the treatment, and the need to make meaning of one's life despite advanced age and chronic disabilities provide sufficient reasons to develop new models for thinking about the care of frail and dependent elderly people.

Autonomy Revisited: A New Approach

To conceive of a new ethic for long-term care of the elderly, we must have a concept of individual autonomy that can accommodate the realities of chronic illness within a framework that (a) assumes family involvement in critical health care decisions and (b) acknowledges the wealth of knowledge and resources available to the older person and the health care team through the family.

Thomasma's Five Freedoms

Thomasma (1984) has suggested that there are five discrete but overlapping freedoms associated with autonomy. By using his construct of autonomy, we refine our thinking about the nature of the older person's independence and discover specific ways in which we can, in our close relationship with our older patients and their family members, help protect or even facilitate the autonomy and self-direction of the frail and dependent elderly people with whom we deal.

The first of Thomasma's freedoms is the freedom from obstacles to carrying out one's desires, meaning the absence of coercion or constraints. Freedom number two is the freedom to know one's options—that is, to have access to the information needed to make reasonable decisions. This includes not only understanding the options, but also being informed about their consequences. The third freedom is the freedom to choose—the freedom to make one's choice a goal, and, furthermore, to be able to marshal the resources needed to meet the goal. This freedom also includes the notion of making practical judgments. The fourth freedom is the freedom to act. Thomasma gave the examples of voting and of, having chosen a partner, committing one's actions to that decision. The last freedom is the freedom to create new options. Thomasma believed that this is the highest freedom in most respects, since, as in the Kantian sense of autonomy, the self creates its own laws.

The scope of this paper will not allow an in-depth discussion of Thomasma's framework of autonomy. Instead, we will briefly explore these freedoms to help us find ways in which the older adult's autonomy can be upheld and supported.

Applications

One example of a challenge to the freedom from obstacles discussed by Thomasma is the physician who makes a private decision that a patient is not a good candidate for a certain procedure or therapy, such as occupational therapy. In such cases, a patient who may have wanted (and needed) those services has lost the freedom to carry out his or her desires because of the physician's decision. Other examples include physical and chemical restraints that prevent nursing home residents from carrying out their reasonable wishes, and unchallenged stereotypical attitudes that often limit what a professional or non-professional caregiver sees as the potential of the older person.

The freedom of the older person to know the treatment options and their consequences can be easily compromised when occupational therapists or other health care professionals neglect to explain the purpose and outcomes of their treatments. Patients may refuse treatment or refuse to follow through with treatment because they do not understand the consequences of their actions. Perhaps this is due in part to the mundane nature of the training they need to restore independence in activities of daily living. After all, older adults have been dressing and grooming themselves for many years. They believe they already know how to dress and question why they should learn these skills again.

It is not uncommon for older chronically ill patients to believe that they will recover their independence in activities of daily living without occupational therapy. Even knowing therapy is available, they perceive that their choices are between staying in bed and being cared for or struggling to get out of bed, to brush their teeth, and to sponge bathe. These patients are, of course, choosing from a limited pool of options and are not aware of the consequences of their choices.

The older patient's freedom to make choices about
health care is often problematic. Thomasma’s third freedom— the freedom to choose and to accept responsibility for one’s choice—is illustrated when a patient refuses to follow through with occupational therapy services even though his action results in dependence on others in activities of daily living. This decision can present a frustrating dilemma for the therapist, yet our Code of Ethics states that occupational therapists “shall respect the right of potential recipients of service to refuse treatment” (AOTA, 1988, p. 795).

Thomasma’s fourth freedom, the freedom to act, is, like all the freedoms, dependent on the others. Consequently, the freedom to act can be confused with other elements of autonomy. Collop et al. (1990) have made a valuable distinction between what they called executional incapacity and decisional incapacity. They wrote that “because elderly clients cannot carry out certain choices or activities without assistance, caregivers may disregard [the elderly person’s] capacity to make choices or have preferences about these activities” (p. 8). Thus, the person’s inability to dress himself or herself (executional incapacity) is confused with the person’s inability to choose which shirt to wear (decisional incapacity) (Collop et al., 1990).

Thomasma’s last freedom, the freedom to create new options, is perhaps the most spiritual and challenging of his freedoms. The most moving examples of this freedom are found in the Holocaust literature, which shows how the human spirit has been able to rise above unimaginable mental and physical anguish. As Victor Frankl (1965) wrote,

> In a position of utter desolation, when man cannot express himself in positive action, when his only achievement may consist in enduring his sufferings in the right way—an honorable way—in such a position man can, through loving contemplation of the image he carries of his beloved, achieve fulfillment. (p. 59)

Certainly older adults must have the freedom to create new options that will help them maintain their ability to achieve fulfillment, even if that option is acceptance of imminent death.

By viewing autonomy as having five overlapping but distinctly different freedoms, we no longer have to frame our patients’ autonomy in all-or-nothing constructs of self-determination, but can recognize that one or all of these freedoms are potentially available to the older frail adult, whether institutionalized or living at home.

The Partnership Model

In addition to a concept of autonomy that accommodates the mundane, everyday realities of chronic illness, we need a model of ethics that includes the family in both the daily living of the older adult and in his or her critical health care decisions. This model should include the family as a potentially important resource for the older person and the health care team. As mentioned earlier, such a model should also address the significant differences between acute and chronic care and should be broad enough to include a variety of nonmedical problems (e.g., transportation, housing, and recreation) (Crabtree, in press).

The partnership model meets these criteria. It borrows the concepts of partnership and agency from business law. According to the Uniform Partnership Act of 1914, “a partnership is an association of two or more persons to carry on as co-owners a business for profit” (Frascona et al., 1981, p. A11). An agent is someone who is authorized to act on behalf of another (Random House Dictionary of the English Language, 1987). In business law, “an association as partners is not a master/servant or employer/employee relationship. It is a relationship that makes each member a coprincipal and a general agent for...transacting partnership business” (Frascona et al., 1981, p. 679).

The partnership model as an ethical framework for long-term care makes it conceptually possible for one or more family members, or even a close friend, to be the agent of the older frail adult when necessary. For this to occur in a way that upholds the autonomy of the older person, as in business law, the parties must “agree that one is to act on behalf of the other, subject to the other’s control” (Frascona et al., 1981, p. 213). Each partner then has both express and implied authority to act on behalf of the partnership.

This model, without the legal trappings, conceptualizes the family unit as a partnership that always includes the older frail and dependent adult. The partnership model conceives of the older adult as an active member of the partnership and also empowers the family members to speak for the older person when necessary. Caplan (1985) wrote about the importance of empowering family members:

> If health care providers make a sustained effort to involve family members early on in discussions with elderly patients about their care, then family members will be in a better position to act, not as surrogate decision-makers, but as what might be termed "proxy amplifiers.” (p. 14)

The older adult may always be competent and capable of expressing his or her wishes. In such a case there is no need to use any member of the family as an agent. However, when the older person is incapable of expressing his or her wishes, for whatever reason, in the partnership model there is an agent who can speak for the older adult with authority.

In cases of legal incompetence, the partnership model of ethics extends beyond the business partnership analogy. When one agent in the business partnership becomes incompetent, the partnership may be dissolved. However, it is precisely at the point when the older adult becomes incapable of appropriate action or of making needed care decisions that the partnership model of bio-
medical ethics is useful. It is at this point that the family can step in and advocate for the older adult’s needs.

It is important to note, however, that family members may live so far from the older adult that they are not available to participate in any decision making. Other family members may not be inclined to participate in the partnership because of family dynamics, financial problems, or lack of competence; at worst, some may even attempt to undermine nonfamily partnerships that the older adult has developed.

Although there are instances when a family will not or cannot act in the older person’s best interest, it is more likely that one or more family members acting as partners can be counted on to be supportive, to make reasonable decisions, and most of all, to carry out the wishes of the older adult when he or she is unable to act for himself or herself.

One formal example of how another person can be expected to act fairly on behalf of another is through a durable power of attorney for health care. This is a legal document in which older adults can appoint a family member or friend to make health care decisions on their behalf under prescribed circumstances. The person appointed under this document can make all decisions about the older adult’s health care and is subject only to limitations specified in the document or those imposed by law (Law Offices of Kato & Feder, 1988).

Conclusion

We have suggested that currently accepted concepts of autonomy are not well suited to the needs of the older adult with a chronic illness. To help develop a more adaptive concept of autonomy for the occupational therapist working with persons with chronic disabilities, we have explored a concept of discrete freedoms within the broader and often abstract notion of autonomy. This concept provides a practical way of looking at the autonomy issues of older people requiring long-term care and allows the therapist to see and support the daily opportunities each frail older adult has for independence.

In addition, we have introduced a partnership model that includes the family as an integral part of the older adult’s daily care and his or her critical decision-making process. This model takes into account the characteristics of chronic illness, such as its long-term nature, the need for active family participation, nonmedical problems such as housing and transportation, and the need for active participation by the older person. Perhaps most important, this model assumes that the older person will continue to find meaning and purpose in life, despite severe limitations or dependence on others.

The partnership model recognizes that the older adult and the family are intertwined and that any decision made by one has an impact on the other. By conceiving of our older clients and their families in this way and recognizing that autonomy is not an abstract concept but a composite of discrete freedoms, we can help to support frail older persons’ potential for continued growth, no matter how brief; their potential for achievement, no matter how small; and their creation of new options, no matter how mundane.

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