Autonomy, Personal Empowerment, and Quality of Life in Long-Term Care

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The philosophical principle of autonomy provides a conceptual framework within which an understanding of quality of life for the elderly can be developed. This structure provides the basis for designing interventions to enhance the quality of life of older persons by maintaining their autonomy in spite of long-term care service needs. Such programs should encourage proactive strategies to anticipate and plan for potential health crises, promote empowerment of the elderly, expand knowledge, and clarify personal and familial values regarding service options. Examples of the kinds of programs needed to enhance autonomy in community-based and institutional long-term care settings are presented to illustrate how independence can be supported even under conditions of increasing frailty and service needs. These applied approaches to enhancing personal autonomy give explicit recognition to the importance of ethical concepts in developing and implementing long-term care services to improve the elderly's quality of life.

Interest in the relationship between a sense of control or autonomy and successful outcomes in aging has recently drawn considerable attention from gerontologists (Rodin, 1986; Rowe & Kahn, 1987). Increased research linking positive health outcomes and a sense of personal control over one's life underscores the need for developing programs to enhance the autonomy of elderly persons. A recent expression of the linkage between health and control is the growing

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recognition of the value of self-care for the elderly (DeFriese & Woomert, 1983; Kane & Kane, 1986; Moody, 1985).

In response to this awareness of the relationship between autonomy and the quality of later life, several initiatives have recently been developed to support personal freedom of choice among the elderly, particularly in long-term care settings in which decision making may be affected by physical frailty or mental impairment (Retirement Research Foundation, 1986). The implicit purpose of these programs is to enhance the quality of life of elderly persons, especially where powerful external forces—both institutional and familial—may pose a clear threat to personal dignity, freedom of choice, and self-determination. Most of these initiatives propose the use of short-term interventions or legal devices to expand the range of personal freedom of choice.

This attention to the positive effects of a sense of control over one's life should not be interpreted as an endorsement of the view that successful aging must entail total independence and lack of reliance on the support of others. The development of the concept of "active life expectancy" (Katz et al., 1983; Katz, Greer, Beck, Branch, & Spector, 1985) with its emphasis on the maintenance of functional dependence—rather than on death as the outcome of interest—must be cautiously applied when developing and targeting policies and programs. The temptation to equate quality of life with functional independence must be guarded against.

Indeed, all humans depend on others to varying degrees. Parallel with Gadow's (1983) analysis of the geriatric dialectic of frailty and strength, it is necessary to consider all persons as embodying a balance between independence and dependence. Indeed, recent attention to the social perils of overemphasizing fierce individualism (Bellah, Madsen, Sullivan, Swidler, & Tipton, 1985) serves as an exhortation to beware of the limits of narcissistic autonomy. This notion is nowhere more relevant than in an analysis of the dialectic between dependence and autonomy in advancing age, particularly when long-term care services may be required to support the individual's personal needs. The need for assistance, for relying on others to meet one's basic functional requirements, does not connote a devaluation of the worth of the individual. What is required of service providers is a sensitivity to how each person strikes the balance between dependence and independence in his or her own life (Lifchez & Winslow, 1979).

The inherent tension between dependence and independence is a central feature of the concept of autonomy as it relates to quality of life in long-term care settings. How this dialectic unfolds in a way that enhances quality of life becomes the issue—one that is not simply an academic armchair exercise. Rather, how to enhance autonomy even within the constraints of a system that can easily overwhelm individual expressions of control becomes a challenge to be assumed by the "reflective practitioner." This is Schön's (1987) term to describe the professional or service provider who is able to perceive and grapple with those "gray areas" of practice in which value dilemmas intrude to call into question the everyday patterns of behavior and practice. I attempt to highlight areas in long-term care where individual autonomy may be enhanced by skilled practitioners who are sensitive to the dilemmas intrinsic in caring for the frail elderly.

To blend these philosophical and practical elements, I briefly review the ethical issues in defining quality of life and develop the concept of personal autonomy as a framework for understanding how life quality for the elderly may be conceptualized and enhanced in a variety of contexts. Concrete examples illustrate how autonomy can be encouraged in community-based and institutional long-term care settings in which increasing frailty and service needs require a shifting of the independence/dependence balance. The argument throughout will be to demonstrate how insights based on the ethical principle of autonomy can enhance the ability of the reflective practitioner to balance the competing claims of increased service needs and the maintenance of a sphere of individual control over one's life.

Ethics and the Quality of Life

Although the discipline of applied ethics has emphasized the difficulty of defining quality of life, it has nevertheless stressed the importance of taking into account values and personal interpretations of life experience. This approach has resulted from such historical events as Nazism, with its development of the notion of a "low-quality life"—a "life not worth living"—to justify the wholesale extermination of ethnic and racial groups (Steinfels & Levine, 1976). Ethical issues emerge in the geriatric clinical dilemmas when quality of life judgments are encountered in debates over withholding treatment and even nourishment from the "hopelessly ill" elderly (Callahan, 1983; Caplan, 1982; Lynn & Childress, 1983; Wanzer et al., 1984).

Similar issues also emerge at the policy level: scrutiny of ever-growing expenditures on health care has triggered suggestions that medical resources be withheld from the elderly and channeled to other, "more productive" age groups (Evans, 1983). The implicit argument underlying this position is that the actual or projected quality of life of older persons is not sufficient to justify the expenditure of large quantities of costly health care resources, an approach that has been challenged on ethical grounds (Avorn, 1984; Clark, 1985). Other studies have focused on the interdependence of generations as an antidote to the divisive policy perspective of age-group competition for a finite amount of social resources (Kingson, Hirshorn, & Cornman, 1986). In an attempt to bridge the gap separating these two positions on intergenerational equity, Callahan (1987) has recently proposed an ethical argument for withholding government support for certain types of life-extending medical services from individuals who have attained a natural life span, provided that social resources are devoted to enhancing the health and well-being of persons who have not yet reached it.

In contrast to its reactive response to pressing clinical or social dilemmas related to geriatric care, ethics may be proactive by suggesting the basic structure of programs and policies to enhance older persons' quality of life. Rather than simply "raising a red flag" when individual rights are in jeopardy, moral reasoning can help develop interventions that are life enhancing. Although this approach may not provide a detailed definition of what constitutes quality of life for older persons, it may nevertheless contribute a broad structure and general guidelines for what kinds of programs and policies are needed and how they might be developed and implemented. The ethical principle of individual autonomy can clarify our understanding of the concept of quality of life and guide the development of programs to enhance it in long-term care settings.

The Concept of Autonomy

The philosopher H.L.A. Hart (1955, p. 175) has asserted that "if there are any moral rights at all, it follows that there is at least one natural right, the equal right of all men to be free." A more recent statement of the ethical centrality of personal freedom is found in Rawls's (1971) theory of justice. This value has been prominent in American culture since the founding of the country. Indeed, its existence has been described and its effects debated from the time of Tocqueville to the more recent work of Bellah et al. (1985), which suggests that the American obsession with individual freedom may prevent meaningful individual commitment to the welfare of the community.

Although the concept of personal autonomy is frequently appealed to and infringements on it widely railed against, its precise shape, structure, and implications are seldom analyzed. This situation occurs because of personal autonomy's intrinsically nebulous nature, multifaceted aspects, and tendency to alter in meaning in different contexts (Collopy, 1986). Personal autonomy has been variously described as self-determination, individual liberty, independence, self-rule, deciding according to one's own principles, and following one's own life plan.

The intrinsic complexity of autonomy should not deter attempts to apply it to specific situations, however. Indeed, it is through the concept's application that its precise usefulness and limitations emerge. According to Miller (1985), the philosophical basis for autonomy can be understood at least partially in terms of the concepts of autonomy of action and autonomy as a capacity of persons.

Autonomy of action focuses attention on whether a particular act is voluntary and intentional (not performed by manipulation or deception) and whether it is "authentic"—that is, consistent with an individual's past behavior. In addition, this aspect of autonomy encompasses two dimensions of particular importance in long-term care: "effective deliberation" (the ability to think consciously about an action) and "moral reflection" (the ability to apply one's values and life goals to a particular situation). For example, individuals and families facing decisions about appropriate long-term care placement or services and elderly persons planning for the possibility of increased dependence must have access to accurate information and be able to enunciate the underlying values that direct their life plans and goals (Clark, 1987). The lack of these resources may limit their ability to make satisfactory choices about important long-term care options and thus undermine their satisfaction with the process and outcome of long-term care decisions.

Autonomy as a capacity of persons connotes "agency"—the ability to act with independence of judgment—and includes personal power—the ability and the resources to work toward some perceived future good. This concept is closely tied to a person's sense of self-respect, a value that has achieved philosophical prominence (Rawls, 1971) and been closely linked to the elderly's quality of life (Christiansen, 1974; Schwartz, 1975). As a principle, self-respect includes an individual's conviction that personal plans and goals in life are worth achieving and the confidence in one's ability to attain them. Self-respect is thus tied closely to personal empowerment, demanding greater personal responsibility for one's life and health and the provision of social resources to support the expression of this responsibility (Clark, 1987).

Personal autonomy is not synonymous with quality of life, yet the two concepts are closely linked. Recognition of the value of autonomy demands that older persons be respected as individuals and their ability to pursue their life plans and control their lives be enhanced. Respect for autonomy provides the essentials for individuals to be free to pursue their own definition of the "good life," whose content is shaped by individual preference and experience. Autonomous lives are not, however, free from contacts, ties, and relationships with others. All humans exist in a community where interdependence is required for individual health and well-being. In this sense, self-perceived quality of life may be a function of an individual's degree of satisfaction with how the balance between dependence and independence has been struck.

Enhancing Quality of Life in Community-Based Long-Term Care

The conceptual framework of autonomy finds expression in a number of programmatic approaches that should be developed to enhance the elderly's quality of life in various community-based long-term care contexts. These include advance planning for long-term care, improved levels of information, and values clarification.

Advance Planning for Long-Term Care

Although the greatest fears of the elderly are declining health and growing dependence, older persons do not anticipate or plan for future health-related crises (Kulys, 1983; Kulys & Tobin, 1980). Support for the autonomy of older persons, particularly those within long-term care settings, must not begin simply at the time of hospitalization or placement in a nursing home. Currently, however, the only help most individuals receive in making decisions about long-term care services occurs at discharge from a hospital. At this time; the social worker attempts to find the best source of support for the impaired person. Unfortunately, little time is available to consider a complete range of alternatives; options requiring lengthy preparation are not feasible. Worse, "solutions" to an individual's or family's long-term care "problem" may be recommended by persons having different values, life experiences, and loyalties. For persons in the community who are considering long-term care service options, including nursing home placement, the prospects of receiving information and support are even bleaker. Recent research by Schofield and Bass (1986) has substantiated what many families and service providers already knew: that elderly individuals and their families are isolated and have difficulty getting assistance regarding nursing homes and their alternatives.

Epidemiological research by Ostfeld (1985) suggests several dimensions of elderly individuals' lives that may be strengthened to improve their ability to weather life crises and to enhance the quality of their lives. These "buffers of old age" include improving the individual's emotional and cognitive status and extending social and familial networks. The preparation of these buffers in advance may avoid or delay the need for institutionalization and enhance the quality of life even if an impairment or health problem does occur.

What can be done to enhance autonomy by bolstering the resources available to elderly persons and their families to prepare them for the time when health problems and impairment may make living independently no longer possible? The principles of autonomy of action and autonomy as personal capacity suggest some program approaches. The enhancement of autonomy and quality of life must begin much earlier than hospitalization or nursing home placement and be conceptualized as a *process* whose goal is to maximize the ability of older persons to live the way they want, in spite of possible health problems or impairments. Planning offers opportunities to enhance the sense of control one experiences over life and the future, especially when done in a way that takes into account the possibility of health-related crises. Currently, interventions attempting to enhance elderly autonomy focus predominantly on the individual already in an acute or long-term care setting and for whom autonomy-enhancing programs may have only limited success. A more proactive stance, as recommended by Collopy (1986, p. 207), must be taken:

> Rather than deal with problems of autonomy *reactively*, in the very midst of loss, long-term care should encourage the elderly to be "proactive" in dealing with the contingencies of frailty. This would mean a commitment to maximizing choice and options for the elderly, to creating a context where agency and responsibility are expected of and respected from the elderly.

Pratt, Schmall, and Wright (1987) echo this theme by suggesting that the elderly have a moral obligation to plan for their own future health care, thereby increasing the probability that their own wishes will be fulfilled and lightening the burden of decision making for family and professionals.

Although some devices currently encourage this proactive stance, they tend to be limited to legal mechanisms useful in a narrow range of circumstances. Moreover, they do not create a process through which personal agency and responsibility can grow. The principle of autonomy of action suggests that this process should be conceptualized as a developmental one within which the varied dimensions of autonomy can be addressed and supported. This process may be considered analogous to the stages that some theorists (Kohlberg, 1971; Perry, 1970) have suggested characterize the acquisition of successive levels of moral reasoning. This process culminates in a state comparable to the "reflective equilibrium" Rawls (1971) suggests, the result of a dynamic process of comparing one's principles and judgments until they coincide. This state is not necessarily stable, however, as changing conditions cause the individual or the family to reassess their principles and courses of action. For example, a sudden decrement in an older person's functional level may cause a reassessment of the family's desire and ability to continue caring for him or her.

The need for a process to enhance deliberation and reflection is made evident by the research of McCullough, Soldo, Lipson, and Agree (1984), which indicates that elderly individuals and their families do not have these capacities. For example, a family may want to fulfill a parent's wishes and keep him or her at home for as long as possible, but they cannot clearly identify the principle that underlies this goal. Indeed, the work of Bellah et al. (1985) suggests that most Americans have difficulty in enunciating or explaining the moral principles underlying their actions and life plans.

The deliberative and reflective processes demanded by the principle of autonomy underscore the importance of anticipating and planning for future life events and preparing to cope with them. This approach suggests the importance of developing an educational intervention to assist elderly persons and their families in planning more effectively for a future holding a risk of impairment and decreased function. One such program, currently operating at the University of Rhode Island, has developed three different planning products to be used with elderly persons at risk of growing dependence.[1]

(1) The *Lifestyle Risk Profile* is a risk assessment instrument, including questions about the individual's health-related behavior, social and familial networks, home and neighborhood environment, and financial resources. Answers are scored with a computer, and the individual receives a written assessment of his or her risk of becoming impaired or institutionalized and a set of recommendations on how to reduce this risk.

(2) *Choices: Growing Old Successfully* is a personal planning guide that helps elderly individuals and their families identify their goals and resources and determine the gaps between them, while maintaining independence in the face of potential losses. It goes beyond simply providing information by assisting the reader in exploring personal values and choosing actions corresponding with them. Each chapter deals with a topic critical for developing successful planning skills to anticipate future lifestyle changes and challenges.

(3) *Group workshops and a facilitator's guide* supplement the personal planning guidebook by providing a structured group format in which participants explore their values and goals for the future under the direction of a professional facilitator. The workshops are offered at various community sites, including senior centers and senior housing sites.

Other proactive programs strengthening the ability of the elderly and their families to plan for long-term care decisions are clearly needed. Such programs must go beyond a narrow focus on retirement planning in the traditional sense and encompass broader domains anticipating the risk of future health problems and impairment. An essential component of this type of intervention is empowering older persons to assume more responsibility for their lives and futures. In addition, autonomy as personal capacity suggests that individuals and their families require certain types of resources, skills, and abilities to chart their future life course and to realize their life goals, such as a sense of control over life, assertiveness in relations with others who are sources of advice or services, and confidence in one's ability to follow one's life plans.

In addition, supports are needed for the individual to achieve these objectives. For example, if independence in the face of declining functional ability is one's long-range goal, then strong social and familial support networks, a supportive and safe physical environment, the assurance of sufficient financial resources, and a change in health behavior, which may prevent or slow the decline in functional status, are all required. Autonomy also requires the provision of social resources to expand the range of service choices available to individuals and families, and the assurance of public assistance to provide them if necessary (Clark, 1987). Without these resources, empowerment becomes a meaningless charade of exercising choice in a world with no options.

Improved levels of information. The principle of effective deliberation and the concept of personal empowerment suggest that elderly persons and their families must be given improved information about aging and the types of long-term care services available. Better knowledge about the normal aging process and how to distinguish it from disease is an essential component of teaching individuals and families "defensive health behavior" to question the "pat diagnoses" of health professionals (Kane & Kane, 1986). Better information on service alternatives, particularly those options allowing for maximal independence of an impaired person, would allow families to resist overly directive advice from physicians or other professionals. The education of the elderly person and his or her family about the range of service options available makes operational the principle that the best case manager is the individual, provided that he or she has appropriate information or the knowledge of how to get it.

The old phrase that "knowledge is power" captures the thrust of this appeal for the need to educate the consumer for empowerment. Yet it would be a mistake to forget that the physician or other health professional must also be educated about the importance of involving the patient and family in decisions about care, particularly long-term care. This includes training the "reflective practitioner" in the importance of understanding the personal and familial values at stake, in particular decisions regarding choices among long-term care service options. Educating the consumer for empowerment in the tradition of the self-care movement (Levin, 1981), without a complementary effort to change provider attitudes about the patient's involvement in care decisions, would be to raise patient expectations only to have them dashed on the medical model of control. This insight suggests that cooperative empowerment must develop between the health care provider and the consumer, a situation in which the physician provides essential information about the nature of an individual's health condition and the likely medical outcomes associated with alternative care choices (Clark, 1987). Complete client control of decision making or provider parentalism obscures the basically interdependent nature of decisions about long-term care and threatens to undermine satisfaction with the resultant quality of life.

Kapp (1985) suggests an example of how this approach may be implemented. He proposes that the physician initiate the taking of a "medical future" to chart potential patient outcomes analogous to the traditional medical history's summary of significant health-related events in the past. This device would stimulate mutual patient and provider concern for the future and how to plan for desired outcomes.

Values clarification. Elderly persons and their families need to be encouraged to reflect on the values and principles guiding their lives in order to make long-term care decisions with which they will be satisfied.

Recent research (Townsend, Deimling, Noelker, & Bass, 1986) has revealed how family caregivers' nursing home placement decisions are fraught with ethical conflict. Similarly, Pratt et al. (1987) empirically determined a number of dimensions of ethical conflict in family caregivers of demented patients, including family reciprocity and conflicting obligations. Other researchers (McCullough, Soldo, Agree, & Lipson, 1986) have developed interventions to clarify the values of the acute care patient considering nursing home placement. Additional models are being developed and tested (Retirement Research Foundation, 1986). Preliminary empirical research (Clark et al., 1986) has indicated three major loci at which values play a pivotal role in the long-term care decision-making process: criteria for decisions, rules for decisions, and criteria for assessing satisfaction with outcomes.

"Criteria for decisions" are the ethical standards that give general direction to an elderly individual's search to resolve the problem of "what should I do" in the decision about long-term care alternatives. For example, persons going home after hospitalization report that happiness and self-determination are more important, while those entering a nursing home indicate that protection is a more crucial guide.

"Rules for decisions" are the guidelines for action based less on principles than on personal loyalties and sense of commitment (Potter, 1969). They come into play at times when a conflict between two principles exists, and a resolution creating their rank ordering is sought. Use of these guidelines is one indication of the dynamic nature of the long-term care decision-making process, in which principles alone are not always sufficient to guide behavior. Such conflict is an example of Lemmon's (1966) third type of moral dilemma in which a person ought to do something and ought not to do that same thing. Earlier research on values in long-term care decision making (McCullough et al., 1984) has indicated that such conflicts frequently occur along particular value axes, such as autonomy versus parentalism. In these situations, nursing home residents appear more likely than persons going home following hospitalization to accept directive advice, such as a physician's recommendation. When faced with a dilemma in which a conflict exists between the needs of the parent and those of the child caregiver, those returning home are more likely to balance the needs of the parent with the child's. In contrast, those in nursing homes are more apt to consider the needs of the child to be paramount (Clark et al., 1986).

"Criteria for assessing satisfaction with outcome" refer to standards applied by persons who have recently made a long-term care decision. These criteria describe their personal reasons for being happy with its outcome. The availability and adequacy of supportive services seem to be a more significant factor for those in nursing homes than for those who return home following hospitalization. The same may be said for the availability of social opportunities—such as the ease of making new friends. Importantly, contentment is more commonly reported as a significant factor for those returning home from the hospital than for those persons entering nursing homes (Clark et al., 1986).

The central role values play in choosing among long-term care alternatives and their importance in determining ultimate satisfaction with these decisions suggest that elderly persons and their families must be encouraged to reflect on the principles guiding their lives and to apply them to situations in which decisions about long-term care services may be required. This is the essence of the concept of "moral reflection." Although model programs to encourage the development of this ability have been developed, greater experimentation with different types of approaches should be an agenda for researchers and practitioners.

Enhancing Quality of Life in Institutional Long-Term Care Settings

Although discussion thus far has focused on preparing the well elderly to anticipate long-term care decisions and on empowering the more frail elderly individual in the midst of an actual long-term care choice, concern with empowerment does not end at the time of institutionalization. The enhancement of nursing home quality of life continues to depend on striking a sensitive balance between resident dependence and independence, particularly because the range of options and the level of available resources may have been diminished. The importance of supporting the institutionalized individual's involvement in making decisions about life and care continues to be paramount.

Rather than connoting failure to maintain one's independence, admission to a nursing home must be seen simply as a transfer to a more appropriate place in which to receive increased services. For this to become true, however, the loss of personal identity and the development of feelings of helplessness and hopelessness that tend to be created by the institutional long-term care setting must be countered (Wack & Rodin, 1978). Although the nursing home is comparable to other "total" institutions with regard to the dependency and lack of control it fosters (Goffman, 1961), researchers have demonstrated the efficacy of specific types of control-enhancing interventions in improving happiness, activity levels, and participatory behavior (Langer & Rodin, 1976;

Mercer & Kane, 1981; Rodin, 1986). Although most interventions have been modest in scope and duration, improved health status and reduced mortality have been reported as additional results (Rodin & Langer, 1977).

While some observers might argue that the increasing frailty and cognitive incapacity of nursing home residents in recent years make autonomy-enhancing interventions problematic, it is nevertheless apparent that some residents would benefit from even relatively simple provisions giving them an increased sense of control over their lives. Possible options range from the more simple one of allowing greater menu choice to the more complex, such as the development of nursing home resident councils. Clearly, there are different levels of cognitive impairment, and each has different implications for decision making. For example, a person may be unable to keep track of personal financial matters but may still be competent to make decisions about the desirability of certain types of medical treatment. The "reflective practitioner" must realize that it is important to provide choice and promote independence even under conditions of substantial impairment. Great sensitivity to the dialectic of dependence and independence is called for in such circumstances—a sensitivity that may be difficult to express under the conditions that characterize many long-term care facilities. Two specific points of ethical importance should be made here:

(1) *Labeling the nursing home resident.* The elderly are as influenced by the stereotypes of aging as anyone else. For most, the prospect of entering a nursing home and becoming a "patient" (rather than the more acceptable term "resident") implies the surrender of self-determination and the assumption of dependence. As a result, an individual's sense of self-respect may be dealt a severe blow. Although labels may order our individual experience and determine roles and relationships, they can be applied to restrict individual autonomy and life chances and opportunities. Indeed, the very language used to describe entering a nursing home—"placement"—connotes passive and nonparticipatory involvement of the individual in a major decision affecting present life and future possibilities.

The nursing home staff also is influenced by the power of a label. The staff members' realization that they have been hired to care for residents can reinforce a passive and nonparticipatory role by their dressing and feeding individuals who might be able to do these activities for themselves, given sufficient time and encouragement. The dictates of administrative efficiency and short staffing conspire to create a downward spiral of increasing resident dependency (Avorn & Langer, 1982).

This situation can be characterized by Christiansen's (1974) concept of compounding the losses of the frail elderly. When others perceive that an older person's range of physical or cognitive abilities is narrowing, there is a tendency for them to restrict the individual's freedom still further. Instead of carefully tailoring support and services to meet the precise needs of the care recipient, there is often a wholesale assumption of complete care. Thus, rather than supporting and encouraging the person to maintain as many areas of independent functioning as possible, care providers contribute to the creation of total dependency on the part of those for whom they care.

This development of iatrogenic functional disability within the institutional long-term care setting has implications for the quality of life of the care recipient. The principle of individual autonomy suggests that the frail elderly in nursing homes be given as much independence in self-care and control over their lives as possible. It is apparent, however, that some individuals may be incapable or unwilling to exercise this control. There is considerable variability in individual preferences for control, and studies in health care settings indicate that some individuals benefit more than others from being informed about and involved in their own health care (Rodin, 1986). This approach to care underscores the need for each person to strike a balance between dependence and independence, with sensitive support from the care provider. While some might argue that a complete restructuring of the nursing home industry is required to achieve this goal (Rango, 1982), others point to recent positive indications of change in the ways nursing home residents exercise some control over the course of their care and the quality of their lives.

(2) *Nursing home residents' rights, councils, and regulatory reform.* The appearance of the concept of patients' rights can be attributed to a growing consumerism in health care and the emerging field of biomedical ethics in the decade of the 1970s (Clark, 1987). It is not surprising that the plight of the nursing home resident, along with that of such other "vulnerable" groups as mental patients and prisoners, received scrutiny during this period. The response to actual and potential threats to the dignity and self-determination of the nursing home resident was increasingly seen to lie in the development of nursing home patients' "bills of rights," which carefully delineated the types of rights that could be asserted to assure quality of life, if not quality of care. Typically, these included the following: contract rights; rights of association and communication; rights related to admission, transfer,

and discharge; property-related rights; rights of autonomy or choice; privacy rights; rights related to physical security; procedural rights; and the maintenance of human dignity (Harris, 1982). Although residents' rights provisions became incorporated into federal regulations, their lack of elevation to a condition of participation in the Medicare and Medicaid programs and continued concerns about their enforceability raised questions about their overall impact on quality of nursing home life (Caldwell & Kapp, 1981; Wilson, 1978). To many, the assertion of residents' rights became a virtually meaningless exercise because of their rather vague nature and the difficulty of exercising effective sanctions against nursing homes that either overtly or covertly disregarded them.

Following Reagan administration attempts in 1981 to deregulate the nursing home industry, public outcry and concerted consumer lobbying efforts led to the development of new proposals to bolster the extent to which quality of life considerations were included in the development of standards for certifying nursing homes and in the actual survey process to determine if nursing homes were in compliance with federal regulations. These proposals came from consumer groups (National Citizens' Coalition for Nursing Home Reform, 1983) and from the federal government itself in the form of a new survey process to be used by the Health Care Financing Administration (Balcerzak, 1985). In addition, a major study by the Institute of Medicine has produced a report calling for developing outcome-of-care measures more accurately reflecting concern for the quality of life of nursing home residents and for the greater participation of residents and resident councils in nursing home surveys (Institute of Medicine, 1986).

These efforts have culminated in the recently enacted Nursing Home Reform Amendments of 1987, which give residents' rights a statutory basis, require minimal training for nurse's aides, mandate an annual comprehensive assessment and care plan development to maximize resident functioning, and provide other requirements to enhance quality of care and life in nursing homes. Although their effects may not be felt for some time, these amendments will certainly play an important role in highlighting the central significance of personal autonomy and quality of life in the institutional long-term care setting.

Conclusion

The concept of quality of life is frequently discussed, yet it remains defiant of facile description and pat characterization. Personal values are clearly at the very core of those attributes with which we attempt to define quality of life. The concept of personal autonomy can be used to advance our understanding of quality of life and, more important, to develop programs to enhance it in long-term care. In particular, a focus on autonomy draws our attention to the dialectic between dependence and independence and the necessity of striking a realistic and sensitive balance between these competing forces in everyone's life. The achievement of this goal becomes a challenge for the reflective practitioner, whose actions must be guided by ethical principles but tempered by the recognition of the possible.

New programs will be needed in the areas of advance planning for long-term care decisions, the empowerment of long-term care consumers and their families, the education of consumers and providers, and the recognition of the importance of values in framing the dilemmas encountered by the frail elderly and their families facing a long-term care decision. Unlike current initiatives focused primarily on the acute care setting and often using legal models, new developments for enhancing personal autonomy must emphasize the continuous nature of long-term care decision making and the types of functional impairments creating the need for them. Autonomy-enhancing programs must be available to the well elderly anticipating long-term care decisions in the future and planning for ways to reduce their risk of dependence. Similarly, interventions must be developed for the frail elderly facing a decision during a crisis—such as acute hospitalization—as well as for those who, after a crisis has been resolved, need to be empowered to exercise control over their lives, even in institutional settings.

While it is apparent that new developments promise to enhance the elderly's autonomy and quality of life in long-term care settings, it is also clear that much more needs to be done. The concept of autonomy provides us with criteria for defining this objective and measuring how successful we have been in attaining it. Whether and when it is achieved will depend on the political, social, and economic forces shaping long-term care services in this country. Nevertheless, the empowerment of the long-term care consumer and his or her family represents a goal in itself and a means for enhancing the quality of life for our country's growing elderly population.

Note

1. Further information about the availability of these materials can be obtained by writing to the author, c/o Program in Gerontology, University of Rhode Island, Kingston, RI 02881.

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