

## Care of the Elderly Patient: Policy Issues and Research Opportunities

Council on Health Care Technology, Institute of Medicine

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# Care of the Elderly Patient: Policy Issues and Research Opportunities

Report of a Forum of the Council on Health Care Technology

Jeremiah A. Barondess, David E. Rogers, and Kathleen N. Lohr, editors

Institute of Medicine

NATIONAL ACADEMY PRESS WASHINGTON, D.C. 1989 THE INSTITUTE OF MEDICINE was chartered in 1970 by the National Academy of Sciences to enlist distinguished members of appropriate professions in the examination of policy matters pertaining to the health of the public. In this, the Institute acts under both the Academy's 1863 congressional charter responsibility to be an adviser to the federal government, and its own initiative in identifying issues of medical care, research, and education.

THE COUNCIL ON HEALTH CARE TECHNOLOGY was established in 1986 by the Institute of Medicine of the National Academy of Sciences as a public-private entity to address issues of health care technology and technology assessment. The council is committed to the well-being of patients as the fundamental purpose of technology assessment. In pursuing that goal, the council draws on the services of the nation's experts in medicine, health policy, science, engineering, and industry.

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### **Preface**

In the recent past, the interests of different groups concerned with health care have focused on the use of medical technologies—their safety, efficacy, and effectiveness; their cost-effectiveness and cost-benefit; their impacts on quality of care; and their social, legal, and ethical implications. The sum of these varied interests is the field of health care technology assessment.

The Council on Health Care Technology was created to promote the development and application of technology assessment in health care and the review of health care technologies for their appropriate use. The council was established as a public-private enterprise at the Institute of Medicine, a component of the National Academy of Sciences, through the Health Promotion and Disease Prevention Amendments of 1984 (P.L. 98–551, later amended by P.L. 99–117). In 1987 the U.S. Congress extended support for the council as a public-private venture for an additional three years (by P.L. 100–177).

The goals and objectives of the council, as stated in the report of its first two years of operations, are "to promote the development and application of technology assessment in medicine and to review medical technologies for their appropriate use. The council is guided in its efforts by the belief that the fundamental purpose of technology assessment is to improve patient well-being and the quality of care." In pursuing these goals, the council seeks to improve the use of medical technology by developing and evaluating the measurement criteria and the methods used for assessment; to promote education and training in assessment methods; and to provide technical assistance in the use of data from published assessments.

The council conducts its activities through several working and liaison panels. Members of these panels reflect a broad set of interested constituencies—physicians and other health professionals, patients and their families, payers for care, biomedical and health services researchers, manufacturers of health-related products, managers and administrators throughout the health care system, and public policymakers. In addition, the council carries out activities of interest to more than one panel.

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The Forum Series is one of the councilwide activities. The Forum Series seeks to facilitate an exchange of views among the many and diverse groups concerned with health care technology. Themes addressed by these symposia include the interdependence among medical technology assessment, quality assessment, and assurance of the quality of patient care; the performance of existing technology assessment activities; the appropriate use of technology to minimize risks posed to special or vulnerable patient populations; and the development, application, and appropriate use of technology.

A guiding principle of the council is a special focus on outcome measures that coincide with patient well-being, quality of health care, and quality of life. In keeping with this principle, a forum conducted in October 1987 dealt with care of the elderly patient. This report is the record of that symposium.

WILLIAM N. HUBBARD, JR., CHAIRMAN

JEREMIAH A. BARONDESS, CO-CHAIRMAN

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# Introduction to the Council on Health Care Technology

William N. Hubbard, Jr.

The Council on Health Care Technology was established within the National Academy of Sciences and the Institute of Medicine in 1986. The council is responding to selected problems that are related to technology in health care:

- Improving the availability and interpretation of information already in the literature on technology assessments.
- Improving methodologies that are used for health technology assessments and the selection of appropriate methods.
- Improving professional and public understanding of how the outcomes
  of using specific technologies affect the benefits of health care.
- Improving the efficiency of technology assessment by developing a more systematic procedure for establishing national priorities of technologies to be assessed and fostering their execution.

Many interested parties are concerned with the assessment of health care technology. The perspective from which the council proceeds is that the uniquely valid outcome marker is the well-being of the individual patient. We do not, therefore, orient our concerns specifically to entitlements or reimbursement patterns or organizational issues or even technical safety and efficacy; rather, we orient our own concerns toward demonstrations of the relationship of an intervention to the well-being of the patient.

With these interests in mind, we have instituted this series of public discussions—the Health Care Technology Forum Series. The theme that ties the initial meetings of the series together is the issue of

quality in health care as it relates to assessment of the use of technology and as it is defined by demonstrations of individual patient benefits. The first forum of the series emphasized what may be obvious but certainly has not been clearly pursued in practice—the indivisibility of evaluations of effectiveness and quality. These tend to be two different communities of investigators. The interdependence of these two descriptors of technology assessment was the focus of the first meeting held in May 1987.

The problem of appropriateness of use of all interventions by the health professional in the patient's course comes down to selecting and adapting that intervention to the individuality of the patient. This is particularly pertinent, as we see technology becoming more and more autonomous, under pressure to be more generally effective and its use being cost controlled.

As we observe the operation of technology in care of the elderly—the focus of this forum—it becomes obvious that the overarching principle of all interventions being individualized has a particular poignancy when technology confronts the elderly. It is that confrontation and the efforts that are appropriate and necessary in order to individualize intervention that we will focus on today.

### Quality of Care and the Health Needs of the Elderly Patient

Avedis Donabedian

The aged are Everyman. They share in the human condition in all its aspects, all its vicissitudes. They are rich and poor, well and ill, competent and disabled, resilient and brittle, enlightened and ignorant, autonomous and dependent, familied and bereft, involved and isolated, contented and troubled, full of hope and despairing. In all these ways the aged are as we all are. It is unlikely, therefore, that what they need or look for shall be, in any fundamental way, different from that which we all need or wish to have.

Yet, we all know that the aged are also different. They are different in the odds that they face of experiencing the evils and blessings of living, and in the future duration of life itself. Even at their healthiest, the aged are vulnerable and fragile; they have a smaller fund of reserves to draw upon, whether these reserves be physiological, psychological, social, or economic. Should an old person fall off the razor's edge into disaster, recovery is seldom complete. There is a bias toward irreparability in the misfortunes of the aged. And these misfortunes, when they occur, tend to be many and interconnected, forming a constellation of physical, social, and economic ills that kindle and fuel each other. So, the ills of the aged persist and they progress in a hardly containable decline into debility, disablement, dependency, and disengagement. In the end, the aged may become too passive, too accepting of all they suffer, even severe illness tending to masquerade in less alarming, though treacherous, masks.

Therefore, health care for the aged, if it is to be successful, must overcome the many handicaps that the aged more often face. Even the meaning of quality may have to be altered to adapt to the particular

circumstances and perspectives of the aged. Appropriateness and adaptation will be, therefore, my central theme in this discourse. But, since these properties are also necessary attributes of quality in all health care, I hope to show that what is distinctive of quality in caring for the aged is only a set of differences in emphasis, rather than a radical departure. In seeking quality for the aged, we shall rediscover the principles that govern quality for us all.

### THE MEANING OF QUALITY

I must begin with the meaning of quality itself, since we must understand and agree upon the property that we seek before we can take steps to find it.

Quality, as an attribute of health care, is usually held to be proportionate to the improvements in health that health care can achieve. But, because our ability to achieve improvements in health is limited by the state of our knowledge and our technology, quality is more realistically definable as a ratio of improvements achieved by any instance of health care to the improvements that could have been achieved by the best health care. If this ratio is taken to be a measure of "effectiveness," the property of "effectiveness" and the property of "quality" become the same.

By defining quality as effectiveness, in the manner described, we lose sight of the means that we use to achieve improvements in health. We seem to say that the means do not matter, so long as the objective of health improvement is attained. But this is hardly the case. Not all the means are equally approved; some may even fail to be legitimate.

We should also entertain the possibility that the greatest achievable improvement in health may be, in some circumstances, an inappropriate objective. It is best, therefore, to define quality as the attainment of desirable objectives using legitimate means. If so, we need to examine, in turn, the objectives of health care and the means for attaining them.

### THE OBJECTIVES OF HEALTH CARE

For the sake of simplicity I shall accept the objective of health care to be an improvement in health, putting aside, for now, the uses of health itself. In order to assess the quality of care we would need to know, therefore, the natural history of morbid conditions when untreated, when treated by the "best care," and when treated by the particular example of

care that we wish to provide or to assess. With regard to all these items of information, our knowledge is often inadequate. And considering how complex and how unstable the problems of the aged are, I would expect that, in their case, our ability to make valid judgments is even more subject to question. Yet, seeing how little the aged have in reserve, and how much even small losses must count relative to that smaller balance, a precise accounting of prospects becomes even more necessary to a wiser choice.

Knowledge contributed by the health care sciences is, therefore, the rock upon which all quality and all assessments of quality must rest. We need to know more about the natural course of illness and the relative efficacy of alternative methods of management in the aged, as in everyone else.

Next, we need to come to an understanding on what we mean by "health"—the several components that make it up, the many aspects of performance that it subsumes. Consensus on these matters is not easy to achieve, and it may be particularly difficult for us to agree where the aged are concerned. We disagree on what is inevitable and what is remediable in the manifestations of aging; we are unsure to what standard of health the performance of the aged is to be compared.

Then, there is the problem of valuation. Because measurement always implies valuation, it may be foolishness to speak of objective measurement. Rather, we may need to consider whose valuations determine the measure: those of the health care practitioner, those of the patient, those of family members, or those of some social instrumentality, more or less legitimate.

It is generally accepted that, in choosing among alternative methods of management, the valuations of the patient are paramount or, at the very least, are to be seriously considered. Yet, even if we were willing to make a determined effort to do so, our ability to obtain fully informed valuations is limited at best. How are patients to assess future consequences that they have not personally or vicariously experienced? How are they to weigh rather small differences in probabilities for which personal exposure provides no familiar counterpart?

When intellectually impaired or emotionally withdrawn, the aged are even less able to accomplish these tasks. And should one or more family members undertake to do so, we cannot be sure whether the judgments made are those that the patients would have made or whether, out of selfishness or a sense of duty, those judgments undervalue or overvalue the patients' prospects.

In the choice of alternative methods of management, it is, of course, the *individual* patient's preferences that matter. But, it would be interesting also to know if old age, as a shared attribute, introduces biases in the valuation of survival and in the quality of life during the period survived. It would not be surprising if the lowered expectations of survival and good function that ordinarily accompany aging were to influence the valuations that the aged place on alterations in these expectations. If so, interventions that represent the highest quality might differ, on the average, for the aged as compared with others.

These considerations would also influence the judgment passed by patients on the present consequences of past care. We often hear that these expectations are frequently too high. If so, the patient may not have been properly informed. And, on the contrary, it is also possible that the patient is content only out of ignorance of how inferior the results experienced are, compared with what might have been reasonably expected.

It follows that a well-informed, assertive patient is a key player in the process of defining and assessing the objectives of care. The patient's role, as we shall see, is at least equally critical in the choice and assessment of the means for achieving these objectives.

### THE MEANS FOR ATTAINING THE OBJECTIVES OF CARE

I shall discuss the means for attaining the objectives of care under five headings: (1) access, (2) the practitioner's contributions to care, (3) the patient's own contributions to care, (4) the contributions of health care programs and institutions, and (5) money.

I realize that by including access in this particular list I do violence to the purity of my classification. Nevertheless, it is important to begin with access to care because, without initial access, no care can be given and, without continued access, care is prematurely discontinued. We must be disturbed, therefore, when we hear that gains in access achieved during the recent past are now in danger of being lost. The aged, especially if also poor, are apparently among those affected by this reversal. In particular, we need to know if the methods of cost containment that seem to single out the old, because they are the beneficiaries of publicly financed programs, have had an adverse effect on the duration, content, and outcomes of care.

The duration and content of care are, of course, matters that health care practitioners have traditionally controlled, although recently other

agencies have intruded more and more on the practitioners' prerogatives in this domain. Still, the practitioners' contributions to care, irrespective of whether the contributors are fully autonomous or partly constrained, are the key determinant of quality.

It is customary to distinguish two components in the clinical role of practitioners. One is the management of technical care and the other the management of the personal interaction with the patient. For this occasion, I shall add a third: the management of the patient's social situation.

Technical care is, itself, divisible into components; these include knowledge, judgment, and skill. If I may be allowed a brief digression, I would like to remark that in our usual assessments of process, based upon medical records, we are more able to evaluate knowledge and judgment than skill. Skillful execution usually reveals itself in the health outcomes achieved.

More to the point, in our present context, are the peculiar demands that the medical problems of the aged, as already described, make on the technical competence of practitioners. Special preparation and experience are needed. That means more attention to the education and training of clinical specialists in the field. It means a larger emphasis on learning about care for the aged in the education and training of health care generalists and specialists of every kind. It means the reorganization of care so that the aged, at least when very ill, have the benefit of specialized attention, either directly through care by specialists in specialized units, or indirectly through established policies and procedures for consultation and support to generalists who assume the burden of primary care.

The second component of professional care is the management of the personal interaction with patient and family. This includes respect, concern, personal interest, courtesy, understanding, privacy, confidentiality, and a single-minded devotion to the patient's interests. Meticulous attention to the patient's wishes and values is particularly important. If these are legitimate, the practitioner is under an obligation to comply. If they are not, the practitioner is obligated to explain the matter and arrive at an ethically defensible conclusion.

To an audience as expert as this I need not expatiate upon the central importance of the patient-practitioner interaction to the quality of care. In this respect, we owe the aged what we owe to all our patients. But, the aged, if frail and handicapped, will require even more time and attention. The aged, deeply rooted in times long past, and sometimes also

in a possibly alien culture, are partial strangers in this more tumultuous present.

The management of the patient's social situation is the third component in the contributions of the practitioners to care. Once again, this is a responsibility to be faced in caring for all patients. It assumes greater importance when the patient is older because of the social and economic vulnerabilities to which I have alluded already.

In almost all the practitioner's ministrations the contributions of the patient are, of course, of critical importance. The patient provides information necessary for diagnosis and management, doing so at the initial encounter and throughout the care that follows. Without the patient's participation, the practitioner's recommendations are implemented poorly or not at all. The patient has an additional responsibility to pursue a more healthful mode of living. In some cases, the aged may be more willing to make the modifications necessary to improve their threatened prospects and more able, by virtue of circumstances, to take the time to do so. At other times, the aged may be unable to communicate or collaborate, and, because of their relative isolation, there may be no one else to speak or act effectively on their behalf. As a result, plans for care that might earn admiration when the patient's medical record is reviewed do not translate into improvements in health because the patient has failed to cooperate.

I shall add the contributions of institutions and organized programs to this catalogue of means for achieving the objectives of quality. I do so only to remind ourselves of the critical importance of social effort in providing the resources that enable patients to gain access to care and make it possible for practitioners and patients to collaborate effectively in the production of care under circumstances that are satisfying to both. The critical resource, of course, is money, an instrumentality so important that I have given it a separate position in this list.

The purpose of care for the aged, as of course, for everyone else, is appropriateness, which is the precise matching of care to medical need. Without it, we may have too little or too much. In the technical care of the aged, redundancy and surfeit in the process of care are particularly attractive responses to uncertainty in the practitioners and to nonresponsiveness or inevitable fatality in the patients' illness. Our too-ready recourse to prodigal technical care is also abetted by a widespread tendency to "medicalize," as some have said, so many of our problems. Thus, we create spuriously "medical" representations of problems that could be more

amendable to successful management by means simpler and less costly than outpourings of technical care. The solutions to this misapplication of technology are, first, a level of technical expertise sufficiently high to recognize the limits of technology; second, the availability of expertise in the alternative modalities of care; and third, the presence of the social mechanisms that permit a choice of the most appropriate modality of care.

For some reason, we have provided more readily for highly technical health care than for health care that is less dependent on technology; and we have been more willing to provide for health care than for care that does not fit so easily in that exalted category. As soon as we can, let us forsake this foolishness. We can, then, pursue maximum improvements in health at a cost that we may perhaps be able to afford.

There are those who tell us, however, that maximum effectiveness, even if it is obtained with due regard to efficiency, is not the proper goal for a society to pursue. This is because, in any given situation, these critics say, there are elements of health care that, though useful, are too costly in comparison to the improvements in health that they can be expected to confer. Therefore, we are told, optimum effectiveness, not maximum effectiveness, should be the goal.

The choice between maximum effectiveness and optimum effectiveness as the proper goal for health care policy is not confined, of course, to the aged. But the welfare of the aged is peculiarly sensitive to the consequences of the choice. The aged are usually unemployed and, therefore, get very much undervalued in methods that set a monetary value on the benefits of care. Besides being "unproductive" in this sense, the aged tend to need larger amounts of care and, if kept alive even though ill, will require more and more in the future. Thus, in addition to being unproductive, the aged are a drain on our collective treasure. And even if the rules that govern the availability of care were to reject a crass economic calculus and, instead, value the life and well-being of the aged as highly as those of anyone else, the much shorter life expectancy of the aged would give them much less to bargain with.

Following these baleful lines of reasoning, the aged would be denied useful interventions that would be available to a younger person with the same disability. In some cases, no care might be thought worthwhile beyond that needed to relieve pain or to assure a degree of comfort. No one denies, of course, the right of the ill, at any age, to decide that added survival may carry too large a burden of pain and disablement to be worth accepting. But, should anyone else have the right to make that decision?

We are told that rationing of health care is now taking place, as it always has. If so, we need to know who does the rationing, on what grounds, and with what consequences. And if still more rationing is to be expected, the same questions will need to be answered. Do we wish to strip the patient of insurance coverage so that economic necessity becomes the rationer, while we stand at a distance, seemingly innocent? Shall we, openly or by insinuation, suggest to the aged that they have a duty to expect and ask for less? Should we make health care practitioners more direct accomplices in the deed, by placing upon them a duty to put the public interest above that of their individual patients? Or do we intend, rather, by differential reimbursement to providers, to subvert their judgments so that they conform more readily to our implicit social purposes? And who, in all these questions, are the "we" who both ask and answer the questions? In what arena? By what right?

These and similar questions, lead us to the most fundamental issue we must face: the nature of the social commitment to health care in general, and to the care of the aged in particular. Respecting the aged we have proceeded waveringly, every fit of progress seemingly followed, first, by hesitation, and then by an insidious retreat. It is against this background of uncertainty that we must, alas, consider those features of system design that are needed to accommodate the peculiar requirements of the aged.

### SOME ASPECTS OF SYSTEM DESIGN

The secret of success in planning health care for the aged is to take a comprehensive view of their total situation, so that its many complexities can be accommodated by corresponding features of system design. Accordingly, we cannot consider health care independently of the social services required to support the aged when their individual capabilities begin to decline. And the system of health care, itself, must consist of many finely articulated parts, each serving a distinct function, yet each closely related to every other part. Only in this way can we achieve the many objectives that we pursue. Among these are preservation of function, maintenance of autonomy, effective therapy at reasonable cost, and resort to institutional care only when all else fails.

As I have already said, access to care is the first consideration. It is particularly so for the aged, since many of their disabilities are perhaps easier to prevent by anticipatory care than to remedy once they have become established.

Access depends, most fundamentally, upon a method of financing that makes care affordable. Because the financial resources of the aged, even when relatively ample, are usually nonreplenishable, as little health care as possible should be financed from current resources, and as much as possible from funds put aside for the purpose in advance of retirement. Regrettably, at least in this regard, recent history has been a record of unremitting retreat.

But lack of financial means, although critical, is not the only barrier to access. To get to the sites of care the aged must overcome the barriers of physical and psychological remoteness while hampered by their own relative immobility and isolation, and also by the unavailability of suitable transportation. Even when they can reach the sites of care, the physical design of the environment may impose further discomforts on the disabled and infirm. We must, of course, create the means by which the aged can be brought to health care. At the same time, the outposts of the health care system can be placed closer to where the aged live, making these sites both handy and familiar.

Home care, itself, can be regarded as one means by which services are brought to patients in a setting that offers much in patient autonomy, social integrity, familiarity, safety, efficacy, and low cost. Through the availability of home care we reduce our dependence on the hospital; we lessen exposure to its depersonalizing effects, to the pernicious consequences of the immobility it may impose, and, above all, to the costs and injuries of that frenetic playing out of the "technological imperative" for which the hospital is the natural stage. Through home care we also avoid, or at least postpone, the horrors that, too often, attend consignment to certain institutions. For these reasons, and many others, we applaud and endorse home care as an advance of signal importance. Nevertheless, with respect to home care, as with all else in the health care system, we must maintain the wholesome skepticism that leads to further research, on the one hand, and to further improvement, on the other.

Even after so many years of experience, there are some doubts as to whether home care for the chronically ill and disabled reduces costs, raises them, or leaves them largely unchanged. It is clear, however, that the costs of home care, whatever their magnitude, are in danger of being shifted, more of the burden falling directly on patients or on members of their families. To this are added the many other responsibilities attendant to the patient's remaining at home. We must find a remedy for all this.

There is also a degree of uncertainty about the effectiveness of home care in improving the health of the chronically ill, or, if small

improvements do occur, about the justificability of the high cost of achieving such improvements. Partly, these uncertainties may reflect the "over-medicalization" to which home care is not immune. Possibly, although this may sound even more heretical than what I have said so far, the quality of home care needs to be more carefully assessed and monitored. I doubt that nursing care is immune to the failings to which all professional performance is heir; and it is even possible that too much of it, besides being costly, may debilitate personal and familial responsibility, leading to an overreliance on the kindness of strangers. Even the privacy of the home, one of its crowning attractions, may also do harm by obscuring the visibility of professional performance, while isolation and infirmity expose the homebound patient to neglect, manipulation, intimidation, or abuse, usually at the hands of nonprofessional personnel who perform housekeeping functions.

In the professional domain, a major weakness has been our inability, so far, to determine the appropriate balance of nursing initiative and physician responsibility in caring for the homebound patient, and to make that necessary partnership of equals a working reality. The attenuation, even the disruption, of physician responsibility is itself part of the larger problem of assuring a seamless continuity in care as the patient moves from hospital to home, to nursing home, to physician's office, round and round, in a sorry peregrination to an ultimate departure. Of all the necessary objectives of system design in caring for the aged, coordination and continuity are the most fundamental and, seemingly, the most difficult to attain.

Greater coordination and continuity can be achieved to some degree by making more effective use of devices already at our command. Discharge planning for the hospitalized patient can become more prevalent, more judicious, and more thorough. The communications that accompany patients as they are transferred from site to site can be more timely, more discerning, and more complete. But, ultimately, we need to assure, by some means, a direct responsibility for the care of the aged, in wellness and illness, irrespective of the site of care. So far, that pluralism in our health care system in which we take so much pride has obstructed progress on this path. There are, nevertheless, promising developments.

It is no longer so farfetched to conceive of an integrated system of health care facilities that includes at least a health maintenance organization, a hospital, a home care program, a nursing home, and a hospice. In a context such as this, assuming that a parallel system for financing care

were present, the patient, aged or otherwise, could move from site to site assured of appropriate placement in each and continuity of care throughout.

A unit record, on paper or in the computer, and a flow of other information of similar kind could serve as the vehicles of continuity. No doubt, patients and members of their families, if properly instructed, could also play a more active role in bringing about a higher degree of coordination and continuity. But perhaps the most effective vehicle would be a health care practitioner who would give care or at least oversee it at all sites. I will betray a personal bias and an inalienable attachment to my own professional roots by saying that I hope that practitioner to be the patient's personal physician; but some other health care practitioner could assume that role, or perhaps no more than a patient advocate versed in the intricacies of the system, able to pull the right ropes.

A concomitant of this design would be an ability to assess and monitor the quality of care not in artificially disjointed slices, as is now the case, but for functionally related wholes. In doing so, it may also be possible to accomplish something so many have so devoutly hoped for: to rely more heavily on the outcomes of health care than it has been possible to do when no one could tell who was to be held responsible for what.

### **CONCLUSIONS**

In these ways and others, we ought to offer the aged, in their declining years, release from needless pain, impairment, neglect, and humiliation. For the prospect of a liberated but protected old age is a gift not only to the aged. Sometime, sooner or later, we shall all be as they are. Their present is our own future. In serving them we serve no other than ourselves.

### Home and Community Care of the Elderly: Introduction

Mary O. Mundinger

I would like to welcome you to the first day of this forum devoted to technology issues in the care of the elderly patient. The Council on Health Care Technology has a central and enduring concern for appropriate use of technology in the delivery of care, and the two days of the forum are opportunities for us to deliberate these issues in terms of the settings in which we care for older patients. Today we will focus on the community setting, where more and more care is being delivered, partly because of reimbursement incentives under diagnosis-related groups and partly because technology has brought the possibility of transferring more care to the home and community settings.

One of our concerns in the council has been the absence or unavailability of data on home and community care. Very little is known about the parameters of care delivered in the home to elderly patients. Although Medicare pays for home care, it does so on the basis of payment per visit, requiring only that the care be "skilled," or primarily hands-on, short-term illness resolution services. It is not clear what the scope of services is that are actually delivered or what those services accomplish. It is the sense of most policy analysts that Medicare home care was not established to meet the home care needs of elders, but was intended only as a substitute for extended hospitalization. Substituting care in the home for hospital care requires more than transporting the technology; successful home care relies on the presence of a supportive environment and back-up services, and on the stability of the patient's condition. None of the Medicare criteria for home care addresses these necessities. As an observer of how Medicare home care policy is operationalized and evaluated, I have learned that the link between what is allowed under the law

and what is actually provided is very different, with providers giving care that is needed, whether reimbursable or not. Evaluation of care is faulty because what is provided is not what is documented for reimbursement purposes.

We lack data not only on Medicare home care, but also on community-based services that may be available but inadequately accessed because the population has no organized way to take advantage of the services. Our assessment of the burden of illness on patients is seriously biased by the lack of data about out-of-hospital care—its cost, both direct and indirect, and the nature of informal supports that are needed.

These data deficits impact on the council's ability to evaluate technology application and quality in the home setting. The nation's research and policy agendas for community care are growing in importance as health care continues to shift toward community-based care and as the demographic profile shifts dramatically toward an aging population whose care needs will be chronic and long-term. Our discussions today are aimed at shaping those research and policy agendas to yield the important data that we will need to plan for that future.

## Home and Community Care of the Elderly: Framing the Issues

Robert L. Kane

When I was invited to this conference, its name was Care of the Sick Elderly. It has since been changed to Care of the Elderly Patient, a sign that we recognize the increasing difficulty of distinguishing between the sick and the well elderly. Many remarks during the course of the forum will be directed toward that very difficult distinction.

My task is to frame some of the issues surrounding care of the elderly, and I shall begin by laying out some basic principles. First, we shall look at the problem of changes in severity of care that people receive resulting from changes within the acute care system. Second, we shall look at distinctions between the site of care and the type of care. Third, we shall examine the need for linkages, or what Dr. Donabedian referred to as coordination, between the acute care system and the chronic care system. We need to recognize that we are looking at "care careers" of people over the course of a whole lifetime. We shall approach some of the distinctions between the form of care and the way that form has been shaped by the way that we pay for care; we will discuss the distinctions between who performs these services and what is done; and finally, we shall look at some of the issues around quality.

### CHANGES IN SEVERITY OF CARE

Let us look at some of the causes for the changes in severity of care. We have heard a great deal in recent years about the effects of

<sup>&</sup>lt;sup>1</sup> See Avedis Donabedian, "Quality of Care and the Health Needs of the Elderly Patient," in this volume.

imposing prospective payment in the hospital. We hear frequent accusations about discharging people quicker and sicker. We must recognize, however, that documenting the shifts in some of these areas is relatively difficult. For example, the literature reveals conflicting data about admissions into nursing homes (12,15). It is not clear whether there is a difference in the rate of change among characteristics of the people admitted to nursing homes today as a result of the introduction of this new payment system in the hospitals.

We are also seeing a tremendous growth in the development of new technologies in acute care that has allowed us to change the nature of the survival rates of people treated in that system and thus, potentially, to change the nature of the people who move from incidence into prevalence (4). One of the topics increasingly debated today is whether there exists a compression of morbidity in a segment of the population, particularly the middle aged and young elderly, who have benefited from our improved abilities to treat illness (1,3,9,13,16). Is the aging population more impaired or less impaired than it has been in previous years? In other words, we have a great deal of conflicting information about whether the prevalence of morbid conditions among the elderly is declining or increasing.

We are also seeing some impressive changes in demography regarding, first, increased likelihood of survival (life expectancy among the elderly is increasing), and second, the effects, particularly the projected effects, of changes in birth cohorts (with more persons in the older age groups).

Another factor to be considered is changing mores. It is reflected in part by the change in the title of this forum. What do we now define as disability? Our threshold for defining disability has changed over time (10). For example, the standard measures for defining disability have changed for people applying for benefits and early retirement through Social Security. Because these measures have not been consistent, but have been very much socially and politically determined, we cannot make valid comparisons or extrapolate to see whether one is seeing true differences over the years or simply measurement differences.

### SITES AND TYPES OF CARE

To confound the problem we are beginning to see a fascinating blurring between the site of care and the type of care. If one looks at the

quality of care literature of just a few years ago, one finds statements about how care ought to be delivered. Profound and unambiguous pronouncements were made about the "right way" to treat a particular condition. Often the patient was put in bed for an extended length of time in a hospital and required intensive supervision. Many of the these very same patients are now being managed on an ambulatory basis or with home care. We are seeing a transfer into the community of very sophisticated home care in which people are maintained on expensive and elaborate machinery that formerly required the constant attention of highly qualified technical personnel, carefully supervised within an institution. It is much harder to make judgments about the nature of that care.

We are also seeing the distinction between acute and long-term care begin to blur more and more. We are recognizing that one leads to the other and that it is very difficult to tell where acute care ends and long-term care begins. In many cases it depends on whom you ask. If you ask the people in long-term care, they say that it begins as soon as the patient is admitted to the hospital. People delivering acute care say that long-term care begins as soon as we want to get rid of the patient. The distinction has become increasingly arbitrary and, as we will see, it is driven by external factors other than professional judgment.

We have used a term in the past about location of care in the home, and we have distinguished among different levels of medical practitioners, but many of the distinctions in community care revolve around whether care is delivered in a home nursing model or a homemaking model. Much supportive care depends on the kind of organization that provides that care, the kinds of professional sponsorship, and often, the kind of fiscal sponsorship—who is paying and what are the criteria of eligibility. We certainly see distinctions between various modalities of community care. Some current research has tried to distinguish the relative efficacy, for example, of methods of home care versus day care. Another important question relates to transportation—is it more efficient to transport caregivers to the home or to transport patients to some kind of a central facility?

When one examines the relative efficacy of different kinds of care, one really must look at the ramifications of the total-care delivery package, not just a part of it. We need to think about the kind of care that we want to provide in terms of availability of that care. Much care in the community is available only five days a week and only at certain times of the day. For example, it may be more efficacious to provide care for

people with Alzheimer's disease at night than during the day. We have not yet begun to address how to develop the kinds of attendant systems that provide care when it is needed rather than when it is made available. Certainly, we have observed, even from very general national-level data, enormous variations across the country in the availability and consequent use of different forms of care. In addition, a great deal of substitution occurs of one kind of care for another when a certain kind of care is not available. Rehabilitation is one area in which variations are most pronounced, particularly now that it is exempt under Medicare.

### LINKAGES BETWEEN ACUTE AND CHRONIC CARE

Let us look at some of the linkages between the acute and chronic care. Dr. Donabedian has already alluded to the importance of hospital discharge planning. The hospital is a major launching point for the long-term care careers of many patients. Currently there is enormous variation in the degrees to which important care decisions are made, in the ways that they are made, and in the persons participating in the decisions. Dr. Donabedian has addressed at length the importance of patient autonomy in decision making for discharge. Not too long ago, one heard national authorities state that a good hospital discharge plan was one in which the patient knew where he or she was going.

We have not come too far from that point in many circumstances. Very few places have both the leisure and the willingness to engage in careful decision making with all the participants regarding this very critical question. Very few hospitals in this country can permit patients to sample some of the alternatives available. Even fewer places have alternatives available at the particular time when one wants to make that discharge. We are really asking patients—if we, indeed, are even able to involve them in the decision making—to make critical decisions, which may affect the rest of their lives, on the basis of very fragmentary information.

In many cases, none of the parties critical to the decision making know much about the alternatives that they are discussing. Sometimes, the hospital personnel have never visited the nursing homes, have no idea of the real competence of the home health agencies, and talk in vague generalities about places about which they have no personal experience. In some of the worst cases, the staff knows from personal experience that they would not put their own mothers in a particular home, but they are

under pressure to move the patients out in a hurry and therefore coerce or encourage patients, or in some cases simply ship them to inferior facilities.

Another reason hospitals have not given the needed attention to discharge planning is that under the current system of hospital reimbursement, there are strong counter-pressures to spending time planning discharges. The costs must be absorbed by the hospital even though the time spent will affect care once the patient leaves the hospital.

### GERIATRIC ASSESSMENT

We have raised the "white knight" of geriatric assessment as a technology to counter the problems associated with some discharges. Indeed, some of the experiences with geriatric assessment suggest that a careful, organized look at patient characteristics—looking at a broad range of functional abilities, making careful diagnoses that may detect previously undetected, but treatable problems, and looking at the social and physical environment—might produce a discharge plan that has profound positive consequences for subsequent functioning; in some cases it may even, in a relatively short period, save money from subsequent hospitalizations and avoid nursing home care (14). As one looks at the field of geriatric assessment more carefully, one has to dissect the critical elements of the assessment process to find how it might become more affordable (2).

Geriatric assessment units begin with a belief that something better can be done for the patient, almost the total antithesis of most discharge planning. Indeed, the literature on geriatric assessment shows that one can produce very positive effects with a wide variety of inputs (8).

One does not need a multidisciplinary team on the order of Noah's Ark to do geriatric assessment. One can even do it with a single person—a nurse or a social worker—and produce virtually the same outcomes as with more elaborate teams. What seems to be needed is attention, a positive attitude, and an ability to convey optimism to other caregivers in the system. A specific area for more research on this technology is the study of what aspects of geriatric assessment make the difference for the patient. Is it systematically collecting information? Is it providing that information to appropriate people? Is it the sense of optimism, or does it really require a mutually supportive group therapy session for care providers?

### ALTERNATIVE MODES OF CARE

An area that has presented great problems for distinguishing between acute and chronic care in the community has been the domination in research during the last decade of the so-called "alternatives mentality" (5). We have probably lost a great deal of impetus for good research into the technology of community care by thinking of community care as an alternative to the nursing home, rather than looking at the values of community care as a primary objective. We have set up a paradigm in a disadvantageous way—disadvantageous because, among other things, if one starts with a community-based population, relatively few of those people are likely to enter a nursing home. So you have a natural ceiling on your potential benefit—preventing nursing home admissions. We have spent much time and money looking at that question and generally have concluded that, indeed, community care does not necessarily prevent admission to nursing homes.

But we have not addressed more fundamental questions such as, Is community care a legitimate and important vehicle for providing care on an ongoing basis? If one asks patients, families, and providers, few will vote in favor of nursing homes over community care. Yet somehow we think that the only value of community care is that it prevents nursing home care. It may be disadvantageous to the whole field to believe that, not only because it raises a question unlikely to be answered positively, but because it distracts attention from the nursing home to the community.

Both the nursing home and the community are important, legitimate sources for providing care for the chronically ill elderly. Indeed, we should spend more effort on improving nursing home care rather than striving to do away with it. If we can move away from this "alternatives" paradigm, we may begin to pursue better quality care in nursing homes, a legitimate activity on its own, rather than viewing it as a failure of community care.

### **Care Coordination**

One of the frustrating things for me has been the failure of the health care community to recognize that in the area of chronic disease we are talking about careers of care, not episodes of care. We have allowed the way we think about care to be defined by the way that we pay for it. We

have even set up our statistics to reflect this distinction. We collect a great deal of data on hospital discharges, nursing home admissions, and nursing home discharges. The only problem is that they are all wrong. People do not usually get discharged from nursing homes. Most are discharged only temporarily. If they do not die, they go to the hospital and then they come back to the nursing home (11). The hospital is really just a visit; it is not a discharge (and I do not mean short stays where you hold beds). We need to find out what happens to people at the interface between the acute and the long-term care system.

We need to find new ways to look at this problem and set up our data bases very differently. We need longitudinal records that indicate the success of an intervention over a period of time, not that simply record when a patient goes in and out a door. We have also been guilty of this event fixation in the acute care hospital and in the doctor's office. We continue it as we move into chronic care. We are using models that worked poorly, but relatively adequately in circumscribed areas, and we are trying to apply them to chronic care.

Chronicity lasts a long time. This is the heart of its definition, and yet we treat chronic care as if it were a variant of acute care. We have set up information systems around mistaken ideas that reinforce the wrong stereotypes. We need to recognize that we are looking at a series of changes in location of an individual who is going through a series of life transitions. The hospital is a critical point of departure for most of the long-term care careers in this country, but we also need to look at the expected outcomes of nursing home care. Very few studies in the literature trace people over a period of years after they move out of nursing homes. Where do they end up? Is the discharge successful if you simply move the person out of a nursing home?

Again, driven largely by the funding system, we have developed a new set of terminologies that we call transitional care or post-acute care, in which patients go somewhere after discharge from the hospital (7). We are beginning to explore this area to see whether various modalities of discharge—to home care, to skilled nursing facilities, or to rehabilitation—produce different outcomes. Does it make a difference where the patient goes? Can we understand how those differences relate to what occurred earlier during the period of hospitalization? If we are going to produce a rational program for chronic disease, if we are going to develop data bases that will support the practice of geriatric care in all of its

branches, then we must begin to shift our thinking so that we can influence policymakers to think in terms of investments.

The paradigm of geriatrics invests much energy and effort up front in doing a better job of evaluating, assessing, and determining the needs of elderly patients, with the expectation that this investment will pay off by producing better outcomes and even by saving costs over time. The more we constrain the payout period for that investment, the narrower our outlook, and the less likely we are to recoup that investment.

### QUALITY OF CARE

The most striking question in long-term care is the lack of concordance between what we do and what happens. Given the difficulties of correlating process and outcome, it makes more sense to me to look at what happens to a patient rather than to debate orthodoxies of treatment. We have spent much energy in the area of chronic care developing measures of the "right way" to do these things. We would be better served by developing a system that recognizes a variety of possible outcomes, even if the outcomes are measured in relatively short units of time. Such a system might be integrated appropriately into a payment system that could then provide positive incentives for caregivers to achieve positive outcomes.

To accomplish this, we would need a system that did not necessarily require a positive outcome, but rather an outcome that was in the realm of expected outcomes (assessed by comparing the actual outcome with the expected outcome). A good outcome is one that is as good or better than what would reasonably be expected for a patient with those particular kinds of conditions (6).

In this way, we can shift our attention from a system that deemphasizes function to one that defines outcomes in a wide variety of parameters including physical, cognitive, psychological, and social functioning. In addition, it would encourage the development of environments conducive to those kinds of function, and it would provide a series of reinforcers for the kinds of results that we were trying to achieve. We would, of course, think carefully about developing appropriate units of scale and data sets for these measurements that would allow us to measure changes in functional terms.

### RESEARCH OPPORTUNITIES IN TECHNOLOGIES

This brings us to research opportunities for the delivery of care for the chronically ill. We are on the verge of a very exciting technological breakthrough. These are essentially "low technologies" compared with nuclear magnetic imagers and the like, but nevertheless, they are very important; they are in the area of information. These technologies will provide structure and reinforcement to many of the workers in the long-term care system—including nursing aides and homemakers—who tend to come from the lower educational strata in society.

As we provide information support to care providers that will allow them to make better decisions and to have a better understanding of the changes occurring along the relevant parameters, we have something that is very exciting.

### **Bar Code Readers**

In Minnesota, we are beginning to introduce a bar code reader, about the size of a credit card. Imagine a nursing home or a home care agency in which each patient, instead of having the traditional ID bracelet, has a bar code. The caregivers would wear a similar bar code on their name tags, so that each caregiver and patient is identified. By using some very basic technology, information can be collected about when care was delivered to which patients; you can set up bar codes for entering any information. We have developed a hand-held bar code card that is used for behavioral training in incontinence; you can develop direct reinforcers that record when the patient was toileted. The bar code reader has a clock that gives the time and date, which is recorded when care is delivered. The bar code reader produces a direct readout so that, at the end of each shift, the material is entered into another reader that generates a printout showing exactly what was done in each ward. We have suddenly made available to nursing supervisors an enormous amount of information about who is getting what kind of care, how various staff members perform, and where there are patients who were scheduled for toileting but did not get toileted.

Medication errors within a nursing home can be eliminated by using this kind of very simple, but revolutionary, technology. By using the bar code to compare the patient's identification with the encoded orders, the system can assure that the right drug is given at the right time to the right

person. Moreover, by recording the caregiver's identity at the same time, it can develop a tamper proof medication record.

The bar code reader can be used even more effectively in home care, in which a chief problem is how to monitor off-site care, as Dr. Donabedian pointed out. This device provides a very good way of accounting for people's time and the activities that they performed.

### **Medical Information Systems**

The other major breakthrough of note is the development of medical information systems for long-term care. In Minnesota, we have begun working on a laptop computer that can be taken into the patient's room. It presents an outline for a standardized history and assessment, and structures the type of information collected. It eliminates duplication and redundancy that often occurs when several individuals enter information into the record. A desktop computer can take this information and generate an ongoing printout in both graphic and tabular form that allows one to chart changes over time in patient status. This form of data display can help address one of the most pressing issues in long-term care, namely, the supply of caregivers. If long-term care is to continue to attract minimum wage workers (even at slightly better minimum wages), the job must become intrinsically more rewarding. An important source of reward is the sense of accomplishing something. By demonstrating the progress of patients, especially when compared with the expected course of similar patients, the information system provides a graphic picture of achievement. Moreover, it encourages the caregiver to think in terms of change over time instead of static events. Similarly, the structured information collection and the computerized guide to translating assessed problems into care plans provides a mechanism for directing care, and, hence, it may permit lesser trained individuals to play a more active role in caregiving. Thus, the same philosophy can be easily extended to support the care given by informal providers as well.

We are beginning to see some tremendous advances in the potential for this kind of information technology. I would suggest that major breakthroughs in long-term care will come with the evolution of these kinds of technology. We hope that information technology will change the environment in which people practice, make it more attractive for them, and make them more efficient in providing home and community care.

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## Framing the Issues of Home and Community Care: Response

Earl M. Collier, Jr.

The current Medicare, Medicaid, and, to a large extent, commercial payment systems reinforce and perpetuate the organization of the health care system as it was in 1965—given what society wanted then from its institutions and what the technology of the time allowed. Today, however, technology has changed greatly. As population demography and our own lives have changed, we realize that we want something different in the way of services that are delivered, and we want different kinds of institutions to deliver them.

Perhaps because I am a lawyer, I am most interested in *process*. I have no answers to substantive issues such as the right way to increase access to the system, the right amount of quality, or the right way to measure quality. Those things are elusive to me, and I prefer the kind of processes that will permit relatively good, substantive judgments to be made, given the circumstances at the time, and that will permit those judgments to be reexamined and changed as time passes.

In the simplest terms, the process that I am most interested in is one that I think has some hope of assisting the health care system in its transition from its place in 1965 to where we want it to go. I also think that money will be provided to let it happen. For want of a better word, I call this process "case management," a currently used term that means many different things to different people.

#### CASE MANAGEMENT

I see case management as having three parts.

- *Identification of the case*, as early as possible. The case has its own context: it could be a career of care, as Dr. Kane mentioned<sup>1</sup>; it could be a limited, perhaps catastrophic, episode of illness; or it could be the balance of life of a frail or an unfrail elderly person.
- Assessment of the case, first by the person who wants to purchase or
  obtain the services necessary to the case, and then by the person who
  will provide the services necessary to the case. There must be as
  complete an assessment as possible in the circumstances by both the
  person wanting the services and the person wanting to provide them.
- Provision of the services in a coordinated fashion. Present techniques for coordination do not work very well because they are tied to outdated types of institutions and old definitions of the system. In the "old days," a patient's primary care physician would see a medical episode of illness and would coordinate with specialist consultants (usually in an inpatient setting in which the facility provided, under one roof, a fairly well-coordinated enterprise with charts easily available and continuity in the nursing care).

#### CHANGES IN MEDICAL CARE

We now see significant changes in two areas. First, the episode, instead of being a medical illness, is becoming increasingly non-medical in nature. It will be much more difficult for the old institutions defined around medical needs to carry out their coordinative functions. Second, the doctor's role is undermined because the doctor is trained in and primarily focused on medical management.

An enormous amount of technology exists today that allows online information to be available for remote site management, for continuity development, and for keeping up with a complex plan of therapy; a great deal of technology is available to assist in case identification, both

<sup>&</sup>lt;sup>1</sup> See Robert Kane, "Home and Community Care of the Elderly: Framing the Issues," in this volume.

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medical and social, for case assessment, and even for case coordination after assessments have been completed. People have not thought in these terms, however, and they have been slow to use these technologies.

As a tactician, I regard Medicare as a poor innovator. It is good at taking the system as it finds it, dealing with it, and reinforcing it. That is what Medicare did in 1965—it assigned a legislative and regulatory definition to hospitals as the institutions were then understood, and proceeded.

When Medicare can find institutions defined in ways that are trustworthy and that it can understand and feel comfortable with, Medicare has little resistance to accepting them. A hospice is a good example of an institution that was not well defined in the early 1980s, but when they became accepted and they were given a normative definition, then Congress allowed Medicare to pay for hospices. The difficulty, therefore, is not changing Medicare when something well-defined comes along; it is defining something new in acceptable terms for Medicare.

#### OPPORTUNITIES FOR PROGRESS

I see a few short-term, rich opportunities for progress coming. One area that is drawing a lot of attention is catastrophic illness. All the payers have spent a lot of money on consultants who have told them that all their insured groups, of whatever size or location, have far less than 10 percent of the insured people incurring 50 percent or more of the cost. The money will move in that direction, and the case management process will follow it because those cases are so big that case management is an affordable overhead for the payers, even though it is a rudimentary technology at the present time. As catastrophic case management in a medical setting begins to take hold and the technologies for case management become a little clearer, case management will move away from a medical focus toward the "careers of care" that Dr. Kane described—episodes that embrace both medical and social activities and services.

The second rich opportunity for progress that will be well supported is the development of long-term-care insurance policies. Most of the good long-term-care policies reflect the elements of case identification and case assessment. These policies will allow flexible benefits of a social and medical nature as long as the cases have been assessed first, as long as the care is coordinated, and as long as the insurance company is

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thoughtful about it. I would particularly recommend looking at recent filing on long-term care insurance that the Rochester Blue Cross placed with the insurance commissioner of New York State.

The third opportunity for private funds, and which we would like Medicare to pick up eventually, is housing. Housing is the biggest problem of long-term care because it incurs the biggest expense. The simplest way to solve some of the problems in home care is to redefine what is the home, which should be very easy to do over the next 20 or 30 years for this cohort of people.

Last, the provider industry, particularly at the local market, is consolidating. Bringing providers together in more integrated systems through ownership of contractual relationships is good for the health care industry and should be encouraged, so that by 1997, the system will be reorganized, a new set of institutions will be in place that is more well adapted to our complex service delivery needs, and it will be adapted to our new technologies. Then Medicare can put the money behind it and reinforce it.

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# Special Perspectives on Home and Community Care

Patricia P. Barry

My comments today are from the perspective I gained as a primary care physician on the Home Medical Service (HMS) at Boston's University Hospital. Home Medical Service has provided home care in Boston for over 100 years, and begins with a comprehensive initial evaluation consisting of medical, social, and functional assessment, routine laboratory studies, and electrocardiogram. Follow-up care is managed by an HMS nurse-coordinator and consists of case management and home visits by physicians. Many of the patients are frail or sick elderly, with serious medical problems including dementia, congestive heart failure, angina, chronic obstructive pulmonary disease, and malignancy. Although many have end-stage disease, every effort is made to maintain their quality of life and to continue their ability to live in the community, often with family members, for as long as possible—a major goal of many health care providers for the elderly.

#### HEALTH SERVICES

To provide care at home, it is essential to maintain the patient's functional status and coordinate the services of both family members and community agencies including nurses, home health aides, and homemakers. These arrangements are often precarious and can be easily disrupted, especially by acute hospitalization. Admission to the hospital may result in immobility, a decrease in the capacity for activities of daily living, and a subsequent collapse of the support system as the patient assumes a "sick role." Family members may "burn out," and in some cases hospitalization precipitates further institutional care. In addition, old age increases risk

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for iatrogenic complications of hospitalization that may prolong the stay and increase disability. Thus, a major goal of elderly patient management becomes the avoidance of unnecessary or optional hospitalization and, therefore, careful consideration of the risks and benefits of the diagnostic and therapeutic modalities available there.

Geriatric services, however, are usually viewed as a source of inpatient admissions by many hospital administrators, to whom the "bottom line," despite diagnosis-related groups (DRGs), is still admissions (and timely discharges). Physicians, as the primary decision makers, may find themselves caught between conflicting responsibilities as hospital staff members and, more important, as patient care providers.

For physicians in private practice, the Medicare reimbursement system clearly favors hospital care in an acute, procedure-oriented setting: primary care practitioners struggle to receive adequate reimbursement for lengthy home visits, assessment, family counseling, and multidisciplinary teamwork, while their technologically oriented colleagues have no problem collecting for radiologic or laboratory studies, or invasive tests that may not only be uncomfortable but also pose risks to the patient. Unfortunately, such invasive tests (intravenous pyelograms, angiograms, endoscopy) may be ordered because they are available, with little thought given to the way in which the results (diagnoses or staging) will affect the treatment of the patient. This is particularly true of the frail, sick elderly, for whom treatment options may be limited because of patient (or family) wishes or the physiologic ability of the patient to tolerate therapy.

Thus, although appropriate medical diagnosis and treatment may be important in the care of the sick elderly in the community, these cannot be the only goals of medical care. Maintenance of function and attention to psychosocial needs through coordinated care may be even more essential to the patient's quality of life. Being at home has previously "protected" the elderly from technological interventions; as those techniques become increasingly available in the home setting, it is critical that we better understand their risks and benefits to the patient.

Health services in this country have focused recently on one component of the triangle of health care—reduction of costs—with too little emphasis on access and quality. Quality is not synonymous with technology: more is not always better; and access is not synonymous with institutional admission. Consideration of the patient's needs and goals is critical to determine whether the care is of sufficient quality and whether

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access has been provided to appropriate services. Issues of cost reduction need to be related to real cost and benefit.

Frail elderly in the community have unmet needs. Policymakers must better understand the way that the health care system, by its structure and methods of reimbursement, fails to provide for these needs. Greater emphasis must be placed on the preservation of function and the provision of community services in locations other than institutions. The payment system must be shifted from its preferential emphasis on hospital-based acute care and technology to provision of adequate compensation for complex patient assessment and management, as well as those essential, although less technological, services provided in the community, including transportation and homemakers.

#### **EDUCATION**

The second critical component of our society's ability to provide appropriate medical care for the elderly is the manner in which we train our physicians. The growing trend in residency programs, such as family practice and internal medicine, emphasizes health care settings outside the hospital as well as long-term care. The HMS is part of a required one-month community medicine rotation for senior medical students at Boston University and for second-year internal medicine residents. Students rate the experience highly, as do the residents, many of whom comment that they are as impressed by the frailty of those patients kept at home as by those admitted. The HMS is often their first medical experience outside the acute hospital setting.

Earlier this year, a panel discussion of home care at the American Medical Association considered changes in the education of physicians at all levels to include functional assessment, pain management, home care, disease prevention, discharge planning, understanding of community resources and the reimbursement system, and ethical issues. These areas are seldom covered in the medical school curriculum, during residency, or in continuing medical education courses despite their importance to the appropriate care of frail elderly patients.

Medical education must continue its shift toward training physicians to provide care in noninstitutional community settings including the home. Physicians also need a better understanding of the value of their interventions in geriatric patient populations and the risks and benefits of their diagnostic and treatment modalities. The importance of comprehensive assessment and functional status must also be emphasized.

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#### RESEARCH

We cannot always predict the value of our technological interventions in the elderly patient population, because most tests and treatments are developed and studied in younger patients with more clearly defined and isolated problems, better functional status, and less complex goals. More information must be obtained about the specific health care needs of the elderly. We recently completed a study on the HMS which demonstrated that elderly patients who refuse hospitalization often have negative feelings about the health care system in general and about hospitals in particular; they tend to be less seriously ill than patients who accept hospital care; and they usually have appropriate outcomes in terms of location, health status, and function. How can we better identify those elderly for whom our interventions will be productive and provide a real benefit as opposed to a needless disturbance or a prolongation of the process of dying?

Important research areas include better delineation of the unmet needs of this population and careful evaluation of programs designed to help them, including home care. The effect of health care reimbursement policies on the overall quality of life and health of the elderly must be better understood. Appropriate clinical care requires research efforts to understand the effectiveness and appropriateness of diagnostic and therapeutic interventions, especially those that pose important questions of risk versus benefit, such as invasive procedures and intensive care units. We especially need to understand the significance of age as a risk factor in predicting outcomes of technological interventions. We must not automatically impose upon or deny to the frail elderly those technological interventions developed for younger, healthier people without adequate evaluation.

#### CONCLUSION

Widespread application of available health resources to this special population has the potential for great benefit as well as considerable harm. We must consider the special needs particular to this group, develop our policies and design our programs thoughtfully, educate our health care providers in the necessary knowledge and skills, and, finally, carefully and continuously evaluate our efforts toward providing the most appropriate care to meet the needs expressed by the patients themselves.

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## **Special Perspectives on Home and Community Care**

Eileen M. Quinlan

We all know that there is no place like home. At no time in one's life is this more true than in old age. The benefits of remaining in the community are readily apparent. The positive psychological, social, and physiological effects encourage a maximum amount of independence despite functional limitations. Community living is generally less expensive; it allows individuals to support themselves. Living in the community usually delays the need for public funds and reduces the need for institutionalization—certainly all goals for the future in health policy.

#### INFORMAL CAREGIVERS

#### **Demographics**

Liu looked at the long-term care needs of the aged and found that one-fifth of those needing long-term care intervention were institutionalized (1). Seventy-five percent remained in the community with informal care providers, and only 5 percent of persons needing long-term care received all their care from paid sources. The single most important characteristic differentiating these groups was the family's self-reported ability to care for its elderly. Family, here, is defined loosely as an individual's support system. Informal caregivers refer to persons who provided unpaid care to elderly persons who have some degree of physical, mental, emotional, or economic impairment.

According to the Informal Caregivers Survey, a component of the 1982 Long-Term Care Survey conducted by the Department of Health and Human Services, 2 million informal care providers provide care to at

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least 1.5 million elderly needing some type of assistance with activities of daily living (ADL) (2).

Elaine Brody speaks about the myth of the abandonment of the old by their families in this country (3). She believes that long-term care of elderly relatives is becoming a normative experience. In my years of practice, the care and commitment of families has consistently impressed me, whether it be the Brantley sisters—three schizophrenic sisters who have struggled many years in central Harlem with their chronic disease—or the frail couple in the northwest Bronx—he has a serious cardiac condition and was dependent on her, until her confusion became apparent, secondary to Alzheimer's disease.

Definite changes are occurring in the family structure that increase the stress on the family, including the increased proportion of women returning to the work force, the divorce rate, the geographic dispersion of offspring across the country, and old persons caring for even older persons. According to the House of Representatives Select Committee on Aging report, who are the informal caregivers in the United States (2)?

- Seventy-two percent are women; 29 percent are daughters and 23 percent are wives. Nine percent are sons; 13 percent are husbands. The rest are a cadre of folks, such as daughters-in-law, sons-in-law, grandchildren, and friends.
- The average age of the informal care provider is 57. Twenty-five percent of these care providers are between ages 65 and 74; 10 percent are over age 75.
- In 1963, 1 out of 4 persons of age 45 had one surviving parent. In 1970, 1 out of 5, or 20 percent, of persons age 50 had one surviving parent. In 1980, 40 percent of persons age 50 had one surviving parent. Ten percent of persons in their late sixties had one surviving parent, and 3 percent of persons in their seventies have one surviving parent. One out of 10 persons age 65 and older have a surviving parent.

For the first time in this country the average U.S. couple has more surviving parents than children. The average U.S. woman will spend more time providing care to her elder parents and in-laws than she will raising her children. In the future, this support base will shrink. Clinksdale looked at fertility rates from 1930 to the year 2030 to calculate the elderly offspring and dependency ratio (4). As you know, adults during the Great Depression had decreased fertility rates. These folks are now our old

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people and comprise the temporary peak in the ratio of elderly to dependent care providers. The baby boom, however, will provide more offspring to care for their parents, but the burden on children of the 80-year-olds and older—those most likely to need long-term care—will increase in the next 15 years. The ratio of elderly (greater than 80 years old at this time) to offspring will peak in the year 2000, decrease for 20 years, and then reach an even higher peak in the year 2030.

Caregivers are less likely to be employed. Sixty-two percent of all women between ages 45 and 55 are employed; yet less than 50 percent of female care providers are employed (2). What is the job like? Eighty percent of caregivers give care 7 days a week, with a minimum of 4 hours per day.

Most people derive satisfaction from giving care. Spouses, especially, feel that their work as care providers contributes to their feeling of self-worth. Limits on personal life, however, contribute to stress for the caregiver. When a woman's childbearing responsibilities are heavy at the same time as her elder care responsibilities, she is sandwiched, as is well described by Brody (3). This sandwich effect will increase as women delay their childbearing.

George and Gwythen reported three times as many emotional stress symptoms in care providers as in the general public (5). The care provider and the recipient generally agree that caregiving should not interfere with labor force participation, and few people (less than 11 percent) quit their jobs to become exclusively care providers. Twenty percent generally cut back on work hours. Thirty percent rearrange their schedules, although this is usually the luxury of the professional or managerial worker. Less than 20 percent take time off without pay, usually the option of the blue collar worker. In other words, employment is not necessarily related to the overall amount of help provided. This is especially true among women. Male care providers who are still in the work force, at least the statistics show, generally cut down their participation in the work force (2).

Schorr, in his 1980 work on filial responsibility and family policy wrote, "The independence of family caregiving patterns from public policy is more impressive than the connections" (6). Family life flows on untroubled by scholars and columnists, and politicians, too, I might add. Is it not time for us to support and protect this most-important resource we have in caring for our sick elderly, the informal care provider? No high-tech therapy is appropriate if the client's basic physiologic and safety needs are not being met.

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You might wonder why I even raised this topic, and yet, I feel strongly, both emotionally and from my practice perspective, that without the support system, you have no foundation on which to rest the entire health care system. One cannot even begin to plan for the health care of this nation without relying very heavily on the informal care providers.

Informal care providers think of their service more as a loss of leisure time than as work. They want their service to be rewarded more as an altruistic behavior in terms of appreciation and gratitude. Herein lies one of the basic problems that care providers for victims of Alzheimer's disease encounter, in that there is very little interaction on the personal level with the family member who is suffering from Alzheimer's disease.

#### **Support for Informal Care Providers**

What options are there to support this essential group of people? Ideally, support would include distributing information about preventive health care, self-care, monitoring, and health screening. This would also help the caregivers reach their own old age better prepared and healthier. There should be mechanisms to seek out high-risk groups, such as the recently widowed, the poor, and the isolated. On the more realistic side, training programs are now in place that deal with specific problems that informal health care providers encounter, such as aphasia, incontinence, and behavioral problems.

The special needs of the informal health care provider of patients with Alzheimer's disease need to be addressed at this point. I have had the privilege of working with two day-care programs, one in the Bronx at the Albert Einstein Medical Center and one in Greenwich Village in the Village Nursing Home, that provide day care to Alzheimer's patients. We see changes in the patients themselves, but the beauty of the day-care programs is the support networking taking place among the care providers group. Respite care is something that we should emphasize with all care providers but especially care providers of patients with Alzheimer's disease.

#### Respite Care

Respite care is a key support item for this cadre of people. Respite care refers to short-term substitute care provided in or outside the home on behalf of, or in the absence of, the primary care provider. I believe

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strongly that if there were a decent respite care system, much of the support system could be kept intact while catastrophes were taking place.

#### Case Management

I have had many discussions over the years on what the public sector should provide to these informal care providers, such as tax credits, vouchers, or direct payment. I now favor that the client or family or both be taught case management skills. If they are not able to learn case management skills and manipulate the system themselves, then they should be given a case manager or a patient advocate. As Dr. Donabedian said earlier, we must teach the care provider how to negotiate the system.

#### **Private Sector Help for Informal Care Providers**

The private sector has started to work very closely with some of the informal care providers. The American Association of Retired Persons (AARP) has produced a series of workshops as part of their program called "Caregivers Workplace Project." This project makes available to the business community ways to help their working care providers understand the aging process, negotiate the maze of the community and institutional services, and cope with the responsibilities of elder care. The University of Bridgeport Center on Aging, together with Corporate Elder Care, have been working with Remington, Pitney Bowes, and the Peoples Bank to provide on-site respite care, hotlines, and supportive networking.

#### OTHER CAREGIVERS

When informal care providers need additional or supplementary assistance in caring for the elderly client, to whom do they turn? It is not news that nurse's aides or home attendants provide most of the care to the elderly client. The least educated, usually the most poorly paid, but also very well-meaning staff members are providing the majority of care to the sickest, most complex clients in the health care system.

The 1986 Institute of Medicine (IOM) report on the quality of care in nursing homes recommends preservice training for nurse's aides (7). New York State recently mandated 100 hours of education for all new nurse's aides in the state. I applaud this as a beginning, but continuing education for nurse's aides should be required on all levels.

<sup>&</sup>lt;sup>1</sup> See Avedis Donabedian, "Quality of Care and the Health Needs of the Elderly Patient," in this volume.

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Closer attention needs to be given to the education, assessment, and evaluation of nurse's aides. This could probably not be more true than for the nurse's aide in the home where supervision is often minimal. To be able to motivate and seek change in this hardworking group of people is most rewarding but not done as often as it should be or could be.

#### **Professional Nursing**

If you read any newspaper, you know that there is a nursing shortage. This is not new, however, in gerontological nursing. There always has been a nursing shortage. Geriatric nursing, as is true for other health professions, does not have a strong draw. This may go back to our nursing school experiences, but I think that it probably goes back to childhood and societal experiences. In professional schools, particularly in nursing, the baccalaureate programs must look more closely at the didactic and clinical exposure to the elderly client. Despite the demographic swing toward the aged, resistance still remains to teaching geriatric content. This is true not only in nursing schools but at all levels of the professional schools. The 1986 IOM report addressed this issue of attracting and retaining students and staff for care of the geriatric client (7). Among the issues of concern would be data on the numbers of students who express an early interest in gerontology, their characteristics, and an assessment what they would see as supportive measures while they are in school.

Obviously the staff already working in geriatric settings or expressing an interest in working with the aged have to be examined. These nurses have special educational needs that schools of nursing have not even begun to address.

#### RESEARCH ISSUES

#### Reimbursement

I have a few thoughts on research directions. Diagnosis-related groups are transforming the clinical profile, although as Dr. Kane mentioned, the hard data are in conflict.<sup>2</sup> Those of us in the front lines, however, do feel that patients are coming out of hospitals sicker and quicker. The entire reimbursement system needs to be reexamined. We are providing high-quality, highly technological care to a larger, more

<sup>&</sup>lt;sup>2</sup> See Robert L. Kane, "Home and Community Care of the Elderly: Framing the Issues," in this volume.

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acutely ill client group in the community, and we still have the same eligibility and reimbursement criteria formulated 22 years ago.

The 1985 survey by the National Association for Home Care of 5,300 Medicare-certified agencies showed that 92 percent of the respondents reported a sharp increase in sicker patients; 75 percent reported that a significant number of these patients were without home care services (and many believe that this number will increase); and 67 percent of the respondents thought that there was an increase in the number of claims denied after the care was delivered (8).

I work one day a week as a geriatric nurse practitioner in a New York City Health and Hospitals Corporation Hospital. Our biggest problem there is the patient who is medically ready for discharge but is being held for social components to be put into place, such as placement of home health aides or, more commonly in Harlem, for the Medicaid process to be approved.

These patients are placed on alternative levels of care. Not only do alternative-level-of-care beds have lower reimbursement rates, but these beds, in New York State, do not count in the state census that determines the occupancy rates. Every hospital within the Health and Hospitals Corporation system fell a few percentage points in the occupancy rates when the alternative-level-of-care beds were discounted, which resulted in a projected decrease in allocated beds. Should the hospital discharge the patient inappropriately, or should they lose the beds?

The home care industry is exploding. Baxter-Travenol, a leader in home transfusions, had an income of \$46 million in 1983. It jumped to \$195 million in 1988. How are we monitoring this growth, both in the profit and non-profit sector? The reimbursement mechanism must go beyond medical management and cover appropriate levels of nursing and ancillary care.

#### Rehabilitation

In the clinical arena, incontinence costs millions of dollars; it is usually the last straw in the home situation and prompts institutionalization. Some encouraging research has been done on rehabilitation of incontinent persons. Can we disseminate the results to educate both the professional and the lay care provider? Perhaps the producer of adult disposable diapers could help us in developing the type of bar code to which Dr. Kane referred.

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#### **Ethical Issues**

My last thought is that we should look at advanced directives in ethically related research such as living wills and durable power of attorney. Work has started on such controversial issues as "Do not hospitalize, do not feed" and must continue. Hospice and terminal care are very much a part of the care of the sick elderly patient and should be further funded and expanded.

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# Special Perspectives on Home and Community Care

Susan A. Walker

I find home care in an odd position today. On the one hand, it is touted as the alternative to institutionalization. On the other hand, because of the efforts to reduce health care costs, patients' home care benefits are being drastically decreased so that, although more patients are being discharged to home care, they have less and less support to remain at home.

Home care agencies, whose mission is to help patients remain at home, are struggling to balance patients' perceived needs against their allowed benefits, rising costs against cost caps imposed by third-party payers, and the need for visits of both the patient and the home health agency against the financial intermediary's denial for service deemed unreasonable and unnecessary. Consequently, all around the country, those of us in home care are seeing home care agencies fight for survival, and many are losing.

Yet, while home care agencies are struggling, patients are thriving under home care. Their successes reaffirm the resilience of mankind and attest to the courage of human beings. Home care also reaffirms the value of the family and attests to the incredible strength of the family in providing home care. With minimal support, families are providing care that used to be provided only in the intensive care units of hospitals. Patients are being cared for at home with intravenous equipment and other infusion therapies, kangaroo pumps, ventilators, chemotherapy, and other high-tech treatments.

Families are as dedicated as home care agencies about keeping patients at home, often until death. All that patients and families are asking is for a place to turn for teaching, advice, support, and respite as

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they expend superhuman effort to provide care. Yet the programs that have evolved to meet their needs and to help them are like a maze in the effort to obtain the resources. Many families give up in frustration until, completely overwhelmed and in crisis, they come to the attention of the system.

#### PROGRAMS FOR HOME CARE

Medicare is the program that older Americans and families believe will provide them with home care coverage. But like all services that meet real needs, home care is growing too quickly. Although home care is only 5 percent of the national health care budget, it is the fastest growing area, and therein lies the dilemma. How does Medicare provide services yet cut costs when Medicare has reduced allowable visits, and consequently the amount, frequency, and duration of services have been drastically affected? Many services cannot be provided at all for certain diagnoses, or are allowed for such short duration that the interdisciplinary benefits of home care are reduced. I know that health care costs must be considered, but are we looking at the wrong end of the problem? Should we, instead, be looking at out national health care policy, as well as the effects of the policy? Because health care policy reflects how our medical care should be provided, when, by whom, and how it is going to be paid?

One misconception of the present policy is that home care is cheap. Home care is not cheap. Individualized attention given in the patient's home by a highly skilled professional team does not sound inexpensive to me. Although research is limited and sometimes conflicting, it would appear that the benefits of home care are to reduce hospitalization. That is the contribution of home care to cost containment. One of the solutions is to conduct research to see what home care really gives us for our dollar, and then we must decide if and how we want to pay for it. We may be able to arrange benefits for the results we want, but, what if home care just makes people happier? Are we willing to pay for happiness with our tax dollar?

I would like to see our academic institutions and our home care agencies link their expertise and produce research on home care, but neither group can afford to do it without financial assistance or incentive. I hope that money will be put into research in the future instead of into huge regulatory systems, which probably cost as much as they save and drive dedicated professionals out of home care.

#### HOME CARE PROFESSIONALS

Who is providing the care? I assure you that programs that were developed to help families are not doing so. Not because they do not want to, but because the demand is so great for the service offered that the program can neither staff nor budget sufficiently for the demand. So, they limit their services by limiting eligibility or the amount of service provided, until families feel that they cannot get help anywhere or that help is too little, too late.

Case management is touted as a solution, but when the case manager is overwhelmed with cases, the family still cannot get the individual attention it needs. I would like to see families paid a stipend for providing care. Then, they would have the funds to pay for additional help, if needed, which they could purchase in the marketplace; they would regulate the care through their purchasing power. This solution recognizes changes in the family structure such as families with unmarried heads of household or two-career families in which the members cannot afford to leave their jobs without getting recompensed or obtaining financial assistance to pay others. If the patient is not cared for at home, the taxpayer ends up paying anyway.

#### CASE STUDIES

Although this is a difficult time for home care and the frustrations are many, it is still a most exciting field. It is because of the patient who uplifts us every day. For this reason, I would like to close with the stories of two patients.

The first case, that of Mr. and Mrs. L., came to our attention because their church group was concerned about their care needs. They had no children and the relatives were distant. Mr. L. was chairbound due to a stroke. Mrs. L. was senile and could not remember to feed her husband, get food, or let the dog out regularly. Their church asked if we would come in because every other home care agency had been fired by the couple. I did not think that we would last much longer than any other agency, but we were able to keep them at home for two years and to help them make long-term plans. They finally went into a nursing home at the end of two years, but it was their own decision, made because the husband knew that he was dying and he wanted to be sure that his wife was cared

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for. This story demonstrates how complex home care is and how much service agencies must provide if there is no family to help.

In the two years that we kept them at home, we did all their haircutting; we arranged for medical care; we helped repair appliances; we arranged for bee extermination, tree removal, medical services and kennel care for the dog, rug cleaning, and holiday and birthday celebrations; we found lost articles that they thought had been stolen; we coordinated the RN shifts of the home health aides, therapy, and doctors. If they had had family, the family would have done this. Mr. L. seemed to be close only to people he could verbally fight with, which caused anxiety to the staff. So, I would go once a month and fight with him so that he would not pick on my staff. At the end of the fight, he would wink at me, and say, "Thanks for coming, Ms. Walker. It was really good," and that would be the end of it for another month.

After serious bronchial infection and hospitalization Mr. L. decided that he and Mrs. L. needed to enter a nursing home because he was beginning to fail. We arranged, through the courts, for the appointment of a guardian who would look after their interests. We worked with a real estate agent to help sell their house and then to invest their money so that they would have money for the facility they wanted. We helped place Mr. and Mrs. L., the dog, and some other favorite possessions in the nursing home. This is another value of home care—the time to plan well for a patient. Although both Mr. and Mrs. L. died within 6 months of placement, they achieved their wish of remaining at home as long as possible.

The second case demonstrates that you can provide home care, even if you do not have an adequate family. This is a case of an elderly gentleman, an immigrant from Russia, who had a schizophrenic son. When I became involved it looked as if the man was going to need nursing home placement, but the son and the father were so close that we had to separate the care needs to ensure that they could both maintain themselves independently. When we did that, both began to thrive. Now, the father is in remission and doing well. The son is in a vocational training program and looks better than he has ever looked; I think that he will be able to stand on his own as time goes on. Finally, it is important to emphasize that both of these patients needed a lot of special, individual attention, and we could provide it only because we had a special grant for cases of this sort. Medicare was not an adequate source of reimbursement.

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## Special Perspectives on Home and Community Care

Charlotte K. Flynn

The Gray Panthers is an advocacy group that is concerned about people having access to what they need, whether it be health care, income maintenance, or housing, regardless of chronological age. We are also very concerned about "ageism," a subtle factor in our society that sometimes produces problems for older people. The observations I would like to share today come from two perspectives. One as a listener to those who call our office for help and the other as an advocate.

#### SURVEY OF ABUSE AND NEGLECT OF THE ELDERLY

This past year, I have been involved with the State of Texas, coordinating a statewide survey of abuse and neglect of the elderly. The survey was conducted specifically to point out to our legislature the needs for community-based services. We surveyed key informants including people in the medical, judiciary, financial, law enforcement, and social service fields.

The survey was a collaborative effort: the Gray Panthers coordinated the survey; the Texas Senate Select Subcommittee chaired by Senator Barrientos offered support; Dr. Ira Iscoe, chairman of the Gerontology Committee at the University of Texas, assisted us by having all the information from the returned surveys entered into the university computer; the data from the survey was given to Dr. Jeffrey Anderson and Dr. John Thiess of the Texas Department of Human Services, who made the analysis.

The survey provided us the documentation to reinforce the need for an adequate continuum of care through quality community-based

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programs. Providing education and support to caregivers will provide significant help in preventing elder abuse and neglect.

#### PROBLEMS IN CARE OF THE ELDERLY

#### **Case Management and Control**

Our members attach great importance to case management and control.<sup>1</sup> They think that the client or the patient does not have enough say in controlling what happens to him or her. The patient is not being given choices or being informed of those choices. The family and the patient need to participate in making choices based on what the family arrangements are, what the cost of services will be, what types of procedures are needed, and what services are available.

#### Autonomy and Social Support

There are two very important psychosocial aspects of growing older: autonomy or control, and social support. When an elderly person has these, old age can be enhanced; when they are not in place, old age can become very defeating. In their article published in *Science* in May 1987, called "Human Aging, Usual and Successful," John Rowe and Robert L. Kane commented that past research has dealt with the negative aspects of aging and not with the extrinsic factors that might be preventive in the aging process. These factors apply to those who are ill as well as to those who are healthy.

#### **Record Keeping**

Better record keeping would be a great help, from the client's point of view. Collecting records from all of one's doctors becomes a nightmare for patients or their families. I feel hopeful that there will be improvement in this situation after hearing Dr. Kane say that there may be some way of getting a data base that would be transportable from one place to another by the patient or by the family.<sup>2</sup>

<sup>&</sup>lt;sup>1</sup> See Earl M. Collier, Jr., "Framing the Issues of Home and Community Care: Response," in this volume.

<sup>&</sup>lt;sup>2</sup> See Robert L. Kane, "Home and Community Care of the Elderly: Framing the Issues," in this volume.

#### **Continuity of Care**

Continuity of care should be planned so that the patient receives appropriate care. At times, temporary placement in nursing homes following surgery, for example, might be advantageous, especially if the nursing homes emphasized rehabilitation of the patient.

#### **Planning Patient Services**

Patients need their hospital discharge preplanned. Services need to be more specific to the individual patient. If a person has arthritis and needs help in the morning to get going, 1 hour of assistance in the morning every day will be much more helpful then 3 hours every other day.

#### Education

Caregivers need education. Our organization has several members who are hospital social workers and handle discharge planning. They are very much aware of the lack of knowledge on the part of caregivers. As a result, we published a caregivers' manual (1). It lists the services available in Austin, but it also has "how-to's," not only for the caregiver but for the individuals themselves who need the support—helping them to identify their feelings and work through them. This area is an opportunity for the private sector to initiate needed activities.

#### **Payment**

In-home services do not have adequate standards, are often of poor quality, and are very expensive. As a result, many older persons exhaust their meager incomes quickly. This area is a challenge to all of us. We all know that Medicare is cutting back on community care services. One of our survey informants stated that "the only conspicuously absent category of abuse in our list is government abuse, be it by cutback of funds or withdrawal of services." We need especially to look at the problem of the large segment of older people who live just above the poverty level and do not have the resources to pay for those (or indeed other) services.

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## Special Perspectives on Home and Community Care

Lynn M. Etheredge

Government and private insurance should be expanded for home and community care. But third-party payers need guidance so they can insure and administer these benefits. For example, how should insurers define the services that are most important to cover? To appreciate the insurers' needs to answer such questions, we must understand the extent to which home- and community-based care differs from medical care. For example, who is the provider of services? For many years, the answer has been simple for health insurance companies and government. Hospitals and physicians provide medical care.

#### INSURERS' PERSPECTIVES

Who is a qualified provider of home- and community-based care? An insurance company cannot rely on accrediting or licensing organizations. The Joint Commission accredits only about 1,000 of the 12,000 to 15,000 home care providers. Many more people could provide services. But costs will go up and quality will go down if insurers are not selective about providers.

What are the standards of care? Insurance companies have written contractual language for years around the term "medically necessary." That certainly is an elastic term, but the ability to define the benefit for home- and community-based care is a much greater problem. Much hospital care, nursing home care, and social work agency care could be shifted into liabilities of a third-party insurer.

The development of useable standards is complicated by how varied the availability of home- and community-based care is in the

United States. Among the states, nursing home beds per capita vary by 4 to 1; Medicare's home health benefits vary by more than 30 to 1. Only some areas, such as New York, have well-defined home-and community-based care programs.

The Medicare program and Blue Cross/Blue Shield, its major administrators, are now starting to learn some answers to these questions. Medicare has expanded its home health services and added a hospice benefit. The Congress recently added a respite care benefit of up to 80 hours a year. These are not very generous benefits. The moves are important, nevertheless, because Medicare will become more experienced with home and community care providers and how to pay for their services. Moreover, the Blue Cross/Blue Shield system will be able to apply this experience to their private insurance business.

The insurers' difficulty of managing home and community care has led many people to the same conclusion as Mr. Collier stated earlier<sup>1</sup>: the importance of having a case manager for getting third-party payers into this system. Home and community care is such a potentially open-ended benefit that I suspect insurers will ask that case managers be accountable to them and operate within fairly well-defined budget limitations and other rules.

#### **Building a System**

In the traditional medical model, two people interact—the clinician and the patient—and insurers mostly just pay bills. In home- and community-based care, however, many more people are involved in important ways; if we want quality care, appropriate care, and affordable care, expanding insurance coverage is not enough. These actors have to be involved.

- The ability of the *family* to provide care, support, and other services is critical to the success of the system.
- *Physicians* must undertake new roles that involve coordinating with all the other persons in the system.
- Hospitals must be responsible about not dumping patients because the diagnosis-related group (DRG) payment has run out.

<sup>&</sup>lt;sup>1</sup> See Earl M. Collier, Jr., "Framing the Issues of Home and Community Care: Response," in this volume.

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- *State governments* have to be involved in improving Medicaid benefits and in licensure to ensure quality of the people providing services.
- The federal government must improve Medicare and, through the Food and Drug Administration, has a role in the regulation of medical devices.
- Professional associations, such as the Joint Commission, should establish standards of the home care.
- *Manufacturers* have a role in training people and making product instructions clear enough so that equipment can be used at home.
- Providers of services face many more obligations than simply sending an
  aide to a house; they often need to cooperate with other providers and
  have back-up services for training family members.
- Third-party payers must figure out how to interact with the other components and how their payment rules are going to relate to all the other actors.

In all this complexity, we are challenged to ensure that the system and the decision makers help the elderly patient. We must devise systems of care in which all interested parties can work well together, and we must never lose sight of the welfare of the individual elderly patient.

## Home and Community Care of the Elderly: System Resources and Constraints

Susan L. Hughes

CONSTRAINTS

Today, I will address five issues concerning the constraints and resources that influence the provision of community care services: availability of financing, availability of services, reimbursement for community care, availability of low-tech community services, and availability of manpower for community care. I will also include a few words about informal caregivers and conclude with a brief comment on the importance of coordinating available services in ways that optimize their impact and improve quality of care.

#### AVAILABILITY OF FINANCING

Financing is absolutely pivotal in shaping the provision of services for the elderly. Our current way of financing community-based care presents a mixed picture with both good and bad news. But if you take the long view, it is mainly good. We have begun a very significant turnaround in long-term care financing policy in the United States. In 1977, public expenditures for institutional care outweighed community care expenditures by a ratio of 5 to 1. By 1980, the ratio was reduced to 3 to 1 and was further reduced by 1986 to 2 to 1 (1). I do not want to imply by any means that current community-care dollars are adequate, but important strides have been made in redressing the balance of dollars during a relatively short period.

This progress in closing the gap is important to keep in perspective. This change in financing patterns also raises the question: Where are the new community-care dollars coming from? Given prospective payment for hospital care and the shift to ambulatory care that has taken place

over the past 5 years, it is no surprise that the bulk of the increased expenditures for community-based care has come from health, rather than social services, funding streams. Funding for Medicare home health care increased by 251 percent between 1980 and 1986. In 1980, Medicare home care accounted for 18 percent of all community care expenditures of any type. Medicaid contributed an additional 9 percent. By 1986, Medicare paid 38 percent of all community care expenditures, with Medicaid accounting for another 19 percent; together they provided 57 percent of the total amount of public funds spent for community care including Medicare parts A and B, Medicare hospice, Medicaid, Title XX, and the two titles of the Older Americans Act (OAA) that finance home-based services. The bad news, however, is reflected in the zero growth in social services funding over the same period.

Why do we care where the dollars come from? We care because services follow dollars. The growth of Medicare skilled home care predated the 1980s. Growth has been greatest in reimbursements, probably reflecting increases in the number of beneficiaries (i.e., the greater number of elderly) and increases in visits. It is worth noting that the increase in average charge per visit, during the same period, is less than growth in the other two factors.

#### AVAILABILITY OF SERVICES

What are the implications of the increased availability of Medicare home care dollars? As a result of the influx of new dollars, the number of Medicare home care providers has increased substantially. As other speakers have previously noted, Medicare home health care is a highly regulated industry that has become much more competitive in recent years. The net result is that the composition of providers by type has changed considerably since the original passage of Medicare in 1966. In 1966, the Visiting Nurse Associations (VNAs) and the public health nursing agencies dominated the Medicare home health care industry, accounting for 91 percent of all providers. By 1983, their share had declined to 44 percent, with hospital-based, proprietary, voluntary, and not-forprofits taking the lead, accounting for 57 percent of all home health care providers.

These figures do not imply that VNAs are going out of business. Rather, the figures imply that new entrants to the field of home health care are different and that they are probably using more sophisticated manage

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ment and marketing techniques. We do not know, however, what these changes in provider type imply for access to and quality of care over time.

We can conclude from these data that great progress has been made in increasing the supply of a very particular type of community care—Medicare home health care. Medicare home care is, however, a skilled health care service that terminates when the fiscal intermediary decides that patients no longer need sterile dressing changes or whatever other skilled care might be required.

#### REIMBURSEMENT FOR COMMUNITY CARE

Given the combined effects of diagnostic-related groups for hospital reimbursement and prospective case-mix-based reimbursement for institutional care, I think that an important problem in the future may be the growing number of elderly in the community who do not need skilled nursing care but need low-tech, long-term supportive services. The likelihood of encountering this problem will be heightened if two things happen. First, the trend toward prospective, case-mix-based reimbursement for institutional care may cause nursing homes to preferentially admit more patients needing highly skilled care versus those needing lighter, intermediate care. Second, if this happens, *and if* the nursing home bed supply remains relatively constant, we may end up with a situation where patients who need lighter care have nowhere to go. This scenario implies that there may be considerably greater need for low-tech home care in the future. Thus, our ability to understand and document differences in home care models and in their supply and staffing will become increasingly more important.

## AVAILABILITY OF LOW-TECH COMMUNITY CARE SERVICES

At Northwestern University School of Medicine, we have been conducting research for the past 6 years with the Five Hospital Program in Chicago. The Five Hospital Program provides low-tech home care to chronically impaired elderly who need it for a considerable period of time. We recently finished a 4-year longitudinal evaluation of that program.

Our comparison of the low-tech services provided by the Five Hospital Program and national data on Medicare visits by staff shows that

the Medicare home care model is very nurse intensive (1). In contrast, the longterm home care model is much more interdisciplinary, with a greater proportion of visits made by home health aides and by social workers.

In our longitudinal evaluation of the Five Hospital Program, we found that this comprehensive and continuous long-term home care model significantly reduced lifetime risk of permanent admission to intermediate nursing home care by 32 percent compared with controls (2). This finding was accompanied by a 25 percent increase in overall cost, which is considerably less than cost increases that have been reported in earlier studies. For example, the Section 222 day-care homemaker evaluation conducted by Weissert et al. reported a 65 percent increase in cost (3). The Skellie et al. evaluation of the Georgia Alternatives Health Services Program came in at 35 percent (4). When costs run over by 20 to 25 percent, we as a society may be able to institute different management techniques to reduce them, such as deploying workers in more efficient ways, reducing the length of a visit, or trimming high volume users.

It is important to note that clients in the Five Hospital Program also experienced quality of life benefits that accompanied the 25 percent increase in costs. Those benefits included better cognitive functioning at 9 months, that was sustained at 48 months, and fewer unmet needs for care in the treatment group (5).

We see increasing evidence that more humble, low-tech services are needed in addition to the growing need for skilled home care. Low-tech services may not, however, be increasing at as fast a rate as the need. It is important to note that no good information is available on the supply of low-tech home care providers in the United States. The Office of the Assistant Secretary for Planning and Evaluation (ASPE) of the Department of Health and Human Services was planning to conduct a survey on this, but I understand that it was discontinued. We definitely need more information about the availability, staffing, and cost of these services if we are to adequately care for the growing numbers of frail elderly in the future.

#### AVAILABILITY OF MANPOWER FOR COMMUNITY CARE

What about manpower for community care? Due to time constraints, I will address only nursing manpower. A recent article by Aiken and Mullinex (6) in the New England Journal discusses the overall nursing shortage in the United States. I am not aware of any statistics about

manpower shortages in community-based care, but this is an area that definitely needs more study. Prior to this meeting, I asked the director of the Five Hospital Program, who is also the current president of the Illinois Council of Home Health Services, if nursing manpower is a problem for home care agencies in Illinois. She informed me that, yes, recruiting trained and adequate personnel for home care is a problem in the state.

There are two sides to the problem. The good news is that community care is inherently attractive to nurses. Nurses have more autonomy when practicing in a community care setting, and the hours are more regular. The bad news is that more nurses with a Bachelor of Science in Nursing (B.S.N.) degree may be needed to provide community care. Since nurses are increasingly being asked to function as case managers, more—not less—professional judgment is being required of them. As a result of the increased complexity of the nurse's role, most nurses feel that a B.S.N. nurse is the appropriate person to provide them. In fact, most directors of nursing in home health care agencies not only prefer to hire B.S.N. nurses but also prefer those with a year of experience.

At present, as we all know, not enough B.S.N. graduates are being produced by the schools. Aiken and Mullinex have documented a 20 percent decline in nursing school enrollment since 1983. They also report lower Scholastic Aptitude Test (SAT) scores among those interested in pursuing a nursing career. The authors suggest that a more differentiated wage structure and more opportunity for career advancement are necessary to reverse this serious manpower constraint for community-based care in the future (6).

#### INFORMAL CARE PROVIDERS

In community care, formal care providers play a backseat role to the informal caregiver. I support what other speakers at this conference have already noted: we have to recognize what the national long-term care survey documented-that 70 percent of care provided to the sick elderly in the community is provided by informal caregivers.

In our recent randomized study of hospital-based home care in the Veterans Administration (VA), we found that informal caregivers of what we call the "severely disabled" group-veterans who have at least two activities-of-dailyliving (ADL) impairments—are providing 8 hours of care a day, 7 days a week (5). That is, obviously, the equivalent of a full-time job.

Our 4-year longitudinal evaluation of the Five Hospital Program has shown that caregivers continue to provide service over time even after formal services have been introduced; there is not as much of a substitution effect as some people have feared (5). A major question that remains is whether these caregivers will continue to be available in the future. It is projected that by 1990, 70 percent of women ages 35 to 44 and 61 percent of those ages 45 to 54 will be in the labor force. These women will be dealing with the competing demands of children, parents, and jobs. In view of this trend, an appropriate policy response would be to provide long-term home care, respite, and adult day care services that buttress informal caregivers instead of having the family co-pay for institutional care.

#### COORDINATING AVAILABLE SERVICES

Finally, how can we coordinate existing services to reduce fragmentation and assist people in their search for appropriate care? Some states have attempted to resolve this issue by pooling existing funds. This solution presents many problems. Who controls the pot? Even if all public funding were pooled, is there enough money in the pot to start with? Most analysts seem to agree that the total amount of funding must increase, probably through a mixture of public and private funding mechanisms.

More and more has been written recently about the need for case management. I have a number of questions about case management, not the least of which is, Do older people want it? I think that the enrollment and reenrollment experience of the elderly in Medicare health maintenance organizations (HMOs) and the experience of the social HMOs will be very instructive to watch.

Dr. Robert Binstock recently proposed that limited Title III OAA community care funds be used to create a voluntary network of Area Agencies on Aging (AAAs) that would stop providing direct service in areas where they now compete with other private providers. Instead, they would become a uniformly visible, easily assessable network of aging resource centers for help (ARCHs). This proposal is intriguing.

Finally, we are currently conducting the national evaluation of the Living-At-Home Program (LAHP) demonstration that is being conducted with funding from a consortium of 35 private foundations across the country, headed by The Commonwealth Fund and The PEW Charitable Trusts. The LAHP Program office is directed by Morton Bogdonoff,

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M.D., of New York. The Program National Advisory Committee is headed by Robert Butler, M.D., of Mount Sinai School of Medicine, New York.

LAHP is testing whether voluntary consortia of health and social service agencies in 20 communities across the United States can streamline access to community-based care and identify and fill service gaps without the infusion of new service dollars (7). A research team headed by William Weissert, Ph.D., University of North Carolina, Chapel Hill, is providing technical assistance to the sites in the form of computer software to estimate demand for care and prospectively budget services.

The LAHP demonstration will be completed and results from the evaluation will be available by the spring of 1990. As part of the evaluation design we are obtaining data on the characteristics of 1,500 elderly clients across the sites, their patterns of service use, and unmet service needs by site and organizational strategies that produce viable, coordinated systems of care. These data should help to answer some of these important questions about how to better promote access to needed services in the future.

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## Home and Community Care of the Elderly: System Resources and Constraints

John H. Mather

Approximately 20 to 30 percent of the users of long-term care, excluding the mentally infirm, are disabled persons who had a preexisting physical injury. Two hundred thousand individuals have spinal cord injuries in the United States. Of these, about one-third are quadriplegics and about 5,000 are quadriplegics who are ventilator-dependent and institutionalized, each clearly needing long-term care. About 350 veterans have no limbs, and without four limbs these persons are going to be chronic users of long-term care. It should come as no surprise that in two surveys of the membership of the Paralyzed Veterans of America (PVA) in the past 3 years (of about 25,000 quadriplegic and paraplegic veterans), the number one health issue was long-term care.

#### REHABILITATION

One of the most important goals of the PVA is to achieve and maintain the maximum level of functional independence for our membership. We must consider the role of, and the optimum balance between, the formal versus the informal care system. The key issue for those who already have physical disability is rehabilitation. Rehabilitation, for the most part, often becomes a debate between maintenance or restoration. Paraplegic veterans go through an active period of restorative rehabilitation, but once it ends, they seek and need maintenance rehabilitation. These persons are very concerned, for example, about the quality of the cushions in their wheel chairs because it might determine whether they will get decubitus ulcers, which will put them back into an institution.

#### SUPPLEMENTAL VERSUS SUBSTITUTE CARE

The issue of financing centers around whether financing should be directed toward a service or support of the individual. This might mean, for example, a cash benefit for disabled veterans that will enable them to purchase their own care. Should financial resources support supplements or substitutes?

#### **Human Aides**

The first problem is finding aides. In 1987, the PVA completed a study of independent living and the availability of aides. We found that older paraplegics have more difficulty in obtaining needed aides than younger ones. This seems to be a rather poignant issue of attitudes and rejection of aged paraplegics and quadriplegics.

#### **Animal Aides**

The second problem of supplements versus substitutes relates to nonhuman-aides—capuchin monkeys. Dr. M. J. Willard has trained capuchin monkeys to take care of quadriplegics in their home. We know that this represents supplemental care because the family comes home after work and puts the monkey in the cage. The monkey represents a supplement during regular working hours—a form of respite care for the family.

One fascinating aspect of the monkeys is that they represent a means of socialization for the quadriplegic in the home. The animal becomes the talk of the neighborhood, and suddenly, the monkey's presence not only becomes a supplement in a medical sense, but also helps in putting this person back in the community. For us, and for aging spinalcord-injured quadriplegics, this is a very important issue. About 650 quadriplegics in this country could use capuchin monkeys. Exactly 6 have been placed, and each of them was funded through the good offices of various foundations.

#### **Physical Technology**

Taking away the wheels of a spinal cord paraplegic is a very serious issue. Wheel chairs, robotic arms, the use of computers, and the

use of prostheses are all very important parts of maintaining a person at home. We know of many instances of persons who, literally, cannot get their wheel chairs fixed and must, as a substitute for home care, go back into the hospital. For disabled persons the physical technology represents a way of continuing their long-term care support, but not in a way that forces them to be institutionalized.

# ECONOMIC CONSEQUENCES OF SPINAL CORD INJURY

We have initiated a study at Rutgers University that will look specifically at the issue of the economic consequences of spinal cord injury. The study will investigate such problems as: What is the burden of illness represented by taking away a physical technology that an individual used to have? What is the cost of losing your wheel chair? What is the cost of not having a suitable cushion so you will not get decubitus ulcers? Part of the Rutgers study concerns the cost savings of community-based care—What is the cost avoidance and what is the cost effectiveness?

Dr. Kane said, "Let us define effectiveness first, and then we can deal with the rest." That may work for some, but we cannot wait to define effectiveness. Policy decisions need to be made about costs and reimbursements every day. Part of the solution to providing long-term care lies in the willingness of policymakers to accept a spectrum of personal care services and health-related services, not all of which conform to the medical model, for the physically disabled individuals who are now moving into their later years.

<sup>&</sup>lt;sup>1</sup> See Robert L. Kane, "Home and Community Care of the Elderly: Framing the Issues," in this volume.

HOME AND COMMUNITY CARE OF THE ELDERLY: RESEARCH AND POLICY ISSUES

# Home and Community Care of the Elderly: Research and Policy Issues

Bruce C. Vladeck

I will address three policy issues that I think are of great importance in home and community care of the elderly: "high" and "low" technology, service development, and financing.

## HIGH AND LOW TECHNOLOGY

The distinction between high technology and low technology is implicitly made in public policy all the time. To take an example from far outside the field of geriatrics of how policy favors high technology, we are willing to spend unlimited amounts of dollars, I believe appropriately, on premature, seriously ill infants born to crack-addicted mothers in New York City. By the time neonatal intensive care is finished, the mother has disappeared. Because we will not spend money on "low-technology" social workers to develop foster homes or other placements for these children, we have the phenomenon of "boarder" babies in our hospitals.

Providing low technology is not always the only solution, of course, but we tend to be substantially more generous toward high technology than low technology throughout health care and human services. More money is available for high tech than for low tech. Physician reimbursement policy provides another example—we will pay more for procedures and not much for "cognitive services." We see it in home care as well, where we pay an extremely high price per visit for professional services when, in fact, the bulk of the care is given by aides who we pay \$3.75 an hour without fringe benefits and without much supervision. Then we wonder why the quality of services is not as high as we would like it to be.

Two points are important to understand if we are going to achieve better public policy about home care and community-based care. First, the lowtechnology care needs of frail elderly people, frail chronically ill people, or frail disabled people of whatever age are as much the result of pathology or illness as are the high-technology care needs of the acutely ill. It is illness that causes chronically arthritic, elderly persons, because of their medical conditions, to require a homemaker or home caregiver. Second, we are no more or less scientific in determining needs for low-tech services than we are for high-tech services. We have learned a lot in the last two decades about community-based care and home care. For example, we have learned that we can assess an individual's need for services using relatively standardized instruments. Even if those assessments do not produce exact duplicates of necessary services, they are reasonably good predictors of needs; in fact, they have been used with great success by state Medicaid agencies and by many home care programs.

We must not fall into the trap, however, of concluding that a given score on one's assessment form entitles one automatically to, for example, x hours and yminutes of skilled nursing or physical therapy. Assessment is a developing technology that lets us say something about the kinds of help people might need. We are probably nearly as sophisticated in measuring personal needs in terms of chronic illnesses as we are in measuring many aspects of acute illness, where we pay lots of money very blithely. We can no longer use as an excuse for not paying for low-tech care that need is not definable or that services are not illness-related.

#### SERVICE DEVELOPMENT

We completed a study early in 1987 that showed that in New York City in 1985, more Medicaid clients were in long-term care in the community than were in nursing homes, by a ratio of about 1.2-or 1.3-to-1. This situation was the result of a very conscious policy decision made by the state of New York in the late 1970s (as in several other states and localities). The decision was to change the character of long-term care from an institution-dominated system to a community-dominated system—to make community-based services the service of choice and to make nursing homes the alternative to community care, not the other way around. Policies were undertaken to stop feeding the growth of institutionally based services in order to make funds available for home-based

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> services. The policies worked; as a result, substantially more people are cared for in communities than in nursing homes. We are proud of that accomplishment (1).

> When I was doing research on nursing homes in the late 1970s we used to say that 40 to 60 percent of all people in nursing homes were there inappropriately (2). This meant that, with a modicum of service in the community, many persons could be maintained in the community. We no longer think in terms of people being in nursing homes who do not belong there. Many communities have more people who really need to be in nursing homes than can get in.

# **Problems in Community Care**

Now that we have accomplished many of the goals of the past decade, we have to cope with the implications and the problems created by our success. For communities that have not yet swung toward community-based care, we might be able to prevent some of the problems that we experienced. For example, now that nursing homes are filled with sicker people than ever before, we realize that nursing homes, as they are now constituted, are not very capable of taking care of many very sick people. To some extent nursing homes, during the past 20 years, have based their staffing, reimbursement, and organization on the assumption that half of the patients who were there did not really need skilled care. Whatever finite resources were available could be spread over the other half who really needed services. Now that most people in nursing homes truly need more intensive care, many nursing homes do not have the capacity to render it, nor is the system prepared to cope with either the service organization or the economic implications of developing facilities that are adequately equipped to take care of sick people.

In home care, a number of analogous problems crop up. In historical perspective, they are the kinds of problems that one has when any kind of relatively new service or set of organizations develop. They are the classic problems of getting past the infancy stage and into maturity in the organization of the services. Because the problems are not unexpected does not make them any less important.

Home and community care is characterized by lack of organization in much of the field. Not only is it an immature industry, but it is also fragmented in terms of patterns of organization and ownership. The regulatory apparatus is virtually nonexistent in most instances. Problems

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are particularly severe in oversight and supervision when, out of necessity, services are being given in private settings of one sort or another. All of this is made more important because the clientele is particularly vulnerable.

#### **Providers of Home Care**

Who are the people providing home care? What is their training? What is their background? How do we keep them in home care when they hardly get any wage increases or opportunities for advancement? We have not even begun to address questions of supervision or organizational structure in home care. In most communities, formal supervision of a home health aide or a home attendant is done by a registered nurse who is an employee of another agency, an organization that has only a contractual relationship with the employer of the aide. Serious questions must be raised about the kind of professional supervision that results from that relationship.

I want to suggest a hypothesis that might circumvent a lot of research on optimal ways of matching certain kinds of settings and certain kinds of clients and certain kinds of delivery patterns. I think that we will find, over a period of time, that if competent people and a well-motivated family situation or a wellmotivated surrogate family are providing services, then the precise mix of personnel providing the service matters little. And the precise site probably does not matter greatly either—whether it is the patient's home, a day care center, supported housing, congregate housing, or a nursing home. The exact professional skill levels of the care providers might make little difference if the patient's needs are understood and an effort to meet them is made by people who have some knowledge and some reason to be motivated to do a good job. Human beings are remarkably resourceful and remarkably capable of coping. We should not become bogged down in turf fights and secondary questions that promote the interests of one particular way of doing business over another and thereby lose sight of the main problem.

### FINANCING

Service costs and financing policy are the key factors that will determine the future of home and community care. We tend to get sidetracked on questions that are fundamentally misleading. In 1986, I

attended an excellent conference on development of community-based long-term care sponsored by the National Governors Association in Portland, Oregon. The big question was, How are we going to pay for long-term care? I responded, "cash, check, or credit card." To my mind, *how* we pay for long-term care is not the problem—the problem is *who* is going to pay for long-term care. The dynamics of long-term care policy during the past 10 years have demonstrated that everybody wants more care as long as somebody else pays for it.

Another fundamentally misleading question is, How is society going to afford to pay for all the services that people will need in the future? A more rational question would be, How can we best use the allocated amount of dollars that the policy and decision makers determine that we can afford?

I propose that the way to gain control over expenses and allocation decisions in providing long-term care is to have, for want of a better word, a budget. Without going into great detail, if you do not want a society to spend more than x dollars on a service, then you decide that we are going to spend x dollars. If you have to make explicit, allocative, public-rationing decisions of the kind Dr. Donabedian called for, about who can get what, then you must start with a budget and make budgetary decisions. This does not mean that all the money has to originate in the same place, or that a single bureaucratic mechanism should control the budget. It does not mean that one particular set of actors has to receive all the revenue from the budget. A budget can be implemented in many different ways, but it does mean that somewhere in the system there must be some coordination. I believe not only that a budget is the key to many of our questions about financing, but also that it will result in better services, clinical coordination, service integration, and many other benefits as well.

Once a budget process is in place, we will be able to address two other issues. The first is rethinking the role of the general hospital in the system. In particular, we may begin to do something about our obsession with the length of stay. This nation already has the shortest length of hospital stays of any nation in the world. Although it seems to be the only device anybody is able to agree on for reducing health care costs, we should now, four years into the prospective payment system (PPS), have very convincing evidence that it does not reduce costs at all. We are

<sup>&</sup>lt;sup>1</sup> See Avedis Donabedian, "Quality of Care and the Health Needs of the Elderly Patient," in this volume.

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pushing people out of hospitals because we believe that we are saving money but we are doing it in a way that is costing us a lot of money.

If we really believe in continuity of care, if we really believe in moving people in some rational and clinically beneficial way from the hospital setting (which is where most people enter the long-term care system) into home care or community-based care and then to institutional care, enough time must be allowed for the process to take place. For many years, hospitals were indifferent to that process and never had the incentive to do it right. We have a lot to learn about how to do it better. However, a 5- or 6-day hospital stay is not enough time to plan the steps of a long-term care program. There is no benefit, either to the patient or to the total expenditure package, from being in such a hurry for no particularly good reason.

A perfect example of inappropriately rushing patients out of the hospital is the patients who are discharged on Friday afternoon where home care had been authorized, but home care workers are not available on Saturday and Sunday. You end up paying for the clinical consequences of the patients' spending their first two days without the services they need, at a time when keeping those patients in the hospital on Saturday and Sunday would not cost the institution much money. Nor would it cost Medicare anything under PPS.

The second issue, once a budget process is in place, is to recognize that one of the principal elements in providing home care is homes, and one of the ways that we create surrogate families is by the character of peoples' housing arrangements. Data suggest that if individuals are in good congregate housing, then they require fewer formal services because they get them informally from the community in which they reside. There is a growing body of data on the length of time people in continuing care communities remain in their residence rather than entering into the formal care system. Longer residence in communities results partly because of the capacity of those communities to bring services to people, and partly because the community itself provides a set of supports that is not available when people's housing situations are significantly more isolated.

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# Home and Community Care of the Elderly: Research and Policy Issues

Lisa V. Rubenstein

**ISSUES** 

According to Webster's Second New International Dictionary, technology is "any practical art utilizing scientific knowledge; applied science contrasted with pure science." A practical art is "a system of rules or organized modes of operation serving to facilitate the performance of certain actions." By these definitions, home and community care of elderly people ought to become a technology. I am not sure, however, that it qualifies as a technology yet. To become a technology, home and community care needs clearly stated, scientifically based rules or principles that can guide its users and practitioners. To develop such principles, two major types of research are needed. These two types of research, which advance synergistically, might be called "methodologic research" and "policy-type research."

## METHODOLOGIC RESEARCH

By methodologic research, I mean basic research directed toward understanding the organism called "Home and Community Care." What does it look like? What are its roles in society? How can its success be measured? Methodologic research in the area of home and community care includes community-based needs assessments and the development of interventions to meet those needs. It should include the development or further testing of reliable, valid instruments to stratify the populations that would receive care, as well as instruments to measure the economic impact of this care, the quality of the interventions delivered, and the health status and quality of life of recipients of the interventions.

Methodologic studies should also include studies of the effectiveness of particular types of home-or community-care programs. Examples methodologic studies concerned with program development might include studies of methods for educating caregivers, consensus panels on the relative effectiveness of different care strategies, and studies of the relative benefits of variations in the timing, quantity, or content of a particular service.

#### POLICY-TYPE RESEARCH

Policy-type research, in contrast, focuses on studying the impact of programs composed of multiple components. A home care program might include components such as Meals On Wheels, visiting nurses, social workers, and others.

The independent variables for policy studies might be variations in entitlement, financing, or types of services offered. Such research often begins with a methodologic phase during which instruments and interventions are developed, but it ultimately must proceed using the best available knowledge, assumptions, or instruments, whether or not these are adequate to support completely the effort being undertaken. Typically, policy-type studies would include experimental or quasi-experimental evaluations of large-scale demonstration projects. Such projects evaluate the effectiveness of services defined at a level that might be specified in government policy.

For example, policymakers might cover or not cover certain services, change the payment formula, or change eligibility requirements. But policymakers do not specify whether the diets offered by Meals On Wheels will permit ethnic variations, even though 90 percent of the meals delivered may remain on the tray in the absence of such adjustments. That level of specification is left to the practicing health and social service professionals operating within the experimental program.

#### PROBLEMS IN RESEARCH

Do we, as health and social service professionals, know enough about what people over age 65 need and want so we can proceed with the next major policy studies? Do we know the nuts and bolts about our services that would let us design them appropriately? Or, should we urge the granting agencies to spend more resources on methodology develop

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> ment? Both methodologic and policy-type research are imperative if home and community care for ill elders is to become a scientifically based technology.

> On one hand, a field that bogs down in the interminable definition of instruments, in minor variations in education, or in arguments about types of services delivered will not blossom. Policy research must often be done quickly for the sake of politicians faced with making difficult legislative or bureaucratic decisions. On the other hand, policy research based on inadequate data about what it should be testing will be misleading. I believe strongly that the next major priority in home and community care is to make sure that the next round of demonstration projects and randomized trials are based on a substantial, methodologic development phase.

## IMPLICATION OF RECENT POLICY STUDIES

We are fortunate in this field to have access to the results of several large, well-conceived demonstration projects and experiments in the areas of home and community care. Experiments such as the Triage experiment and the National Channelling Demonstration can be criticized on a number of grounds, but they were certainly examples of thoughtful research (1). From the results of these and other studies, we know that home and community care are not simple, low-cost panaceas to shorten hospital stays, to replace nursing home days, or to improve health status. Positive effects on patient and caregiver satisfaction and well-being were found but were not staggering. The lack of positive results from these studies should force us to rethink our goals and methods. Was it the lack of physician and nurse participation that made case management only minimally successful in the channelling study? Was the target population appropriate?

## RESEARCH QUESTIONS

A basic question we have not yet answered is how well our models meet the needs of a community of elders. I thought at first that I would be referring only to care of sick elders, but we do not know at this time whether very sick elders should be the major or the only focus for health professionals in the area of community care.

# **Functional Assessment**

We might also study the population of elders who are able to perform, for example, all basic activities of daily living. People are now expected to live an average of 20 years after age 65, often with chronic diseases. What kind of services does this nonfrail group need or use, if any? Do we know what activities these people usually perform or which activities they value? Do they care for grandchildren? Do they do volunteer work? What happens to these activities during periods of illness? We might want to find out what role medical and community services should play during this period. A successful program for this group would not be measured by fewer nursing home days but by improved function and well-being of the patients at affordable costs.

# Caregivers

Most young women now work. We are headed toward a demographic situation in which a single young worker may be supporting as many as four elders. We do not understand the full economic, social, and health status impacts on these caregivers of caring for very sick people in the home. Caregivers for frail elders are another major population of concern. Caregiver strain and health effects need to be assessed in relationship to different types of community care.

## VALUES

Major research efforts must be undertaken to understand what people value. For example, many elders may not want their children to take care of them at home at major economic and vocational sacrifices. Many elderly people do not want to live with relatives. I have had many patients who have said that under no circumstances did they want to move in with their children. Would it be better to foster the development of small, local, higher-quality nursing homes, perhaps of the 20-bed size, as has been tried in parts of Scandinavia, than to try to care for increasingly more elders in the home as has been the pattern in the United Kingdom? We need answers to these questions.

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# **Community Resources**

Research studies should focus on how and whether we can make better use of existing community resources. For example, we have recently developed a problem-oriented, computerized resource guide. This guide defines problems in terms of impairments in physical, psychological, or social function and can be used by physicians, social workers, and patients.

Ultimately, our approach to all resources should be more problem oriented and less institutionally oriented. We tend to define services in terms of locations and institutions—for example, we think that full geriatric care includes something like a day hospital, an assessment unit, an acute unit, a nursing home, and home care. Much less is known about variations in the patient population, staffing, or services provided by these programs. How many people or patient days in private day hospitals are accounted for by respite care, how many for monitoring of medications, and how many for preparation for colonoscopies or barium enemas? How many patients get assessments? How many get rehabilitation, and of what, exactly, does the rehabilitation consist?

As we measure the effectiveness of different forms of subacute services for elders, we should be sure to measure effectiveness against the best current standard. Previous research has shown that a post-hospital geriatric assessment unit can improve outcomes for a highly selected group of frail elders. Home care and nursing home care outcomes should be measured against a standard rather than against no post-hospital care, as is often done now.

# **Policy Directions**

I think that the next major policy direction from the federal government is likely to be aimed at seeing whether prospective payment strategies that have been so effective in reducing length of stay in the acute hospital, if not in reducing overall costs, can be used to improve the cost-effectiveness of post-hospital care and to increase the hospital's accountability for what happens to patients after hospitalization.

In the face of pressures to reduce costs, we need to improve hospital and home care coordination. We need to build interventions into

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home and community care projects such as education for hospitals about longterm care and education for patients regarding care alternatives. We need to develop new measures for the quality of care delivered in the long-term care setting.

Finally, we must walk a fine line over the next decade between patient advocacy and solid, well-designed research into health care alternatives. We must help promote efficient care but not care that decreases quality of life. Our sick elders are not always able to defend themselves against negative impacts of new policies.

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# The Acute Care Hospital and the Elderly: Introduction

Jeremiah A. Barondess

The entire effort of this forum addresses a real life spectrum, not only of degrees of illness and degrees of dependency, but also of social locus and sites of care. As you are all aware, a number of forces are changing the fulcrum of that balance from the acute care hospital to the community and the various sites of care in the community.

For most sick people, and perhaps especially for the sick elderly, there is an ongoing, potential flux between the acute care hospital and the variety of sites of care in the community. Technologies are singularly important causes and energizers of that flux. The overall issues here are how to harness and rationalize the insertion or the withdrawal of those technologies and how to make them less dependent on the site of care.

From the point of view of the acute care hospital, one could say that it is a locus in which medical technologies are concentrated; our interest is to maximize the effectiveness of the clinical use of those technologies. Subsumed in that term are, I would suggest, maximal appropriateness in the selection and application of technologies in clinical care, maximal clinical benefit, minimal risk, and appropriate cost. I would suggest further that the algebraic sum of all of that is optimal patient outcomes with acceptable costs in time, patient discomfort, risk, dollars, social disruption, and so on.

Of particular interest for purposes of the second part of this forum are the potential negative effects on health status, costs, and persistence of the acute care paradigm that all clinically applied technologies carry; our further interest is to examine the question of whether elderly patients are at particular risk of adverse effects in the acute care hospital and what can be done to define those and to minimize or obviate them.

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The literature in this area is surprisingly thin concerning the risks of hospitalization in general and concerning the risks relative to old people in particular. Most of what we know relates to rather global assessments of the risk of specific clinical procedures—the risk of having a hernia repaired or a general anesthetic or getting a pulmonary embolus under a variety of circumstances—or of the administration of drugs. There are essentially no studies on the negative effects of hospital routines—putting people to bed or interrupting their fluid intake or regimenting their sleep-wake cycles at the convenience of hospital routine or sedating them for one or another purpose or restraining them—low tech, one might say, but so broadly applied across such a large population that the net mass becomes very considerable in size and the aggregate risk potentially very large.

Very few studies on hospital risks have been stratified by age, and even fewer have suggested procedural alterations that might be useful with special reference to older patients. A few things, however, have been examined. Clinical studies have shown, for example, that elderly patients are at increased risk of hospital-acquired kidney failure and, in particular, the risk of aminoglycoside-induced kidney injury increases very sharply with age (1). Other studies have shown a heightened risk among older people of drug-induced illness leading to hospitalization and, further, that a significant portion of those admissions are related to or triggered by the use of over-the-counter drugs that are used more by old patients than by others; among those drugs especially aspirin, laxatives, and antacids have appeared as the chief inducers of drug-reaction-induced hospitalization (2). The risks of intensive care units are also higher in old people, with a higher proportion requiring major interventions like mechanical ventilation and pulmonary artery catheters, and with higher death rates and higher cumulative mortality rates at the end of one year follow-up (3).

In addition to expressions like these—of physiologic frailty, or, one might say, clinical frailty—in the elderly, the importance of today's discussion is pointed out by the fact that old people use acute care hospitals much more than anyone else, as everyone here knows.

Looking for numbers, I found the following figures. In 1979, for acute care hospital days per year per 1,000 population, the rate was 1,224 days for all ages; for those age 65 to 74, 3,124 days per year per 1,000; and for those age 75 or older, 6,062 days per year per 1,000. Overall in hospital mortality among old patients in one community hospital was 15 percent, and, perhaps more important, no elderly patient had, as a result of

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an acute care hospitalization, an improvement in his or her prehospital level of care needs—no one (4).

In the second half of this forum, we want to focus on these and other impacts of acute care hospitalization on the elderly, considering technologies very broadly, and we want particularly to try to isolate issues needing further investigation, policy development, or clinical revision.

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# The Acute Care Hospital and the Elderly: Framing the Issues

Mitchell T. Rabkin

At least three recent achievements have brought us to the state of penury now claimed by payers for health care. One is the advancing life expectancy, which has created a relative increase in the number of elderly. Another is advances in medical technology, which have led to increased applications of diagnostic and therapeutic modalities to diseases in the elderly and increased enthusiasm for hospitalizing the elderly in the face of acute disease or exacerbations of chronic illness. The third achievement, particularly during the decades from 1965 to 1985, has been the significant increase in funding for the care of the elderly—Medicare and Medicaid.

Only one of these three advances—life expectancy, medical technology, and increased funding—is technological; the others are clearly societal. Nevertheless, we are now confronted, as medical care expenditures are being trimmed, with the need to reconsider the various components of that societal burden of rising health care costs. The pressure is on the medical care establishment.

## ACUTE HOSPITAL CARE OF THE ELDERLY

Probably no single component of health care costs is as large as that for the acute hospital care of the elderly. It represents about 40 percent of the inpatient revenue at Boston's Beth Israel Hospital and at many other major teaching hospitals and community hospitals; in some hospitals the figure may be even higher. Yet, we must not forget a fundamental fact: the vast bulk of these dollars is spent on a relative minority of the elderly. Most old people, during most of their advanced

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years, fall within the category of "successful aging," as our former gerontology chief, Dr. John W. Rowe, has written. Thus, we should begin with a caution. If prevention is the most effective medicine, then we had better pay attention to maintaining and extending successful aging among the population whose numbers, life span, and average age are increasing, lest the economic pressures we now feel grow to a size that strains not only our material resources but also our ethical reserves.

The pressures recently applied by Medicare and other payers have had a major impact on the nature of hospitalization, particularly for the elderly. The extent of this pressure varies state by state, perhaps hospital by hospital. It varies over time, too, as we move, for example, from regional to national rates of payment for Medicare. These pressures will probably escalate further. The result will be a real change in who gets admitted and for how long. For many hospitals, the result has already been a sharp increase in the pace of inpatient turnover, especially if the hospital remains full by admitting more and more patients, as ours does.

The turnover pace seems much faster both to the caregiver and the patient with, for example, the loss of the preoperative day; with discharge often occurring before the patient or family can grasp what has been going on; and with postdischarge arrangements made in a manner that often seems to the patient and family as last minute or, if it starts at the time of admission, inconsiderate. The patient has less time to get to know the inpatient unit, its physical geography, and its staff. The patient has less time to form reassuring relationships and to be reassured. The anxiety spills over, not only to the patient's family, but to the caregivers as well. It is less satisfying to be a patient. It is also less satisfying to be a provider of care.

I wrote several years ago about what I labeled the SAG index, an acronym for Sense of Anxiety versus Gratification (1). The days when we no longer hospitalize patients are clearly the days of relative gratification—the patients feel, finally, that they are being cured; the doctors feel that they have been able to accomplish something. The days that remain are the days of anxiety. "Do I know what is going on?" asks the doctor. "Will I live or will I die?" asks the patient. Nowadays, the SAG index has moved up markedly.

Therapeutic goals have become subverted by the utilization review process. Regardless of the vision properly held by the doctor or nurse of a reasonable therapeutic goal for the patient, the fact is that when the patient's condition is deemed no longer needing the capabilities of the

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acute care institution, the patient is pressured to leave. The hospital, aware of the economic consequences of therapeutic charitableness, applies pressure, although not always directly. When the acute illness subsides to a level which could be handled elsewhere, this approach destroys what should be the true focus in therapy in many patients. Coming to the hospital with a background of relatively stable chronic illness and level of functioning, the patient often regresses as a result of the acute illness. The acute care focus tends to deny that proper goal, the restoration of the patient's status quo after the acute illness has been handled. Given the vagaries of subsequent attention in the patient's home or the nursing home, which may be good but too often is not, the patient might or might not ever return to a functional status that might have been achieved under more favorable hospital circumstances.

The relinquishing of responsibility once the acute episode has tempered also assaults the longitudinal continuity so important in care, particularly in the elderly, for whom new scenes and new relationships are often difficult to manage. Even the efficient transfer of information to the skilled nursing facility does little to maintain a true sense of continuity.

#### PROBLEMS OF THE ELDERLY IN THE HOSPITAL

Let us look at the elderly who populate the hospital. What specific problems do most of them present as a result of age and of less, rather than more, successful aging? Aging assails many physiological protective mechanisms, such as clearing of the tracheobronchial tree; the skin is more fragile and breaks down more easily; aspiration of fluid into the lungs occurs more readily. Injury, especially falls, are more common because of decreased peripheral vision, because the elderly cannot find their glasses, because the hospital bed is a different height than their own, or because a bit of incontinence has made the floor slippery.

The new and unfamiliar hospital environment creates confusion made worse by new medications or by drug toxicity, hypotensive agents, or salt restriction. Unfamiliar foods or dishes can lead to burns. Hot packs can burn before the patient is aware. Meal schedule disruptions or the strange tastes of salt restriction may lead to anorexia. Depression is common, even for the patient who did not enter depressed. Sensory deprivation or overstimulation in a new environment and the loss of diurnal clues in the passage of days and nights, particularly in the ever-lighted intensive care unit (ICU) commonly occurs. Ordinary incontinence may be viewed as normal for age even though often it can be

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improved. Bowel patterns, often perverted through needless laxative use at home, may create major problems. The sleep and rest cycle is disturbed. The roommate or the roommate's family may be problematic. Immobility in bed may create more than bedsores and pulmonary problems. A marked decrease in mental functioning can result.

Often the elderly bring to the hospital a damaged sense of their own identity, ability, and self-esteem. The vicissitudes of their life, their retirement, the loss of spouse, the restrictions of age or illness, the youth orientation of the world around them, the lack of respect for the experience and insights their years have brought—these can be sources of self-consciousness, a sense of deficiency, humiliation, and depression. Acute hospitalization itself is no help, for it assaults the strongest of us as we are thrust into a more passive, regressed role. Hospitalization can be made even worse by the expectation of the health care team that the patient will comply with the speed set by these younger, acclimatized, and in-charge people. And to wrap it up, we take away their name and give them a number, we take away their clothes and give them a johnny, and then we lose their dentures!

Too often, the clinical team does not even begin to touch on issues of major concern to the patient. In part, it is the pace of life in a hospital, but sometimes the elderly patient's concerns, for example, concerns about sexuality, are not even considered as being reasonable. Nor is the patient's anticipation of his or her own death considered to be a reasonable concern. We would certainly want to participate in the decision for ourselves if orders are written not to resuscitate. Does age mean that the elderly do not want to? Interestingly, a Beth Israel nurse made a comment to me that sums up some of this. She said, "You know, competency is never an issue when the patient says, 'Yes,' only when the patient says, 'No'."

This litany describes the situation of patients everywhere, and I believe, in practical fact, that we do better at Beth Israel than at many hospitals; but the problem is universal. We must address these questions: How can we change our policies? How can we use technology to improve the care of the aged?

# **Hospital Policy**

Some of the agony of the elderly that I have just described surely must be exacerbated by the anomie of some of our hospitals. No new policies need be formulated, but the successful implementation of exist

ing policies relating to effective management of the hospital is important. For example, hospital workers, from physicians and nurses to transporters and dietary aides, must understand the issues of the elderly and use that understanding to make their systems work to soften the harshness of hospitalization.

It is imperative that hospital management rationalize its operations as effectively as possible. Payers' policies could be changed in relation to length of stay and the resulting pressures for discharge. I suspect, however, that major relief will not be forthcoming until the health care proportion of the gross national product (GNP) decreases significantly, which, I believe, will happen only if the denominator (GNP) grows faster than the numerator (health care costs).

# **Technology in the Acute Care Setting**

In medical care, we find that most technology does not eliminate jobs or save money. Furthermore, many tasks require the exercise of judgment that has not yet been synthesized into machines; the basis of professional expertise is still judgment, which is based on clinical experience.

I liked the idea that was previously mentioned of using bar codes. I would like to see bar codes on wristbands and on unit-dose medication packets, tied in with computer ordering, used for documentation and billing, coupled with purchasing and receiving in the pharmacy, used with a drug incompatibility system and a least-cost drug program, and many other applications.

This is no longer high technology. It is middle-level technology, but the same considerations apply to bar codes as they do with PET scanning or magnetic resonance imagery. Indeed, mistakes occur both in today's systems of administration of medication and in the absence of PET scanning; in both instances suboptimal care and even deadly mistakes can occur because the correct technology is not in place. Will it be worth the vast dollar cost to salvage those few lives? The question is the same, regardless of high tech, middle tech, or low tech. I hope that the answer is "yes," but the reality will always be that the size of the purse powers the purchase.

<sup>&</sup>lt;sup>1</sup> See Robert L. Kane, "Home and Community Care of the Elderly: Framing the Issues," in this volume.

#### PRIMARY NURSING

In service industries, and hospital care is a service industry, the best approach to problems is not invariably technology. So, without retreating from the many ways to think about these issues, I want to propose greater adoption of a "no-technology technology"; one that has great potential—the way in which we use nurses in the hospital.

I call it a technology because it is a way of empowering nurses to improve the therapeutic process. Our previous comments on the risks of hospitalization and problems, often cited in nursing literature, such as the effects of immobility, orientation, lighting and quiet, ambience, and other aspects of the hospital environment, emphasize the importance of nursing.

Hospitals are nursing institutions, not doctoring institutions. Twenty-four hours a day, seven days a week, the professional nurse provides professional nurturing that sustains the patient and allows the physician to touch base periodically to create various perturbations, some for good and some perhaps not.

Much of the difficulties of the elderly hospital patient can be helped markedly by better use of nurses on the inpatient unit. In most hospitals today, nursing is organized under a concept called team nursing, which organizes nursing personnel at various skill levels, with the professional nurse typically directing and supervising the work of others. This has two problems. First, nurses do specific tasks for many patients—the beds, baths, temperatures, and so on—but no one really knows any specific patient. The second problem, worse in times of a nursing shortage, is that the few professional nurses are so involved in supervising that they do not get to know the patients, even though they are the ones who give the medications and treatments that aides are not qualified to give.

The idea of primary nursing arose out of dissatisfaction with this arrangement and was based on the notion that patients, rather than tasks, should be the focus of the professional nurse. The concept is that a professional nurse would be accountable for the care of relatively few patients over the entire 24-hour day—developing their nursing care plans; delivering the total care while on shift, with assistance from others as needed; and then delegating to associate nurses on other shifts the responsibilities for carrying out the plan and reporting what happened.

The continuity in reporting is maintained shift by shift, and as a result the primary nurse becomes able to maintain an awareness 24 hours a day of the patient's physiology changes and psychology; an understand

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ing of how the disease is progressing; an understanding of how much the patient understands and what preparations the patient has made for controlling and dealing with the illness after discharge; the role of the patient's family; and so on. The primary nurse's role becomes an immensely important complement to the physician's activities and awareness. Furthermore, it is gratifying for both nurse and patient.

Beth Israel Hospital's vice president for Nursing, Joyce C. Clifford, instituted primary nursing a dozen years ago throughout the entire hospital. The impact on patient care and patient satisfaction has been tremendous. The impact on nurse satisfaction is such that, over the years, when other major Boston teaching hospitals have had to close beds because of nurse vacancies, we have not needed even to float nurses from one unit to another. And our costs, whether expressed in terms of nursing hours per patient day or nursing salaries, have remained in line with those of the other major Boston teaching hospitals.

If you understand primary nursing, then you can understand why having continuity of care with one responsible individual enables the primary nurse to become a knowledgeable and effective advocate for the elderly patient who, as we have seen, can be severely disadvantaged. The primary nurse acts as support for the older patient faced with difficult decisions in hospital or with discharge planning issues. Because primary nurses gives the daily care, they are able to assess the skills, the strengths, and the deficits of each patient. While they give this care, some of which others may label as grunt work, they are able to talk with the patients and learn more about their hopes, needs, and fears. It is an intimate relationship with the patient, one which is professionally fulfilling. The primary nurse decreases the patient's sense of isolation and becomes a familiar, sometimes dear, friend and the nurse's 24-hour accountability leads to a far more individualized and tailored program and, often, a greater likelihood of compliance.

A leader in American nursing wrote, "Professional services are meaningful only if they meet society's needs. Patient care in hospitals has not done this for a long time, if ever." Primary nursing offers the vehicle to accomplish this service to society. Let us hope that its promise will be realized.

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# **Special Perspectives on Acute Hospital Care**

William R. Hazzard

For many years, my particular focus has been on developing systems that would be appropriate teaching models for the care of the elderly in the acute care hospital. In Seattle, where I began this work, more than half a dozen hospitals participate in a network of teaching arrangements with the University of Washington. I was based at Harborview Medical Center, formerly known as King County Hospital. (This is the hospital where prehospital coronary care in this nation began and where various other hyperacute health care strategies were developed.) The challenge was very clear: if we were to develop a geriatric teaching and research program, we needed to do it in a very competitive environment. Our clientele was distributed between younger patients, mostly alcohol and drug abusers and otherwise indigent, disadvantaged people, and a smaller proportion of elderly. The chief focus was the care of the desperately ill.

## DEVELOPING A GERIATRIC HEALTH PROGRAM

How can you develop a geriatric health care program in that setting? Because of the nature of the hospital, Dr. Marsha Fretwell (currently on the geriatric faculty at Brown University) and I, and others who followed us, decided to begin with the inpatient arena. It was this area that we knew best and could get attention and participation by the house staff and students. In that particular setting, we developed the Harborview SeniorCare Program. Although we developed an entire continuum of care, including nursing home and ambulatory clinic care, the hospital focused and still focuses on the care of acutely ill, elderly inpatients.

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What are the special problems that such a unit or program must face? It faces the fact that scattered throughout an acute care hospital some people are especially vulnerable and disadvantaged by virtue of their age and disease-dependent processes. How can one identify these people? How can one make sure that the set of services furnished to these people was the most appropriate? And, how can one continue to care for these individuals when they leave the hospital and go through the process of convalescence, to whatever their outcome might be?

In that context, we developed a prototype that we subsequently implemented at Johns Hopkins (Francis Scott Key Medical Center in Baltimore). We are now setting up such a program at Bowman Gray Medical School/North Carolina Baptist Hospital.

#### **Consultation Teams**

The process begins with the development of a consultation team to identify individual patients on all services throughout the hospital who might especially benefit by the specialized services developed in a geriatric care program. The consultation team, generally consisting of a nurse, a social worker, and a geriatrician, makes frequent rounds throughout the hospital, identifying the patient with the hip fracture, identifying the patient with the stroke, identifying the patient on the burn unit, identifying the traumatized patient who came in through the emergency room, and indeed identifying any patients who might need a different or focused approach to their continuing care.

The team was often asked to transfer a particular patient to the special unit for continuing care. Oftentimes, the answer was that the patient did not need such special care or that the services they were already receiving, in orthopedics or wherever, were appropriate and need not be interrupted, and the patient could be discharged home from those units. However, in about one-half of the cases, we found that it was appropriate to transfer the patient to the SeniorCare geriatric unit; the current census on that unit is about 12 in a 300-bed hospital, a number that has evolved and seems to be steady at the present time.

# Geriatric Outpatient Clinic

Another part of the care continuum that must be developed—under at least the partial control of the geriatric consultation team, and I empha

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size this—is an outpatient clinic. We developed a primary care outpatient clinic that stressed assessment that generally was multidisciplinary but also was unidisciplinary where appropriate for both front-door, first-encounter assessment and continuing primary care. In Seattle, we became affiliated with three nursing homes, ranging from private nursing homes to a public nursing home, where we could help control and foster the appropriate aftercare of patients under our responsibility, a home care alternative, and a rehabilitation and day care alternative.

The principal function that evolved for the geriatricians was largely that of management; the clinician assumed responsibility for care of patients as they progressed through various stages of convalescence or further dependency. All of this was done in the hospital setting because we needed to be highly visible, we needed to be research oriented, and we needed to recruit fellows, faculty, and residents into the effort.

#### COMMUNITY CARE ALTERNATIVES IN BALTIMORE

When I left Seattle for Johns Hopkins, a different set of problems and opportunities presented themselves. In my opinion, the system that evolved at the Francis Scott Key Medical Center (formerly the Baltimore City Hospitals) is one of the best in the nation because it exists in an institution that has a traditional orientation toward the care of the elderly and that has a major research and intellectual organization in the Gerontology Research Center (sponsored by the National Institute on Aging) as well.

We, the faculty, were responsible for the long-term care of about 225 patients on that campus. The patients were divided into two levels of care—a skilled nursing facility level of care and a chronic hospital level of care. We developed the locus of activities at Johns Hopkins within the Mason F. Lord Chronic Hospital and Skilled Nursing Facility, located about 100 yards from the acute care hospital.

We replicated the consultation team at the Mason F. Lord facility. Under Dr. John Burton's continuing leadership, we developed a rehabilitative unit; much of the continuing care was developed under the leadership of Mary Pat Clarke (now president of the City Council of Baltimore). We developed a series of home care and community-based alternatives, including care of individuals in their homes by a team of physicians, nurses, and social workers who also work with the community to develop better housing, better transportation, better family care, and so forth.

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I have described how we moved from a more focused, acute hospital-based program in Baltimore to a system that eventually capitalized on a series of community alternatives. Physicians-in-training and the faculty were heavily involved in this spectrum of care. Having access to the nursing home beds, access to the rehabilitative units, and access to home care enable this program to manage about 130 patients in their homes. Those patients are as dependent as are those in the nursing home. Actually, they are more dependent, but they are maintained in their homes with the support of their families and have access to the community resources and collaborative relationships that maintain the effectiveness of the geriatric clinicians in this particular setting.

The acute care hospital was primarily an intake point. The problems identified in the acute care setting were resolved mainly outside of it, but the continuum of care and the ability to plug in at all levels made the team effective. If the team functioned only in the hospital, then it would have remained ineffective and frustrated. The point is that any strategy that is targeted only toward the acutely hospitalized patient in that setting is likely to frustrate the clinicians practicing within it.

How do clinicians outside the academic establishment or tertiary care hospitals cope? They cope by having developed, over time, a knowledge of the resources and liaisons that exist in their communities, the trust of their patients and their families, and the knowledge of the backgrounds, tastes, and values of their patients and their families, which allows them, to a large extent, to be effective.

# ACUTE CARE BACKGROUND

I inflected my own interests, from metabolism and endocrinology to geriatric medicine, during a sabbatical year in Great Britain about 10 years ago. That evolution began during a pre-sabbatical visit a year earlier. That first exposure to the geriatric health care system was in the United Kingdom took place in Oxford at the Cowley Road Hospital (the place has since been torn down). Like the Mason F. Lord Hospital, it was built in the nineteenth century as a poor farm out in the country. It provided life care for the disadvantaged from birth through death.

When they showed me the "acute care unit" at the Cowley Road Hospital, I had a sense of being in the wrong place. Patients were in their daily clothes; people were sitting in dayrooms and walking around. I thought, "Something is wrong here. This is not acute care." When I

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asked, "What are you doing with this chap?", they said, "We are investigating his  $B_{12}$  metabolism because he might have pernicious anemia." I asked when they were doing a Schilling test. They said, "The day after tomorrow." "This is acute care?", I thought.

The average length of stay in this unit was about 18 days. I thought that this was not acute medicine as I knew it. But, that particular institution, in the absence of technology, took a more contemplative approach toward a care system that included investigation, rehabilitation, and reintegration into the community over the long term. The hospital served as the entry point to other levels of acute and chronic rehabilitative long-term care and return to the community, similar to the programs later developed in Seattle and Baltimore. The experience made me realize how effective this place, mode, time frame, and pace of assessment could be. It also made me realize that this mode of health care was particularly appropriate to fill a gap in the care of the elderly in the United States.

## GERIATRIC ASSESSMENT

What has subsequently evolved in the United States is the concept of geriatric assessment. It has become known by various names and applies to various modes of health care delivery in this country. In October 1987, the National Institutes of Health (NIH) held a consensus conference on geriatric assessment. Just holding that conference implied that this technology has reached a point at which one can describe it, quantify it, and judge its effectiveness, cost, and the like.

We have demonstrated, for example, that through a more contemplative approach, not just to assessment but also to rehabilitation, the health care of dependent and sick elderly can be improved and that it can be cost effective. Geriatric assessment programs have not been tested to any significant extent outside the Veterans Administration (VA) system. After Larry Rubenstein and his associates in Sepulveda had some promising results, the VA decided that every hospital should have a geriatric assessment unit, and now they are in operation in VA hospitals all over the country. Very few units, however, behave or function the way that Rubenstein set up. But his unit was not really an assessment unit; it was a rehabilitative unit with continuing assessment. The average length of stay is in the 40-day range. The point is that a substantial, targetable, and identifiable subset of patients in the acute care hospital will benefit by a more contemplative and rehabilitative mode of aftercare.

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I have described a mode of care that is a critical gap in our geriatric health care system. Although it has been variously called transitional care, progressive care, alternative care, or rehabilitative care, it is a kind of care that proceeds at a slower pace and that allows convalescence in a supportive, nurturing, and functionally oriented environment to proceed without the time pressure to make a decision about what will happen after acute hospital care.

#### BENEFITS OF A GERIATRIC ASSESSMENT PROGRAM

This system serves a number of purposes. If such a unit or program were available to the health care team, it could prevent acute hospitalization. The goal of much of what should be developed in such programs is to prevent exposing the patient to the acute care environment.

My experience at Seattle, Johns Hopkins, and Bowman Gray shows that hospitals and house staff do what they know how to do best. Once a patient enters the emergency room at Bowman Gray, I can be very sure that no technology available will be spared during the first 12 hours. But, if I am to prevent the unnecessary, hazardous, and costly exposure of patients to this panoply of ready services, I must prevent or at least control the need for patients to enter that system.

For example, we have developed an arrangement with the Baptist Homes of North Carolina at which one of our faculty is the medical director. She and the colleagues in our new section of gerontology and geriatric medicine under Walter Ettinger are the primary care physicians of all the patients in this particular nursing home. About 3 weeks ago, Dr. Ettinger received a call from the nursing home about a 92-year-old woman with advanced dementia, who had developed a pulseless right lower extremity. It was clear that a gangrenous leg was developing that would have a predictable fatal outcome unless something dramatic was done. It was decided, because it had been discussed previously with the patient's family, that advanced high technology or heroic therapy was inappropriate, but a diagnosis nevertheless had to be made.

Dr. Ettinger asked that the patient be brought to the emergency room where he would meet the patient and make a decision. This he did, and despite the exhortations of the emergency room staff, the residents, the students, and others, he made the diagnosis and sent her back to the nursing home. Had he not been there, it would have been impossible, in my experience, for the system not to have followed the usual emergency

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room procedures. This is an example of why control is very important.

With the subacute, transitional level of care, you have the ability to develop a care plan that emphasizes rehabilitation, restoration of function, and support for the patient in a natural evolution toward independence, without necessarily sending the patient to a nursing home. As we all know, if patients are sent from a hospital to a nursing home for convalescence, the risk is great that they will live the rest of their lives in the nursing home. Having alternatives such as we described defers that decision and may avoid it entirely.

Finally, an atmosphere in the transitional care center evolves wherein heroic therapy—application of the ultimate in high technology—is not necessarily the norm. It is a more humane environment, a more nurse clinician-driven environment. Less high technology is used, less high cost is involved, and more humane care results.

#### CONCLUDING REMARKS

These are the hypotheses underlying the development of this transitional level of care. Such care is not explicitly reimbursed in North Carolina or Maryland and because it is reimbursed virtually nowhere, a political and an economic strategy will be needed to overcome its exclusion from the system of payments.

If the hypothesis is correct, if we can develop an alternative form of care of the elderly, then we may be able to reassert control and minimize costs by avoiding the unnecessary application of high technology. In the academic setting, these kinds of programs and units also provide a setting for research where we can test the cost effectiveness and risk/benefit ratio of various technologies and approaches to geriatric health care.

Thus, transitional care—between acute hospital and long-term care—is the missing link in geriatric health care in this country. Specific programs at institutions willing to accept the risks and challenges of leadership will have to develop this level and integrate it into a managed continuum of care in a demonstration mode to test its efficacy. If such demonstration projects prove the efficiency and effectiveness of this system of care, reimbursement can be expected to follow and a mold for meeting the challenge of the "demographic imperative" of an aging society will be available for widespread replication.

# **Special Perspectives on Acute Hospital Care**

Carol J. Gray

Of critical consequence in quality of care are the attitudes, perceptions, knowledge, and skill of practitioners. For purposes of this paper, I sought the opinion of individuals in clinical practice through the means of an interview guide—the format of which included questions about definitions: health care, elderly, the proportion of individuals "in-house" who were elderly, and questions regarding philosophy of care and age-related alterations of that philosophy in terms of (a) access to technology, (b) aggressiveness of diagnostic and therapeutic uses of technology, and (c) termination of technology, such as life support systems. I also included questions regarding the vulnerability of sick elderly to underuse, misuse, or overuse of technology. Finally, I asked questions about need for availability of support services and identification of policy issues and research needs (1).

Discussion that follows is an amalgamation of observations and perceptions carrying no pretense of a research effort. Clearly, the limited data base from which I speak can serve only to generate questions rather than define solutions.

#### THE INTERVIEW SAMPLE AND PROCESS

The participants in the interview sample represented three institutions: a large 1,200-bed teaching hospital, a 500-bed intermediate hospital, and a 250-bed community hospital. The interviewees included clinicians and administrators in general medical-surgical department, intensive care units, coronary care units, and "stepdown" units.

#### **DEFINITION OF TERMS**

To establish a common frame of reference for the interviewees, I defined health technology as the full range of technologies—diagnostic and therapeutic—including but not limited to (a) a set of techniques, drugs, equipment, and procedures used by health care providers in delivering care to individuals; and (b) "mini" technology, which includes standard hospital routines, repeated blood tests, diagnostic tests requiring fluid restriction, extensive bedrest, extensive therapeutic regimes, issues of technological restraint, and biotechnology for use in diagnostic probes (2,3).

Rather than establish a common frame of reference for the term *elderly*, I was curious to know how that population was characterized by the nurse clinicians. Several respondents said that they thought being elderly starts at about age 70. Another, more specific in her definition, identified "young" elderly to be 55 to 60 years, and "old" elderly to be over 60. Yet another respondent took a broader viewpoint by defining elderly as starting at about age 80, but at the same time, some persons are clinically and physiologically very old at 60. Another said that to be elderly is *not*, in and of itself, a state of being inept, sick, or pathological as some might characterize it; rather, it is a phase of life that carries certain attributes.

# THE DISTRIBUTION OF ELDERLY IN ACUTE CARE HOSPITALS

According to the respondents in a large hospital, the general medical and surgical units as well as intensive care units average an increased proportion of elderly. In the smaller community hospital, the proportion of elderly is even greater, attributed in large part to the highly ethnic mix of the population served in the inner city. These perceptions expressed by clinicians parallel the observation of the American Hospital Association past-president, Carol McCarthy. The types of patients being treated in an acute inpatient care setting tend to be older. Admissions for people under 65 are the lowest in over 14 years and the length of stay is shorter than it has been for 18 years (4).

## THE ELDERLY'S ACCESS TO TECHNOLOGY

Asked if age influenced the elderly's access to advanced technology, respondents expressed a common philosophy which was to provide the best possible care for all patients without age distinction. The respondents, without exception, had the impression that technology was applied equally to all and that age-related discrimination was not apparent. One respondent made the point that multiple systems failure occurs at all ages and requires timely evaluation and monitoring.

Professional judgment about a patient's potential for recovery tempered most decisions about the use of advanced technology. One respondent noted that today's approach differs from that 15 years ago when age did play a greater role. Ultimately, the patients themselves or their families often determine the use of technology.

# The Aggressive Use of Diagnostic and Therapeutic Technology Among the Elderly

Respondents identified a tendency for caution with the elderly, for example, in the use of chemotherapy. At one time protocols prohibited intense chemotherapy for individuals over 56. Today, quite aggressive therapy is administered to the elderly. By way of another example, heart transplants were Medicare driven in the past, with a cap at age 55. That restriction has recently been lifted. Cardiopulmonary patients now go to surgery in their seventies. The decision to use aggressive diagnostic and therapeutic techniques is often a function of social variables, individual choice, and the availability of support networks and their ability to support and sustain. Other variables, such as the will to live, enter into the choice of therapy. Bypass surgery is performed on elderly who are not good candidates for other procedures, such as angioplasty, or as a last resort to relieve symptoms.

The impressions of the respondents regarding aggressive use of technology were validated, in my opinion, when I made an on-site visit to some clinical units. Two situations caught my attention. First, in one surgical intensive care unit, a patient was surrounded by four intravenous pumps, one chest tube, one respirator, one EKG monitor, venous pressure equipment, arterial pressure, and a cut-down procedure to infuse hyperalimentation fluids for maintaining nutrition, including lipid replacement fluids and electrolytes. This patient had been admitted for bowel surgery at age 73.

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The second example occurred in an intensive care unit. The patient's diagnosis was extensive right occipital hemorrhage, in other words, a cerebral-vascular accident. He was supported by a respirator, heart monitor, central venous lines, arterial line, heparin flush, nasogastric tube, and intravenous tube for peripheral medications. A Foley catheter, hyperalimentation setup, and infection protocols were also in place. His age was 74. Only one of these cases was in the larger research hospital, the other was in a small community hospital.

# Termination of Life Support Technology in the Elderly

Several respondents spoke to the ethical and philosophical dilemmas associated with termination of life support—"Technology keeps people alive longer, but their quality of life and the family's resources are at risk." Family wishes are generally honored, and age is a major consideration, but decisions are not age-limited. Legislation and living wills have probably assisted in making decisions for terminating the life support systems.

# Vulnerability of the Sick Elderly to Underuse, Misuse, or Overuse of Modern Technology

This question caused a mixed reaction. One respondent compared the aggressiveness of diagnostic and therapeutic approaches in an academic health center with that in a community hospital in which family practice prevails. She responded "yes" on all three counts—underuse, misuse, overuse. Especially vulnerable are biologically older individuals affected in mind, body, and spirit who need help and who acquiesce to anything. Older persons not able to articulate subtle changes that occur and who have no family to advocate or interpret for them might be the most vulnerable.

The difficulty in predicting the value of technology was expressed by several respondents. "It is situationally dependent"; said one respondent, ". . . elderly are especially vulnerable." What is known after the fact cannot be predicted with degrees of assurance. The outcome is most often unknown until it is tried.

The frail elderly are more prone to discomfort, but the question of their vulnerability to misuse of technology was unclear in the respondents' minds. Time constraints driven by prospective payment and diagnosis-related group (DRG) insurance put the elderly at higher risk than

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inappropriate use of technology (5). Same-day surgery on an outpatient basis and procedures for diagnosis and therapy often devastate both the family and the individual elderly patient.

#### IMPROVING SUPPORT SERVICES FOR THE ELDERLY

How might we make better use of support services, and what additional services are needed? While respondents acknowledged the availability of a gamut of services, they also expressed the need for improvement of services, especially for the elderly. The need for a communication system is great. For example, when an elderly person is scheduled for surgery, the records include a written communication between the admitting and attending physician or surgeon, and perhaps one preoperative visit with the surgeon; a surgical checkup might occur weeks after discharge. Communication in the interim consists of a letter between the physicians. Little is noted about rehabilitation and future care.

Informed admissions and discharges could be improved through, for example, a primary nurse serving as a liaison before, during, and after hospitalization. Telephone calls or visits to the patient are helpful when careful explanations are given about the hospital environment, expectations of care, self-help versus help by others, and so forth.

Better information systems are needed that contain more than computerized laboratory reports (6). Frequently, the pre-admission interview is extremely stressful, pressing patients or family for a detailed medical history when they have been taxed significantly just making their way through the maze of long corridors, multiple signs, and queries with strangers.

Another unmet service need is financial counseling. Social workers have provided extraordinary support, but there seems to be an urgent need for earlier, more timely advisement. For example, the postsurgical patient who has had an organ transplant and is placed on daily cyclosporine can expect the bill for drugs alone to be \$50,000 per year.

Finally, same-day surgery and diagnostic procedures place significant physical and emotional stress on the elderly. More choices for services, such as one-day diagnostic procedures and those driven by the DRG system, are needed for patients and their spouses. Older people have great difficulty with an operative schedule in which the patient comes in the morning and goes home that day—for example, cataract surgery on an 82-year-old; right inguinal herniorrhaphy, 70-year-old;

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hemorrhoidectomy, 76-year-old . . . each admitted and discharged the same day.

Examples of same-day diagnostic procedures included cystoscopy on persons age 60 and older; endoscopy for 67- and 70-year-olds; and in one situation, colonoscopy, esophagoscopy, gastroscopy, and duodenoscopy, *all* for a patient of 81 years. Might it be possible to restrain diagnostic and therapeutic technology routines in the acute care hospital to account more humanely for the physiological resources and limitations of the elderly? Responses varied widely: affirmative, neutral, and negative views were expressed, one expressing an emphatic "yes, we are pushing the limits of technology and need universal standards of care for the elderly."

Examples of procedures for which we need restraint include (1) rigid protocols for bloodletting; (2) routinely waking patient to take vital signs through the night—this results in fatigue and confusion the next day; and (3) iatrogenically induced starvation for 3 days from a 3-day diagnostic workup that required nothing by mouth for 3 days followed by discharge to home on the fourth day. The patient was very much weakened and more debilitated than when he entered the hospital.

Other respondents would like to see diagnostic and therapeutic aggressiveness modified especially for life-threatening procedures in which the information is not vital to know. For reasons real or imagined, the respondent in the research institution and academic health center expressed greater concern for diagnostic, rather than therapeutic, restraint. Respondents suggested that better monitoring was needed for elderly patients on medical trials, hypertensive drugs, and so forth. Shorter stays reduce effective assessment in the hospital, while effects on general systems often occur after hospital discharge. The frail elderly, who sometimes have no spouse or other support at home, might have to deal with untoward and unexpected reactions following discharge and become quite frightened. For example, in the elderly, blood pressure can be very labile and subject to orthostatic changes, especially in response to drug therapy days after return to home.

### **POLICY ISSUES**

The policy issues rest in the area of reimbursement—funding or lack of it for prevention and the cost benefits of health over illness. Quality of life and family and societal resources must receive greater

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priority. Sophisticated high technology raises inordinate expectations of cure and recovery, but its use cannot ensure good outcomes. Patients and families need a full accounting of possibilities and expectations, if at all possible, before hospitalization. The fear of acquired immune deficiency syndrome (AIDS) is of growing concern with technology, and many patients worry about contracting the disease while in the hospital. Additionally, legislative issues, resource allocations, and information systems all loomed high in the respondents' identification of policy issues. There is concern for the nontherapeutic effect on frail elderly placed in extremely stressful situations for purposes of both diagnosis and treatment because of compliance with Medicare. DRG directives are also having an impact on the elderly's access to care in the hospital or forcing an early discharge often times in marginal states of recovery from illness and without reasonable support systems (spouse, friends, family) capable of caring for them at home.

#### RESEARCH NEEDS AND OPPORTUNITIES

There is a need for research into the process of socialization and acculturalization of elderly in the hospital setting. That would include expectations and accommodation of their role—by the patients, their families, and health care providers. Research is needed to evaluate *prehospital education*, its effect on compliance, role congruency, and so on. By way of example offered by one respondent, the generation of elderly now in acute care have expectations for care unlike those of the care providers who recognize the therapeutic effect of self-help.

Most urgent is the need for collaborative research among professional care providers to capitalize on experiences of physicians and nurses, clinicians and researchers; to analyze the whole gamut of biotechnology, its systems and design, its application, its effectiveness, and its costs. Is it available both for diagnostic and therapeutic purposes for the population of frail elderly who have the misfortune of ill-health? Is it used judiciously to the best advantage of the population served—that is, are the potential benefits balanced against the potential for harm?

#### SUMMARY

Through means of an interview guide, an attempt was made to sample perceptions held by nurse clinicians about diagnostic and thera

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peutic use of technology in tertiary care hospitals where care was provided to the populations of frail elderly.

While respondents unanimously agreed that *access* to technology was not *age-dependent*, there was among the respondent group a shared concern and some misgiving about the *overuse* and *misuse* of diagnostic and therapeutic technologies applied to the frail elderly. The costs borne by those individuals—physically, emotionally, and financially—seemed to some respondents disproportionate to the benefits accrued. Specifically, in the realm of diagnostic technology, it is believed that greater consideration might be given to the often-compromised state of the frail elderly. However, of greater concern than the occasionally questionable use of technology, is the compression of time allowed for hospitalization of the elderly under the hospital policies driven by the DRG legislation.

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#### APPENDIX

- A. OVERVIEW OF IOM FORUM: purpose, audience, participants
- B. Request to identify individuals as interviewee
- C. *CHARGE:* to speak to the issues related to providing appropriate inpatient care for the sick elderly
- D. QUESTIONS:
- 1. Definition of "elderly" (e.g., age versus physiological, psychological classification)
- 2. Proportion (%) of patients, on average, who are "elderly"
- 3. Philosophy of care: any differential because of age re:
- A. Access to technology
- B. Aggressiveness of diagnostic therapeutic uses of technology
- C. Termination of technology (life support systems, etc.)
- 4. Do you perceive the sick elderly patient to be "especially vulnerable to underuse, misuse, or overuse of modern technologies?
- 5. How might we make better use of support services for the elderly—home, community, and hospital?
- 6. What support and services are needed in acute care hospitals that do not exist now?
- 7. Might it be possible to adapt or restrain diagnostic and therapeutic technology or "routines" in the acute hospital to better account for physiological/psychological resources\* and limitations of the elderly?
- 8. Policy issues
- Research needs

<sup>\*</sup> Cardiac output, tissue perfusion, absorption—alterations in urinary elimination, in perceptions, physical mobility, cognition, vision, support systems, self-conceptual alterations through normative development that impact on structure and function to the human being's physiological processes.

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# **Special Perspectives on Acute Hospital Care**

Jack E. Christy

I want to share the patients' and families' perspectives on caring for the elderly patient in the acute care setting. In describing the concerns people have about the quality of medical care for elderly patients in the hospital, I shall address four things: the issues that drive families' interest in how to assure good quality medical care; examples of public and private actions that advance our understanding of quality in medicine; impediments that keep us from getting as far as we have to go as quickly as we want to move; and some suggestions for advancing quality in medical care.

#### FAMILIES' INTEREST IN QUALITY OF CARE ISSUES

It is no surprise to anyone that health care is a priority concern to older persons and their families. All of the changes in the Medicare program during this decade are causing Medicare patients to examine their basic assumptions about what quality means in the acute care setting.

The prospective payment system (PPS) gives hospitals strong incentives to limit both the length of stay and the intensity of care for their Medicare patients. As a result, PPS has wrought new anxieties among patients about access to care and the continuity of care. Medicare has implemented the new limits by reducing admissions, directing more patients to the outpatient setting, and discharging patients earlier in the hospital stay. Beneficiaries do not regard these events as evidence of poor quality per se, but the operational reality of PPS has dramatically highlighted how poor Medicare coverage is for needed post-acute care serv

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ices and how little is known about assessing acute care patients and monitoring their care from setting to setting.

Although one cannot predict the future, one can safely bet that health care prices will continue to go up. Rising health care costs and the weight of the huge federal deficit portend even tighter controls on Medicare expenditures. Yet more people are demanding more of the Medicare system, but the system is not keeping up. Thus, consumers faced with tightened health care resources and consequent cutbacks in care are questioning, and rightly so, just what it is they are buying for their health care dollars.

The answer to this question arises from the development and implementation of a quality of medical care assessment and assurance system that identifies quality of care problems in a timely way, implements appropriate corrective actions, monitors the effectiveness of those actions, and follows up as warranted. Such a system does not now exist, but it can be developed.

#### ACTIVITIES ADVANCING THE UNDERSTANDING OF QUALITY IN MEDICINE

The good news is that quality of care is on the national agenda. Forums and conferences are taking place all over the country. It began with the Senate Committee on Aging raising concerns about quality under PPS, and it has not stopped since. Physicians, hospitals, consumers, government, insurance companies, and employers are trying to understand quality in medicine. This is all to the good. The American Association of Retired Persons (AARP) is confident that the development of a quality monitoring and assurance system will lead to both better care and more efficient care.

To a large extent the picture of quality in medicine will be developed in numbers. Valid health care data are an essential prerequisite to understanding the quality of medical care. The interest in quality health care animated by PPS is nourishing a new era of quality assessment in the health sector. This new era of health care quality assurance seeks to identify poor quality performance and outcomes by focusing on statistically significant aberrant performances and outcomes.

The Health Care Financing Administration (HCFA) further opened the door to statistically based quality analysis when it published hospital-specific mortality data for hospitals with significantly aberrant records.

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Although legitimate questions could be raised about various aspects of the HCFA data disclosure, the data showed a strong correlation between the volume of procedures performed and outcomes. Thus, although flawed, the HCFA data helped to establish outlier review as a useful way to assess quality in medical care. The HCFA's 1987 mortality data disclosure is a great improvement over the 1986 data. The statistical methodology is strengthened and the affected hospitals have better opportunities to comment on the data. The 1987 figures represent an advance in getting data on quality out to the public. Similarly, HCFA's 1988 hospital mortality disclosure is an improvement over the 1987 figures. The presentation of two years of data, improved validation procedures, and the reduction of variation in the mortality rates continues the process of making the HCFA mortality data disclosures better.

A major step in understanding the outcomes of care is to understand the variations in the provision of care. Only after variations in medical practice are understood will the degree to which health care is clinically efficacious and appropriate in a given circumstance be understood and lead to the development of clear quality standards. HCFA's activity to document practice variation among states and study patient outcomes for selected diagnoses is an important step toward developing a basic quality assurance system.

There was much good news about quality in Medicare in the Omnibus Budget Reconciliation Acts of 1987. In addition to the practice variation study begun by HCFA, the 1986 Budget Act requires the Department of Health and Human Services (DHHS) to develop and implement discharge planning systems to be used by hospitals participating in Medicare. This is a requirement. If a hospital participates in Medicare, it must have a discharge planning system that meets the guidelines set by the Secretary of DHHS. As noted previously, a reliable discharge planning mechanism is crucial to assuring that patients discharged from hospitals receive appropriate follow-up care.

Any accounting of good news in advancing the cause of quality in Medicare would be incomplete without recognizing peer review organizations (PROs). PROs are government contractors and as such must implement federal policies. By their nature PROs reflect and represent the perspective of professionals and providers. At the same time, notwithstanding the pressures and dynamics of having that kind of perspective, Medicare beneficiaries look to PROs as the allies and advocates of the patient community if the quality of care that we hold dear is to survive.

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Despite problems, PROs are one of the bright spots in the advancement of understanding quality in medicine. Much has to be done, however, to make "peer review" a more effective player in the medical quality assurance scheme of the nation.

Even though national attention is focused on quality of care issues now, this is no guarantee that national attention will remain interested tomorrow. The jury is still out on the question of whether public pressure can be sustained long enough to implement a respectable quality assurance system.

#### IMPEDIMENTS TO QUALITY OF CARE

The bad news is that the United States is a long way from having the technical capability to assure high-quality medical care. The nation's ability to assure quality in medicine is directly related to its understanding of what a quality medical outcome is and to its ability to detect promptly and to correct unacceptable deviations from quality care. At the present time, however, the country lacks adequate information about medical outcomes and the quality monitoring system necessary to alert health care providers and policymakers to unacceptable care. It is startling that the word quality is not even mentioned in the Medicare statute, Title XVIII of the Social Security Act. Indeed, fiscal intermediaries and carriers—the administrators of the Medicare program—have no statutory function relating to quality of care for Medicare patients. Moreover, major gaps remain in our ability to account for differences in patient characteristics. The lack of a reliable and affordable severity of illness index limits the usefulness of outcome measures for evaluating quality in medical care.

Even though PROs are part of the good news, they are also part of the bad news. Although PROs are operating, they must continually concentrate their efforts on obtaining the funds that the government contracted to provide and on keeping their enforcement authority that is so crucial to their peer review responsibilities. As a result, much of the potential gain from PRO review is lost or wasted, instead of further developing the base of knowledge on quality in medical care. PRO opponents must be made to understand and to recognize the vital role that PROs will play in the development of our national health care system.

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#### ADVANCING THE CAUSE OF QUALITY OF CARE

The fight to establish a solid, quality assurance system remains, at this point, ours to win. Toward that end, we must continue to insist that determinations of quality be based on the entire episode of illness, not just on a particular setting of care. Developing the linkages from discharge planning to nursing home to home health care to the physician's office is very important to having a complete picture of an episode of illness. HCFA's efforts to link Medicare's Part A and B data must therefore proceed as a high-priority project.

A proper quality assurance system will require much greater coordination among the HCFA contractors administering Medicare. Intermediaries, carriers, and PROs must begin to collect and process basic data elements in a uniform way to assure comparability among providers. Standardizing quality of care measures and methodologies will give greater assurance to beneficiaries about the quality of their medical care and will lead to nationally representative information.

The information collected by such a quality assurance system should serve as the basis for a national epidemiologic data base of relevant, patient-level data on the overall quality of care to Medicare patients, regardless of the setting of care. Such a data base will be an invaluable tool for assessing the access of beneficiaries to the various levels of care, and it will lead to a greater understanding of the ways in which quality affects the health status and quality of life of beneficiaries.

The AARP believes that assessing the quality of health care services is possible. It can be accomplished by considering *population-based rates of utilization*, derived from small area analyses of the practice patterns of physicians, and *primary clinical data*, such as test results and findings from the patient's medical chart. These two elements can help determine the efficiency, the effectiveness, and the appropriateness of care, which is the quality of care being delivered. The combination of small area analysis and clinical effectiveness data provides an assessment of macro-and microlevels of performance. The challenge is to develop the indicators into a coherent system of quality assurance from setting to setting and to translate the data into information useful to health care consumers. The routine publication of information useful to consumers

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will assure that health care providers compete on the basis of quality and that the system dynamics help enforce high standards of care.

Finally, I want to relate a story about the quality of caring, an aspect of quality of care that is sometimes overlooked. It comes from Emily Friedman, a Chicago health writer, and is about a familiar type of patient described to Ms. Friedman by Dr. Paul Raskin as follows: A white female appears to be her reported age. She neither speaks nor comprehends the spoken word. She is disoriented about person, place, and time. She does, however, seem to sometimes recognize her own name. Dr. Raskin worked with her for 6 months, but she does not recognize him. Dr. Raskin pointed out that the patient was completely dependent and had to be fed, clothed, bathed, and changed. When Dr. Raskin asked a group of graduate nurses how they would feel about dealing with such a case, the graduate nurses responded with words such as "frustrated," "hopeless," "depressed," and "annoyed."

Dr. Raskin was describing his 6-month-old daughter. You may have envisioned an 86-year-old woman instead of a 6-month-old child. I think that the story highlights exactly what we mean when we talk about the quality of caring. As we struggle with the complexities of making the health care system more responsive to the needs of patients in the twenty-first century, let us be ever mindful that our humanity and compassion also characterize the quality of our care.

# **Special Perspectives on Acute Hospital Care**

Joseph W. Westbrook

The National Education Association, Retired (NEA-R) is an affiliated program of the National Education Association (NEA). Some 85,000 retired teachers and educational employees are members. All are a part of the 1.8-million-member national organization that functions under the leadership of President Mary Hatwood Futrell.

The major concern of the NEA-R, as well as the NEA, in the health care area is the provision of adequate and affordable health care for its members. Therefore, availability, cost, and quality of services are most important factors. Many of my observations and recommendations may seem simplistic, but they are based on what members tell me. They are worried, they are very concerned, and they want to feel more secure about their health care as they get older.

Many recipients and potential recipients of medical services are covered by some type of insurance or by Medicare or both, and therefore they do not or have not made direct payments for services. The average retired person looks at medical services as a right, not as something that is provided as a welfare handout.

The tendency has been to forget that the health care industry is a business. The profit motive is the force that drives the vehicle. The acute care hospital, whether profit or not-for-profit, concentrates on earning returns on their investments. Development, research, expansion, and technology are at least partly dependent on such returns. The escalating cost of medical care in an acute hospital setting is of great concern to all. Cost-containment measures seem to be one of the dominant forces in hospital management. Medicare reimbursement changes and the advent of diagnosis-related groups (DRGs) have also contributed to this movement.

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The impact of reimbursement by DRG guidelines on the sick and elderly is not clear. Some reports are negative and some are not. My understanding is that this system of reimbursement places a greater strain on hospitals because elderly patients in a DRG may be sicker and require more time and services than their younger counterparts. In addition, elderly patients are becoming the majority in many acute care hospitals. Some administrators report that more than 50 percent of their patients are over age 65 and a percentage of these are age 85 and older. To the patient and family, major research and emphasis needs to be placed on how to care for the sick elderly patient more effectively.

#### NEEDS OF SICK ELDERLY IN HOSPITALS

I am told that the elderly require more services and time than younger patients because they are usually sicker and are not able to perform many normal functions for themselves. They require more attention, supervision, and care by staff persons. In addition to the prescription and administration of drugs, the sick elderly often need more time with the professionals. Shall I say "tender, loving care?" Consultation, counseling, dealing with depression, management of pain, and drug use are time-consuming areas in which doctors' and practitioners' services are sorely needed, but often missing. It seems as if the present system of reimbursement contributes to the absence of these services. Professionals, health care administrators, practitioners, and others need to concentrate on developing a comprehensive, geriatric treatment system and a compensation model that will make participation in such a system attractive.

#### POST-HOSPITAL PROBLEMS OF THE SICK ELDERLY

In the post-hospital setting, many elderly persons are more afraid of living than of dying. The position of the NEA—that adequate and affordable health care be available to its members throughout their lifetime—becomes more acute during the retirement years. The cost increases for health care have been disproportionately greater than increases in income and other benefits. Many people believe that one extended hospital stay can reduce the average person or family to indigency. This is why the greatest problem and concern of many older persons is long-term care beyond the acute hospital phase.

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Data and feedback from NEA-R members verify this fear. When I say that the elderly are more afraid of living than of dying, I am referring to the uncertainty of what might happen to them after they leave the hospital.

- *Home care*. Many patients do not have any suitable place to go after discharge. Usually adequate home care is not available because family members are absent or incapable of providing care. The spouse may be too infirm, or no children or other active relatives are available. A more tragic situation involves hostility in the home, be it that of the patient, the spouse, the children, or other relatives. This breeds neglect and even cruelty or physical abuse. The patient is aware of these problems but is helpless to do anything about them. Hospitals generally are not prepared to deal with such situations.
- Psychological problems. Two major areas in the post-acute care setting
  are alcohol and drug abuse caused by depression, boredom, and
  loneliness. Pain, illness, or the feeling of sickness cause the overuse of
  drugs that usually have been prescribed by doctors because the patients
  complain about feeling sick or hurting.
- The need for nursing home care. The major trauma for the patient revolves around the emotional impact of being removed from the home setting and family, if there is one. It does not matter how poor or meager these resources may be. It marks the end of a way of life and, for many persons, an end of life.
- The quality of care provided by most nursing homes. Neglect, impersonal treatment, abusive, or hostile care are commonplace in many facilities. Even where state standards exist, few facilities meet them. Meeting Medicare and Medicaid guidelines does not ensure the presence of a desirable level of quality of care.
- The cost or economic impact. The financial effect on the patient, family, and estate makes the nursing home the least desirable and most traumatic of all of the alternatives. According to existing practices, one is reduced to indigency by a short stay in a nursing home. A person's lifetime accumulation is quickly consumed, and one is reduced to poverty in order to receive long-term nursing care.

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Victimization. Patients and families are too frequently victimized by red tape, regulations, misinformation, and the absence of complete information about the availability of services and how to obtain them. We have many examples of families that have had all kinds of problems trying to get a difficult or unbearable situation resolved. This might be one of the most widespread problems reported to us by our constituency.

#### NEA RECOMMENDATIONS

Because the NEA is an action-oriented organization, it is appropriate to close with some recommendations.

- 1. All acute care hospitals should have geriatric teams or geriatric evaluation units to plan and direct the complete and comprehensive care of the sick elderly patients.
- 2. All acute care hospitals should be required to have discharge planning teams. Their responsibilities would include working with the patient and family until adequate and suitable continuing care facilities are available and the patient has been placed therein. Follow-up services should ensure continued adequate care.
- 3. A system of not-for-profit nursing homes should be developed by state and local health agencies. Such facilities would be for persons who are able to pay nominal fees out of their retirement income. Once these facilities are established, they would be operated at minimal cost to the state or local agencies but would be quality controlled. A person would not have to become personally impoverished to gain admission.
- 4. Medicare and Social Security should assign health care information specialists to every office. It would be advertised that these persons are available to all families or persons who need information or services. Their jobs would be to inform, direct, and procure needed services for eligible persons who inquire, apply, or have been referred.
- 5. The health care community should universally support federal legislation covering long-term health care for the elderly.

In conclusion, the gap is wide between the "ought-ness" and the "is-ness" in health care for the sick elderly. The "ought-ness" has been thoroughly discussed; I have touched on some of the "is-nesses" in this paper. If the acute care hospital is to continue as the most viable link in

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the care and treatment of sick elderly patients, then it must bring the cost of its services back in line with what persons can pay. Alternative treatment centers, such as health maintenance organizations, preferred provider organizations, and the like, are not universally reliable or desirable and should not represent the wave of the future in universal health care.

# Acute Hospital Care of the Elderly: System Resources and Constraints

#### J. Alexander McMahon

I was asked to talk about system resources and constraints from the point of view of the hospital, but I found it somewhat difficult to do because I am not at all sure that my cohorts among the elderly do not need representation as well.

I would not hold myself out as especially qualified to speak, because I have been neither a provider nor a user of long-term care services. H. L. Mencken, the sage of Baltimore, was wont to say, "It is not what we don't know that hurts us; it is what we do know that is wrong." Nevertheless I am going to address myself to some aspects of the issue of caring for the sick elderly from the hospital perspective that bear touching on. We should anticipate what errors of commission and omission are going to be made so that they can be challenged, at least on the acute care side.

I tried to anticipate the way the conversations at this forum might go and I thought about the sick elderly patient. In the actuality of the discussions, however, I became quite confused. In the first session of this meeting we spent a good deal of time talking about some elderly people. I was not sure whether we were talking about *elderly patients* or, in the social work lexicon, *elderly clients*. We did not draw a very good line between medical care and social services care, and maybe this is an area for some research. If we do not make a distinction, we are going to get ourselves all messed up. We may mess up a very good sickness system, if we try to ask too much of it, but as I thought of the sick elderly, I recognized rather quickly that there are all kinds of sickness and all kinds of elderly. So, we must avoid stereotypes in this area, and I think that we need to disaggregate the group being discussed.

#### RESOURCES FOR ACUTE CARE

I am not sure about resources for long-term and community care, but there are plenty of resources in the acute care world—lots of money, lots of people, and lots of facilities. We spend a higher percentage of the gross national product than any other country in the world. Do we spend it wisely? Do we use the resources wisely? That is the issue, and it is not only a matter for the elderly.

The federal government says that we spend too much. So do other payers, particularly business. They are critical, I think appropriately, of what we are doing. The providers, as you have heard, often say that we spend too little. We could do such a much better job if we just had more money. The courts often say, "You didn't spend enough. Therefore, the plaintiff is entitled to a judgment." No wonder people are confused. Some of the confusion is brought on by people outside the hospital world, but we do add our contribution to the confusion.

#### POSSIBLE SOLUTIONS

The issue is multifaceted, and the solutions vary accordingly; there just is not one solution. To providers I would say that the resources could be used more wisely, with sharper attention to different uses of resources without changes in outcome, with more attention to care instead of to cure, and with more doctor time instead of more procedures. The providers have got to get away from the "we need more" approach. It "ain't" there. It is not there from government. It is not there from business. We are going to have to use what we have better.

With all of its faults (and some have been pointed out), people from other countries still seek our system out, and I say, "For heavens sake, don't mess it up for me when I need it." Every problem really does not have a solution; this has been suggested by a number of forum participants. It is another way of suggesting that we must avoid the errors of the military strategists who always prepare for the last war. To borrow again from Mencken: for every complex problem, there is a solution that is neat, simple, and wrong.

Now, to those ready to offer a quick solution, both on the provider side and on the health care system side, I offer some advice: don't just do something, stand there. The health care system and the environment itself are changing very rapidly—and, remember, a moving target is hard to hit. It has adequate resources, a surplus of physicians, and, it is said, a surplus

of hospital beds; patients have a choice. We are moving from shortage to "overage"; and competition in turn will motivate much better than government direction, and it will encourage more appropriate behavior.

#### **CONSTRAINTS**

I have suggested that the constraints are not financial, and I truly believe it. I think, instead, that there are six constraints. You can make your own list, but I have identified six. First is attitude. Caregivers must focus on how they can do better. A market-driven environment is going to sharpen that focus remarkably, rewarding those who do better and eliminating from the scene those who do not.

The second constraint is expectation. Patients and their families must become much more realistic. All medical problems cannot be cured. Insistence on more procedures and on a malpractice suit when something does not work out as well as someone might have hoped are two engines that drive costs up.

The third constraint is emotional. We see the tendency to blame someone, the view that "there ought to be a law," and the belief that for every problem there is a solution. "Tain't necessarily so."

A fourth constraint is ethical. How do we focus on what is right—when there are choices, and the patient and the family and the provider community, particularly the physicians, may differ on which choice they think is most appropriate? Our lack of attention to this issue poses, I suggest, a real constraint.

The fifth constraint is governmental in nature. Lawmakers should become a little more cautious. They cannot solve every problem, particularly with their strong tendency to overpromise and underfund. Business and the market are modifying the health care system today much more effectively than law and regulation, and the U.S. Congress and the governors of Florida and Massachusetts might pay close attention to that.

One might note that Medicare's emphasis on paying only for acute care services is part of our problem in the care of the sick and the elderly today. Think back 22 years to 1965–acute care was then the preferred solution. There was no objection to it, except by those who did not want any program at all, and acute care was what was needed. We did not have the life expectancy in 1965 that we have today; this is due not so much to the Medicare program itself as to other changes in life style. Nineteen eighty-seven is different, and we have some new solutions, and I suggest that 1997 is going to be different too.

Finally, there is a constraint imposed by some of the mathematical and statistical models that we are offered. Both mathematics and statistics are based on the past, and I tell you that the present is different. The studies that I have seen that were printed in the early part of 1987 or 1986 were often done on 1983 data, and the world is different. Diagnosis-related groups, business, modification of benefit packages, and what people are doing for themselves in the wellness area (better diets, not smoking, lower drinking habits) are changing things remarkably, so that earlier mathematical and statistical models are inadequate, misleading, and occasionally just dead wrong.

I suggest to you that the lessons that might be drawn from an analysis of these constraints, if I am right, are not the obvious ones—reduce costs, increase quality of care, improve access. They are complex; they are changing; they will be different tomorrow, and they suggest caution and not boldness.

#### POLICY ISSUES AND RESEARCH OPPORTUNITIES

I do not see a single issue and, therefore, see no single solution. We did, however, explore and come to agreement that attention to the non-health care needs of the non-sick or not-so-sick elderly—the long-term care issues—probably are the biggest issues that face us. We need to disaggregate, as I suggested at the outset, the sick elderly. Their solutions, their homes, their communities are as different as their conditions, and we need to understand that very thoroughly.

We need to track the resources in the private sector. I think I am right in saying that that is where a lot of very useful experimentation is taking place, and more quickly than through hidebound government agencies. It will not be not sexy, but we need to track those activities and evaluate them. We will see some solutions, and by publishing those different kinds of approaches, we will offer more help for local decisions, where I am sure many of our problems will be solved.

I think that we need to recognize the limits of research. When a piece of research is finished, it is likely that already the environment has changed, so let us be careful. Finally, we need to recognize the limits of some of the new policies proposed, when the present is not fully understood. I am amazed how often people who offer a solution for the future cannot describe adequately and accurately the present.

Once again, I suggest: don't just do something, stand there.

# Acute Hospital Care of the Elderly: System Resources and Constraints

#### L. Gregory Pawlson

I would like to discuss six issues relating to our attempts to understand, rationalize, and control the use of technology in the care of older persons in the United States. Three of them are observations or interpretations and three are suggested steps toward better management of the problem.

- In considering our older persons, it is impossible and undesirable to separate acute care use of technology from consideration of chronic illness.
- The issues of medical care technology use in older persons are not fundamentally different in most respects from that in our population in general. Specifically, remaining life expectancy rather than chronological age should be a criteria for consideration of technology use.
- The implications of our tendency to focus on health care solely as a
  means of prolonging the quantity of life rather than the quality of life
  and to apply all technologies of any possible benefit to all health care
  situations.
- The need for basic data concerning the efficacy and costeffectiveness of technologies, especially as they are applied to older persons.
- 5. The desirability of better regulation and assessment of technology, especially in the dissemination stage.
- The need for a reimbursement and financing system for health care that rewards effective and efficient use of health care of older persons.

Given our tight time constraints, I will only be able to highlight a few major aspects of each of these points. For those interested in a much more in-depth discussion, I would recommend three extensive studies by the Office of Technology Assessment (OTA) (1,2,3).

#### SEPARATION OF ACUTE AND CHRONIC ILLNESS

While it is necessary for purposes of a conference such as this one to group and categorize various discussions, there is the danger that those divisions will be interpreted as fixed. One of our major difficulties in understanding the benefits and limits of health technologies applied to older persons is our tendency to view one part of the system at a time. We use technologies in the acute care setting and assume—because the person leaves the hospital alive—that the application has been successful. Likewise, we attempt to constrain the system at one point, such as the imposition of the Medicare prospective payment system (PPS) for hospital care, and are surprised that costs and utilization increase more rapidly at another point (in Medicare's case, outpatient hospital use). While, as Garrison and Wilensky have noted (4), PPS has introduced some specific problems for the hospital sector in technology use, it is a clinical fact that older patients have few episodes of isolated acute illness that have no impact on resources outside the hospital. Most diseases, even cancer and heart disease, are chronic illnesses, especially given our increasing ability to change the natural course of disease. We are just beginning to recognize that we must focus on the course of illness, including acute exacerbations, functional abilities, and (as I will discuss in a moment) dying, if we are to learn the appropriate use of technology in our older population.

#### AGE VERSUS LIFE EXPECTANCY

There is an increasing frequency, especially in the lay press, to pose the questions as to whether the use of a given health technology by the elderly is appropriate or cost-effective. By so doing we are inferring that technology might or ought to be limited by chronological age. There is often the assumption that all persons over some age, usually 80 or 85, are all "sick" or very disabled. The fact is that the majority of persons who are 85 are living at home and have either no limitations or only one minor limitation in their activities. Further, a healthy 85-year-old may have more years of high-quality survival than a 50-year-old with severe

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chronic respiratory disease. Far more equitable and humane would be to consider the application of technology in relation to the severity of illness and disabilities, the likelihood of improvement, and the anticipated life expectancy. Only in the very extremes of life, at 100 or more, is age a reasonable proxy for life expectancy.

#### FOCUS ON LIFE EXTENSION AND FEAR OF DEATH

Those familiar with international health, even in developed western nations, are often struck by the preoccupation of persons in the United States with life prolongation and what seems to be our national death phobia. In addition, we seem to take the approach that all technologies of "possible" benefit must be applied in almost every situation. Because of these tendencies, and the demographic changes that we have experienced and will continue to experience at an even more accelerated pace, the cost of care for those over 65 will continue to grow rapidly. It is instructive to note that the major driving force in the increase of costs in Medicare expenditures is not population growth or price increases, but increased use and intensity of service in both inpatient and outpatient settings.

To illustrate the effect of our tendency to apply technology at shorter and shorter life expectancies and in situations of questionable efficacy, I would like to use an old trick question from junior-high math: What amount of time will it take you to reach a wall 10 feet away if you travel half the remaining distance to the wall every 5 seconds? The same answer—infinite—applies to the mathematics question as well as to the question of what is the marginal cost of technology applied to situations of ever lower efficacy or to persons with very short life expectancy. This implies that even if we are willing to limit technology by eliminating those interventions that are of zero or negative effectiveness, we still will pay relatively large amounts for infinitely small gains in health.

#### DATA FOR MAKING DECISIONS ABOUT TECHNOLOGY USE BY OLDER PERSONS

One of the more difficult aspects of geriatric medicine is the lack of information concerning the efficacy of the interventions we use with our patients. Many studies of technologies, be they drugs or devices, do not have a representative sample of the population that may be most likely to use the technology—namely the older person with multiple health

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problems. This adds to the data problems that we have with our health care system in general. For example, in most areas of health care, including Medicare, it is virtually impossible to trace even utilization of resources, much less outcomes, through the course of an illness. Susan Foote, in her analysis of key technology assessment issues (5), cites the lack of information about the efficacy and cost-effectiveness of medical technology as one of the key factors that limits our ability to rationalize health care technology. With both drug and device technologies, we have a reasonable knowledge of the safety of the entity, and in the case of drugs, even the initial efficacy. However, once the drug or device is initially approved, our ability to follow the subsequent diffusion, new applications, or long-term effects, either beneficial or harmful, is very limited or nonexistent. With most new procedures there may not even be scientifically valid information concerning their basic effectiveness before they become widely disseminated.

#### NEED FOR REGULATION OF TECHNOLOGY

I realize that for many, attempts to regulate technology are seen as leading to stifling of innovation and progress. Yet at some level the percentage of our gross national product (GNP) that is being spent on medical care will be unsustainable. Whether that level is 15 percent or even higher is not the issue. We simply cannot continue to apply medical technologies with little attention to their marginal effectiveness or cost-effectiveness. There would seem to be only three possibilities to controlling technology: to reduce expenditures on basic research and technology development; to control the diffusion of technology; or to allow rationing at the point of delivery. I believe that it would be unwise to in any way constrain basic biomedical research, largely because of its potential to create breakthroughs, like the polio vaccine, that are not only very effective but often replace high-cost technologies. Rather than de facto rationing based on the ability to pay (like the need for "up-front" payments for heart and liver transplants in some instances), I would propose that we more closely control the diffusion of technologies through both effectiveness analysis and reimbursement policy. One step would be to allow only those groups that are willing and able to supply careful follow-up data to use technologies after they have been determined to be safe but before we have accurate data on effectiveness and cost-effectiveness. In addition, there would be regular reviews of the use and effectiveness of a specific

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technology using longitudinal patient-specific data. This ongoing surveillance is necessary because of the tendency of many technologies to be applied in new areas of unproven benefit. A joint private sector and federal government agency with involvement but not control by health professionals might be the best vehicle for this activity.

#### REIMBURSEMENT AND FINANCING

Because of the complexity of this area, I will be of necessity very brief and more superficial than I would like to be. However, not to recognize the driving force of our reimbursement and financing system for health care on the use and abuse of technology with the older persons in this country would be unfortunate. No technology policy can be effective without close attention to reimbursement policy. We now make reimbursement decisions about the initial use of technologies based on what health care providers decide to charge and at a time when our knowledge about the technology is often rudimentary. There is no systematic review of the level of reimbursement or total expenditures on a technology in relation to its overall effectiveness. Furthermore, in our major publicly financed program, Medicare, we readily reimburse very generously for tertiary care technologies, and yet fail to provide adequate coverage for such proven preventative measures as influenza vaccine and screening PAP smears and breast examinations.

An element that underlies most of the problems that I have discussed is the conflict, almost unique in this country, between our love affair with private enterprise and our increasingly strong belief in health care as a right, one that should not be rationed on the basis of ability to pay. You simply cannot mandate that everyone should have access to medical care technology and expect the free enterprise system to function as the optimal way of distributing that technology. Until we are able to provide a better resolution of this basic issue, we will continue to use medical care technology in our entire population in a less efficient manner than is desirable.

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# Acute Hospital Care of the Elderly: Research and Policy Issues

Jerome Kowal

Cicero stated, "Old age, especially an honored old age, has such great authority that it is of more value than all the pleasures of youth." The average life expectancy at that time was 25 years of age. The old three score and ten biblical life span has really become four score and ten in terms of functional life span. The question for modern medicine is how to make those last 20 years functionally useful in the face of increasing cost of medical technology.

#### CAN WE DEVELOP NON-AGE-BASED OUTCOME CRITERIA FOR SELECTION OF PATIENTS WHO CAN BENEFIT FROM HIGH-TECH THERAPEUTIC INTERVENTION?

Age and economic circumstances may affect decisions for therapeutic interventions, without adequate regard for the underlying morbid condition and useful life expectancy of the individual. There is no question about the need for relatively simple highly technological intervention, such as lens implants for the management of severe sensory deficits. These benefits can never be objectively measured. At the other extreme, brain transplants would seem very impractical today, but they might provide the neurotransmitters to overcome early dementia or Parkinsonism in the not too distant future. Another issue is the determination of the cost-effectiveness and utility of the newer diagnostic technologies (e.g., magnetic resonance imaging [MRI], computerized tomography [CT], and positron emission tomography [PET] scanning) to reduce the potential morbidity of invasive procedures and shorten hospitalizations.

#### THE EFFICACY OF INTENSIVE CARE UNITS

The report of the National Institutes of Health (NIH) consensus development conference on intensive care medicine that took place in 1983 was not directed at the elderly, but some items were very pertinent to them. The conference addressed the empirical evidence that intensive care units (ICUs) caused a decrease in patient morbidity and mortality, and the kinds of patients most likely to benefit from intensive care. The consensus report recognized that the efficacy of ICUs had to take into account the nature of the patient population, the conditions and interventions being employed, and the alternative patient management systems to which comparisons can be made.

ICUs have gone beyond their original purpose of dealing with postoperative patients, monitoring airway maintenance, and mechanical ventilation for reversible neurological disorders. In recent years, the criteria for admission to ICUs have become less stringent. Patients are now being admitted for whom the achievable benefits are much less clear. However, the iatrogenic illnesses associated with ICU care, particularly in the elderly, may outweigh any potential benefit, as is true for some of the psychiatric effects it may have on elderly patients. In this case, less care may be better for some elderly patients.

ICUs are best suited for treating acute, reversible diseases in patients for whom the probability of survival without ICU intervention is low and the chance of a favorable outcome with ICU intervention is high. These patients need life support interventions for acute conditions. Patients with septic or cariogenic shock, however, have a lower potential for survival in an ICU. The ICU results, then, may be affected by patient selection. A third category is comprised of patients who are at risk of becoming critically ill. The ICU is there to intervene, and the outcome depends on the risk. For example, admitting a patient with myocardial infarction and ventricular extra beats to the ICU, as contrasted with somebody admitted only with chest pain and a suspected myocardial infarction, can greatly affect the apparent success rate of ICU treatment.

The question, then, is the allocation of ICU resources and disposition of patients with very low probability of survival. Age may become a factor in the selection process independent of potential outcome. One analogy that I present to students is the following: If there is one ICU bed left and you have two patients —a 50-year-old cirrhotic in shock and

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bleeding with a prognosis of 1 or 2 years, and an 85-year-old with chest pain and ectopic beats but who otherwise is well—who is likely to get that one last bed?

The most appropriate use of the ICU would be for those patients who have the best chance of a favorable outcome, regardless of age. ICUs, however, are not geared toward care of the elderly (e.g., patients may not be adequately mobilized or fed appropriately).

Another area of concern is the impact of ICUs on the hospitals. As more hospitals have pulmonary ICUs, cardiac ICUs, and gastrointestinal ICUs, less and less acute care is being rendered elsewhere. Patients are admitted to the general medicine wards, and the nurses are not equipped to handle problems that formerly were handled very well on such a service. If the ICUs become overloaded and patients spill over into the units, the nurses then must take care of the sick patients. The elderly patients who have special needs are neglected in favor of those patients who are creating the greatest stress among the personnel.

#### SPECIALIZED UNITS FOR CARE OF THE ELDERLY

The efficacy of specific interventions requires careful evaluation, but most ICU research has been directed at morbidity and mortality of specific diseases with very little emphasis on age. In contrast to that trend, in 1983 Dr. Louis Del Guercio and colleagues (1,2) established a special four-bed preoperative monitoring unit specifically for patients over 65 and others considered to be at high risk for chronic diseases. The patient is admitted directly to this preoperative monitoring unit the day before surgery.

Swan-Ganz catheters are routinely inserted and cardiac outputs, intravascular pressures, and arterial and mixed venous blood gases are measured and entered in a dedicated microcomputer for the recording of an automated physiologic profile. The patients are graded into four stages. Stage 1 is the normal range, and the patients may go directly to surgery. Stage 2 patients have mild functional deficits that could easily be corrected overnight with volume expansion to achieve optimum cardiovascular performance. Stage 3 consists of patients with compromised ventricular pulmonary or oxygen-transport function that requires correction by physiologic fine tuning. This might entail combinations of blood volume expansion, inotropic drug therapy, afterload reduction, diuretics,

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pulmonary therapy, and some part-time, total parenteral nutrition. Stage 4 includes those with functional deficits that are uncorrectable.

The papers published by Dr. Del Guercio and his colleagues report that monitoring in this manner reduced the mortality rate of the Stage 1,2, and 3 patients to zero. The research team found that about 53 percent of their patients fell into Stage 2 and 3 and could be corrected and be in the operating room within a day and one-half of these monitorings. In addition, the staff could identify physiologic problems much more accurately than could be estimated by the classic parameters used by anesthesiologists. By continuously monitoring patients during surgery, anesthesiologists were also able to measure the impact on the elderly patients' cardiovascular systems of simple procedures like transurethral prostatectomies. They found that this procedure can have profound effects on both the cardiovascular and sympathetic nervous systems. Although the hospital had to absorb the cost of these interventions, they were able to improve the situation for their patients very dramatically, especially among the Stage 2 and 3 patients.

Recognizing the problems that we have in intensive care units and on acute care wards in private hospitals (where we do not have geriatric evaluation units [GEUs] as in the Veterans Administration [VA]), the question arises, should we consider as a research protocol some type of acute care unit—a geriatric therapeutic unit—with monitoring capability and staff particularly attuned to the elderly patient (3)? These units would not necessarily have the full range of services of an ICU, but should be able to monitor and provide the kind of intensive nursing support specifically needed by geriatric patients. Can units dedicated to meet the needs of frail elderly patients reduce the iatrogenic decline which may be associated with acute tertiary care?

#### CONFUSIONAL STATES IN THE ELDERLY

An example of an important hospital complication that requires investigation is confusion. Although acute confusional states are associated with higher mortality, research into acute confusional states, particularly in the elderly, is virtually nonexistent and largely anecdotal in nature. The differences in clinical features between acute confusional states and dementia have been well delineated; both hypokinetic and hyperkinetic acute confusional states have been described. Most studies of acute confusional states deal with its prevalence and association with

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medical conditions, with the prevalence running as high as 50 percent in some studies. Unfortunately, the underlying medical causes are complicated by psychological and environmental factors that may be as important as the underlying physiological conditions.

How can we identify patients likely to need intervention? Predictors have included: age, mental status examination results, and pre-entry level of activity. Earlier studies hypothesized that acute confusional states develop as a result of a generalized cerebral insufficiency associated with electroencephalogram (EEG) slowing, but even the pathognomonic aspect of EEG slowing has been refuted in recent years. A variety of mechanisms involving oxidative metabolism, acetylcholine levels, and high levels of circulating steroids have been hypothesized, but much still remains to be learned.

#### DIAGNOSTIC-RELATED GROUPS

Diagnostic-related groups (DRGs) pose a potential problem for only about 15 to 20 percent of the elderly hospitalized population. The need for intensive care in the home often negates the savings of shortened hospitalization. A problem for hospitals is that, under the current payment system, they have little incentive to reduce post-hospital costs. But before condemning DRGs we need to determine whether the adverse effects of the short length of stays are counterbalanced by decreased iatrogenesis.

DRGs are prejudiced against excessive screening and preclude comprehensive assessments. The system does not allow much room for dealing with psychosocial consequences of hospitalization. Hospitals are not offered reimbursement to cover the costs of geriatric evaluation units. One possibility is to direct some DRG funds toward demonstration projects to determine whether certain classes of patients may be more effectively managed by an interdisciplinary approach, extending beyond the acute care unit. Perhaps DRGs could include the cost of allied health care personnel for early discharge planning.

Inui (5) and his colleagues discussed various research techniques for identifying hospital patients who need early discharge planning for special dispositions. They set three realistic objectives for a screening process: (1) maximizing the number of patients requiring special disposition, identification, and referral to social work service for evaluation; (2) minimizing the number of inappropriate referrals—patients not requiring

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special disposition toward social work service; and (3) minimizing ward nursing service efforts expended for screening and identification of patients.

Research methods are needed to identify the patient population that can gain the most from early discharge planning while avoiding unnecessary planning for patients who do not need it. We cannot plan discharges for everybody. If we did, we would risk staff burnout.

In 1983, I undertook a study of the Medicare discharges from University Hospitals of Cleveland, in anticipation of starting the DRG system. We examined the lengths of stay of all the patients as related to the overall DRGs. An interesting finding was that, on average, patients age 70 and over averaged less than one day more than the cumulative means of all DRGs per patient; these patients were discharged to their homes (5). Only 4 percent of patients were discharged to nursing home or rehabilitation centers, but they averaged 8 days longer. This 4 percent of the patient population accounted for 40 percent of all the excess days under the DRGs.

We found no age difference in terms of the overall length of stay. Age differences were evident only among the patients being discharged to nursing homes. For example, 2 percent of patients age 65 to 70 went to nursing homes; 16 percent of patients age 85 and over went to nursing homes. We examined about 100 charts to see if we could formulate some predictors. We did notice that among the patients who were going to nursing homes, medical care was completed well before their hospitalization was finished. These patients used a number of administrative days for arranging placement to the nursing home, social worker interaction with the patient, and getting things in order. There is a great need to predict, early in the hospitalization, which patients are going to be faced with this situation.

A repeat of the study using 1986 data, well into DRGs has shown similar results with a dramatic increase in nursing home referrals after a shorter length of stay.

#### CONSULTATION TEAMS

Many researchers have studied the efficacy of consultation teams. Campion at The Massachusetts General Hospital and various Canadian investigators have written extensively on this subject (6,7). From these studies, we can generalize that the efficacy of this activity seems to be in

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lowering the short-term readmission rate to the hospital and lowering the short-term mortality rate.

From my observations, the greatest benefit of consultation teams appears to be related to rehabilitation. Patients who were referred early for rehabilitation improved over time. Where no rehabilitation was factored in, consultation teams seemed to have no impact whatsoever. However, these differences disappear over time, so that by one year, most studies show virtually no differences in mortality and morbidity between the patients who had been exposed to consultation teams and those who were not.

These observations relate to a 3-year study by Hendrickson (4) in Denmark of interventions in patients' homes. The elderly population in a major suburb was divided in half; every elderly person in the target group had a social worker or nurse who visited once every 3 months to ask questions about how they were living; medical intervention was not part of the visit. The target group had 40 percent fewer hospitalizations during 3 years, had a higher survival rate, and actually fared better in the home situation. The cost of the intervention was more than offset by the reduction in hospital utilization.

#### GERIATRIC EVALUATION UNITS

Geriatric evaluation units (GEUs) are prevalent in the VA. Unfortunately, because of the length of stay required and the kind of support needed, they are impractical in the private sector at the present time. As indicated earlier, a more appropriate approach would be the establishment of demonstration "geriatric therapeutic units" where trained professionals study the potential efficacy of early intervention on outcomes of hospitalization.

We are well behind the British in this area and have much to learn from them.

Homer's Ulysses said to his father: "Warm beds, good food, soft sleep, and generous wine. These are the rights of age and should be thine." In summary (in caring for the elderly in the acute hospital), we are on the threshold of recognizing the need for innovative approaches that may deviate considerably from what we have come to recognize as established procedures.

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# Acute Hospital Care of the Elderly: Research and Policy Issues

Stephen R. McConnell

While I served on the Senate Special Committee on Aging, the committee contributed to raising the issue of quality of care to the national agenda. For a long time, the major issue in health care was cost containment; ultimately that will continue to be the chief concern, but at least quality of care has been given some attention.

Two critical health concerns in Congress are how do we contain costs and minimize jeopardy to quality of care and access, and how do we expand protection for acute and chronic care and not break the bank. These are very difficult issues, but I believe that we are making progress toward answering some of the questions. Many of the participants in this forum have contributed a great deal to that progress.

#### ISSUES DRIVING CONGRESSIONAL DECISIONS

Four issues are driving health care concerns in Congress:

- The growth in out-of-pocket expenditures for medical care by the elderly. Because the elderly are now paying more out-of-pocket expenses than they were before Medicare, much concern and debate are generated in Congress about how to keep those costs down.
- The reduction in average length of stay. Adjustments are required
  elsewhere in the health care system because of this, but very little is
  being done to deal with the fact that people are spending less time in the
  hospital and more time in other settings—settings that we have termed
  the "no care zone."

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- The shift from inpatient services to outpatient services. The costs of Medicare Part B are rising dramatically, partly because more services are being provided outside the hospital under Part B. Individuals are now paying, out-of-pocket, 60 percent of physician services because they are outside the prospective payment system (PPS) and, in many cases, outside any kind of monitoring system.
- The focus on cost containment has kept us from focusing on quality of care. Although quality of care is now on the national agenda, consumers are confused about many of the changes. Physicians and hospital administrators are also confused about how to deal with and translate the public policy changes.

# MAJOR HEALTH POLICY ISSUES AFFECTING THE ELDERLY

The impact of prospective payment on quality. Recent legislation has improved monitoring and patient's rights (such as appeal rights), peer review organization (PRO) monitoring, and discharge planning requirements and has prompted study of severity of illness. However, many concerns remain. We need to have a long-term commitment to demonstration project research, particularly in the area of determining quality of care. We need longitudinal studies of patient care to determine the functional status of patients at the time of discharge, and we need to monitor patients over a long period to find out whether early discharge actually ends up costing more than if the patients had stayed in the hospital longer.

We need to address the issue of meaningful outcome measures. We need better collection and use of PRO data—multiple data bases that go beyond the Medicare Part A data bases.

Finally, we need improved consumer and physician knowledge of the payment system. How do we correct misinformation? How do we better educate people about how the system works? With the new emphasis on capitated care, what are the implications of some of the incentives in the system to save money and the implications on quality of care?

*Physician payment.* The local-level debates tend to focus on whether Congress should mandate that physicians accept Medicare assignment. I have been an advocate on behalf of the elderly for a long time, and it is very difficult to say whether mandating assignment is good.

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But, you cannot ignore the many inequities built in to reimbursement, and those provide incentives. What message does this send to physicians? If we require physicians to accept assignment without addressing the inequities, then we simply pile problems on top of problems.

Because physicians control about 70 percent of the total health care spending, of which beneficiaries are paying 60 percent of the total physician charges, the payment issue becomes critical from the physician's point of view and from the consumer's point of view. How do we place controls on cost of Part B and on physicians without limiting innovation and access to care? There are relative value scales. There are many unanswered questions about how to implement and reward cognitive services, but the approach is very important and I hope that we continue along these lines.

Although it is a short-term step toward controlling costs, how do we reduce overpriced procedures? Which procedures are overpriced? What implications will controlling costs have on the quality of care? One argument that physicians make is that doctors do not charge their poor patients for the excess billing, and so if we mandate assignment, we are subsidizing the wealthier patients. Arguments on the other side are equally important. Finally, there is the question of medical practice variations: Is less better? We need to develop a consensus on styles of practice without limiting innovation.

Life-sustaining technology. The Office of Technology Assessment (OTA) released a good report recently on the issue of life-sustaining technology and the relevance of age. The OTA will meet again to decide whether some congressional public policy steps should be taken. One of the OTA study's more important findings was that age is a very poor predictor of outcome. We must continue research to find better indicators of functional status.

One of the first things I did when I came to Congress to work for Claude Pepper was to study the issue of retirement at age 60 among pilots. The Institute of Medicine and the National Institute on Aging were also involved in that study. The conclusion, after several years of work, was that age is a very bad predictor. No dramatic, precipitous drop in performance ability is demonstrated at age 60, but we could not come up with a better age. This dilemma reflects many of our public policy concerns. How do we make decisions about access to technology on criteria other than age? When the study was released the point was made that one does

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not know if a 75-year-old man who has heart problems, chronic arthritis, and a number of other ailments is in a nursing home or sitting on the Supreme Court.

Post-hospital care. I now spend a good deal of my time trying to get the issue of long-term care on the presidential agenda. We cannot start debating the fine points of these problems until we get the policymakers at least to acknowledge that something must be done. The focus now, however, on post-hospital care, particularly in the area of long-term care, has been more on quality of care than on access to care.

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# Care of the Elderly Patient: Summation of the Forum

David E. Rogers

This forum has helped me think more intensely about how we, as health professionals, can do a better job of taking care of our elderly people. During the first session (Home and Community Care of the Elderly) we looked at out-of-hospital care, home care, and community care. This made good sense, for most of our elderly who get medical care sleep in their own beds at night. In the second session (The Acute Care Hospital and the Elderly) we examined the very real problems associated with their care in the acute hospital setting.

Four major areas of concurrence emerged from our discussions on Home and Community Care of the Elderly.

First, it was noted that, for all kinds of historical and financial reasons, we had developed a system of medical care that fitted rather poorly with the medical needs of the elderly. Worrisome was the overuse of high technology in the diagnosis and treatment of the elderly, the overuse of the hospital as a setting for their care, and the virtual absence of any decent financing for long-term care.

Second, we agreed that we tended to ignore and/or underutilize all kinds of human support services that could be useful in improving the welfare and the comfort of the elderly. One of the participants said that "the territory of care of the elderly does not belong to the health professions alone." We should remember that and Dr. Avedis Donabedian's comment "that the aged are everyman."

Fundamentally, the elderly need the same kinds of care services that the rest of us do, except that they are often more delicate, more easily thrown into physiologic or emotional imbalance; more often for them,

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social support services need greater emphasis, while high-technology medical services do not.

Third, we all agreed with the statement that "form follows funding." The design of our public programs (Medicaid and Medicare) almost 25 years ago, as well as most forms of private health insurance, have tended to perpetuate a system of health care as we perceived it should be in the mid-1960s. It probably did not make great sense even in the 1960s. It is clearly ill suited to the needs of today, and considerable evidence was presented to show that it is not working well for us in the late 1980s. The present financing of our medical care system tends to overreward for hospitalization. It tends to overreward for use of high technology. It underrewards health professionals for using their heads and their hearts.

Fourth, it was agreed that new technologies permitted much more complicated care of patients outside the hospital than in days past, and physicians and other health professionals are trying rather desperately to gear up for, or adapt to, this change.

In the second session, we turned to the problems of the elderly in acute care hospitals and, again, certain new and powerful themes emerged. Dr. Jeremiah Barondess set the tone when he asked us to consider carefully when and how we should use the acute care hospital and its technologies for the care of the frail and sick elderly. He pointed out that answers to these two questions were of considerable importance because the elderly are hospitalized about six times more frequently then the rest of us. Further, he noted that in most of our hospitals the elderly constituted the majority of patients on all services except pediatrics or obstetrics. He gave us a yardstick by which to judge care for our elderly. He said, "Maximal appropriateness, maximal benefit, minimal risk, acceptable cost," but freely admitted that we lacked good methods by which to measure those parameters.

Both Dr. Barondess and Dr. Mitchell Rabkin graphically portrayed the special problems of the elderly that we often handle poorly in the hospital. They outlined the very special risks, both biologic and psychologic, that beset the hospitalized elderly: the hazards of organ failure, of adverse drug reactions, and of mentative changes that were too often induced or aggravated by hospital care. Dr. Rabkin called these in hospital events "the agony of the elderly," whom he labelled "fragile." They had fragile respiratory tracts, skins, minds; they had falls that broke bones; they had episodes of confusion; they had episodes of depression.

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In sum, they were delicate creatures with a brittle homeostasis that was easily disturbed. The hospital emerged as often a rather dangerous place for them.

Let me paraphrase another powerful statement made by Dr. Rabkin. He said: "As the hospital stay gets shorter and shorter, it is less and less satisfying for the patient, less and less satisfying for the physician, and neither of them reach a point of closure with which they are comfortable before the patient goes home." This too short period of contact with its absence of real bonding between physician and patient has escalated the problems and frustrations of both parties and has added to the litigious nature of patient and physician interactions.

There were two suggestions for change to improve our management of the elderly in hospital settings. Dr. Rabkin suggested that hospitals should be regarded as nursing institutions, not doctor institutions. He felt that we should introduce the concept of the primary nurse as the principal responsible, in hospital professional who had continuity and 24-hour responsibility for patients even though the primary nurse often delegated duties to others.

Other participants suggested that we should also think about a similar delegation of responsibilities to the nurse in the home care of the elderly. Clearly elevating the importance of the nurse's role in this manner might also improve the recruitment and the retention of nurses in both in hospital and out-of-hospital roles. Indeed, it might come to resemble more the British system than our own. There is no question about who is in charge of a ward in Britain. It is the head nurse. You do not even enter her ward without her permission, and her stature is significant.

Dr. William Hazzard made yet another suggestion for how we might improve our hospital care of the elderly—that we develop in-house geriatric teams. Here he described his own use of teams consisting of a physician, a nurse, and a social worker. This group crosscut departmental lines within the hospital and could assess and evaluate the care of elderly patients and make appropriate plans for them about medication, surgery, or other services. This deserves wider exploration.

Using her survey data, Dr. Carol Gray made a rather powerful argument for us to pay more attention to the issue of the quality of life. She outlined some of the ethical dilemmas of hospitalization of the elderly and also recommended that the nurse play a more central role in their care.

Mr. Jack Christy expressed major concerns about the quality of care in its totality as it pertained to the elderly and made a plea for

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developing better yardsticks by which to judge that care, using the whole episode of illness, and not just a fragment of the acute hospitalization or home care to make quality assessments.

Mr. Joseph Westbrook captured the intensity of the concerns of many of us with his statement that "many elderly people are more afraid of living than dying." He also outlined some of the reasons for that fear: the absence of "tender loving care" in the acute care setting; the expense—in which one hospitalization could bring a patient to indigence; the dreadful absence of any good financing for long-term care; and the humiliation that we put some people through before we pay for their long-term care. These were dreadful commentaries on what we now do or do not do for some of our elderly.

So we generally agreed that we do not do as well as we should with elderly patients in the acute-hospital care setting, despite the fact that they represent the majority of our hospitalized patients, and despite the fact that we have plenty of resources available for their acute care if we deploy them appropriately.

Dr. Stephen McConnell outlined a series of policy issues that surround problems of the care of the elderly, particularly for those in Congress or in other policy-making positions. He suggested that payment mechanisms affect the quality of care of the elderly. Although all of us agreed that this was probably significant, we need to have this documented more clearly. We also need more information on what might be done to slow the escalation of costs and fees now so worrisome to those who pay the bills. Although there has been general agreement that much of the care of the elderly should be moved out of the hospital, there have been worries about how we can determine the quality of that care. One of the positive features of in hospital care is that in this setting all of us who practice there live in a glass house. It is very easy to see who is practicing good medicine and who is not. How we are going to do that kind of monitoring of quality when much of the care is shifted into the privacy of the doctor's office remains a worrisome problem. Further, I have the uneasy feeling that any system of monitoring that we set up in this setting may be more expensive to carry out than the care itself.

To close, let me give you five major areas of agreement that I think emerged from the conference.

First, that we need a thoughtful, sensible, readily understandable integrated system of care that will permit the elderly to be cared for as much as possible out of hospital, but with close linkages among hospital, home, nursing home, and hospice settings.

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Second, that we develop a system that recognizes and integrates within that care the informal care given by families and significant others, and the critical importance of other support systems in their welfare.

Third, that we look more carefully at the quality of life that we can offer the elderly; our medical care should be focused on functional outcomes; we should strive to add "life to years, not years to life."

Fourth, that there is a crying need for more and better research in a number of areas. Dr. Barondess outlined several:

- Use of technologies, particularly big ticket technologies, and their place in the care of the elderly.
- Whether it does or does not make sense to develop intensive care units for the care of the elderly.
- Problems of acute confusional states so common in the elderly in our hospitals.
- Better predictors of how elderly patients would fare with particular disease problems in particular settings.
- The value of hospital-based consultation teams rather like those described by Dr. Hazzard in improving the prognosis of older folks.

Fifth and last, we all agreed that absolutely fundamental, and particularly urgent, was the need to recast the financing of health care of the elderly, both public and private, to encourage imaginative and restrained and discriminating use of technologies, the fuller use of other kinds of support systems outside the hospital for the elderly, and for more and better long-term care. Clearly it is our collective hope that dollars will follow the services that we feel important, rather than dollars dictating where and what care is to be given. Our elderly deserve more from our U.S. system of health care than they now receive.

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