

# CHRONIC DISEASE MANAGEMENT

Geriatrics can be thought of as the intersection of gerontology and chronic disease management. At a time when medical care in general is awakening to the importance of good chronic disease care, geriatrics has been at it for years. Many of the principles of geriatrics are basically those of good chronic care. The basic tenets of good chronic care are summarized in [Table 4-1](#).

Professional roles need to be reexamined to look for opportunities to delegate to less expensive personnel many tasks formerly performed by more trained professionals. For example, nurse practitioners have been shown capable of providing a good deal of primary care that was formerly the exclusive purview of physicians (Horrocks, Anderson, and Salisbury, 2002; Munding et al., 2000).

Expectations must be recalibrated. The familiar dichotomy of care versus cure must be expanded to recognize the role of disease management. Because the natural course of chronic illness is deterioration, successful care must be defined as doing better than would be expected otherwise. This phenomenon is illustrated in [Fig. 4-1](#). The bold line represents the effects of good care. The dotted line represents the effects of the absence of such care. Both lines show decline over time. The difference between them represents the effects of good care. Most of the time this contrast is invisible. All that is seen is decline despite the best efforts. Improving care will require developing information systems that can contrast actual and expected clinical courses.

Appreciating this contrast is critical to both policy and morale. The importance of measuring success by comparing the actual clinical course to a generated expected course is central to concepts of quality in chronic disease. It is also important in maintaining the morale of workers in this field. People who see only decline despite their best efforts become discouraged (Lerner and Simmons, 1966). They need to appreciate the value of their care if they are to continue to give it in the face of so much frailty and disability. Slowing the rate of decline must be seen as positive achievement.

Likewise policy makers, and indeed the general public, are unlikely to support needed efforts to improve chronic care if they do not believe that such care

TABLE 4-1 CHRONIC CARE TENETS

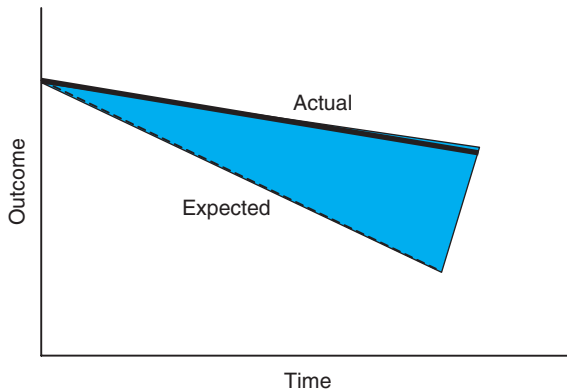
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Aggressive primary care
Proactive monitoring
Early intervention to avoid catastrophes
Patient-centeredness, meaningful patient involvement in the care process
Use of information technology
Teamwork, delegation
Use of time
Assessing benefit in terms of slowing decline

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can make a difference. They must be educated to appreciate these differences and they must be given the information to demonstrate these differences.

Chronic care requires better data systems. Information technology is probably the most important technological breakthrough for chronic care. Structured protocols, based on strong empirical data, become the basis for planning, monitoring, and



— FIGURE 4-1 — A conceptual model of the difference between expected and actual care. The heavier line represents what is usually observed in clinical chronic care. Despite good care, the patient’s course deteriorates. The true benefit, represented by the area between the dark line and the dotted line, is invisible unless some means is found to display the expected course in the absence of good care. Such data could be developed on the basis of clinical prognosis or it could be derived from accumulated data once such a system is in place.

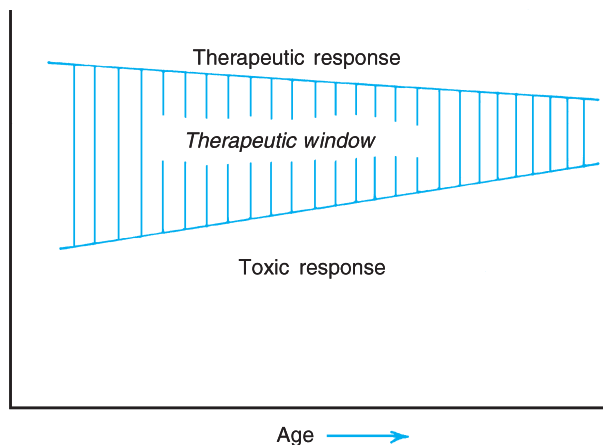
implementing care. These protocols need not always be clinical guidelines, which should be based on strong scientific evidence.

Structuring data helps to focus the clinician's attention on what is most relevant. The goal of a good information system should be to present clinicians with pertinent information at the right time in the form that will capture their attention. Identifying what is salient at the moment is critical, especially in view of the brief contact times allowed. Too much information can be as dysfunctional as too little, because the pertinent facts get lost in a sea of data.

Elderly patients are in danger of being dismissed as hopeless or not worth the effort on the basis of their age. Physicians faced with the question of how much time and resources to spend in searching for a diagnosis will want to consider the probability of benefit for the investment. In some cases, older patients are better investments than younger ones. This apparent paradox occurs in the case of some preventive strategies when the high risk of susceptibility and the discounted benefits of future health favor older persons. But it also arises in situations where small increments of change can yield dramatic differences.

Perhaps the most striking example of the latter is found in the case of nursing home patients. Ironically, very modest changes in their routine, such as introducing a pet, giving them a plant to tend, or increasing their sense of control over their environment, can produce dramatic improvements in mood and morale.

At the same time, the risk-benefit ratio is different with older patients. Treatments that might be easily tolerated in younger patients may pose a much greater risk of producing harmful effects in older patients. As shown in [Fig. 4-2](#),



— FIGURE 4-2 — Narrowing of the therapeutic window.

This diagram portrays in a conceptual manner how the space between a therapeutic dose and a toxic dose narrows with age.

the therapeutic window that separates benefit from harm is narrower. In effect, the dosage that will produce a positive effect more closely approaches one that can lead to a toxic effect. As noted earlier, one of the hallmarks of aging is a loss of responsiveness to stress. In this context, treatment may be viewed as a stress.

Those who treat older patients must also consider the theory of competitive risks. Because older persons often suffer from multiple problems, treating one problem may provide an opportunity for more adverse effects from another. In essence, eliminating one cause of death increases the likelihood of death from other causes.

A useful tool for creating a more proactive and focused attitude among those who care for older persons is the flowchart. Focusing on a few clinical parameters that are both significant and most likely to be affected by treatment helps the clinicians focus their attention and recognize changes early. Because the changes are likely to be subtle, it is often helpful to establish treatment goals with time frames for achieving them. Both the health-care team and the patient can then agree on expectations and follow progress toward the goal.

The goals should be achievable. Small successes are very important and reinforcing. Thus the units of measurement should be capable of detecting small but meaningful changes. In many instances, small gains can, in fact, make an enormous difference. The stroke patient, for example, who regains the use of hand muscles has a greatly improved ability to function. Being able to change position in bed may mean the difference between getting pressure sores and not. Regaining a method of communication, whether by speech or some other means, can restore social contact.

By introducing gradual, small steps, a functional task may appear more achievable. We have all had some experience in getting a bedridden patient to resume a more active role. For an older person who has been on bed rest for a long period, this task requires overcoming both physiological and psychological problems. Small steps will often ease the transition and provide an opportunity to monitor the effects at each stage to minimize risk.

## SPECIFIC AREAS OF GERIATRIC DISEASE MANAGEMENT

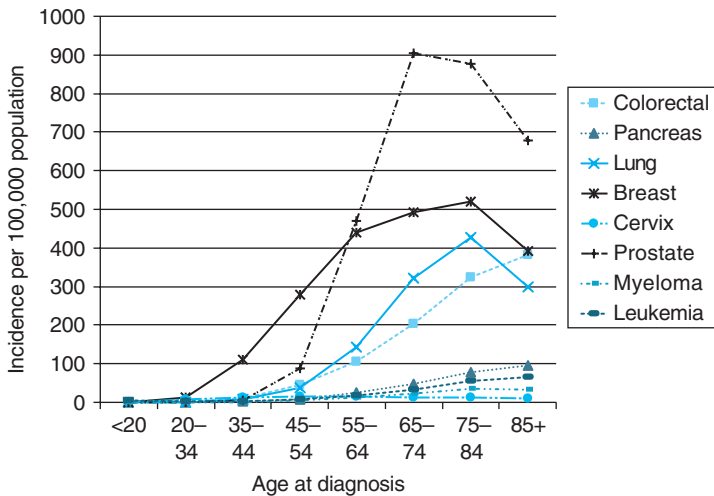
### Cancer Care

Cancer is a frequent event in older persons. Its diagnosis and treatment poses special challenges. Physicians may become less enthusiastic about screening from cancer in elderly patients because they anticipate that these patients already have limited life expectancy and hence are unlikely to benefit from aggressive detection and treatment. These attitudes need careful reconsideration. Some cancers, like breast cancer, may indeed have a more indolent course in elderly patients. Some elderly

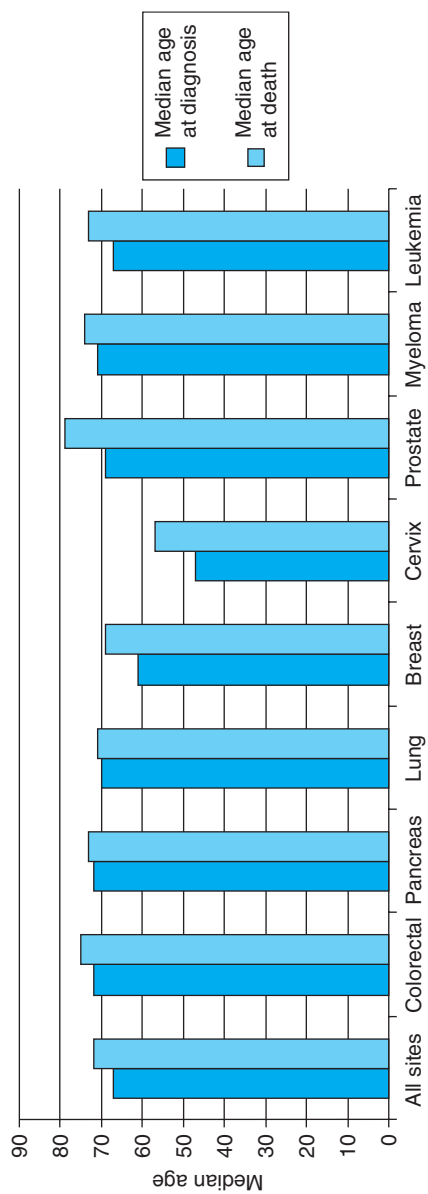
patients may not be able to stand the stress imposed by aggressive cancer treatment; the therapeutic window concept discussed earlier in this chapter applies strongly here.

Nonetheless, cancer represents a substantial risk for older patients and should be approached carefully and deliberately. Figure 4-3 shows that many cancers have their peak incidence in old age. As seen in Fig. 4-4, older people do not survive long with cancer. Indeed, cancer is an important cause of death; about 50% of persons 85+ (75% of 75-84, 90% of 65-74) survive 5 years if they don't die from cancer. For older people, the effects of cancer on death are seen in the first 30 months. Age matters; cancer effects are greater for the oldest patients. Some cancers are more important in older people than is commonly believed. For example, cervical cancer is deadly in older people. Breast cancer affects the age group 85+ harder than those younger. Leukemia hits the elderly hardest. Therefore, physicians should consider active treatment option in older patients and weigh the risk-benefit ratio carefully and individually.

Older cancer patients deserve special consideration. Table 4-2 outlines some specific issues related to age in connection with treating selected cancers. Overall, cancer treatment in older patients requires individualized consideration based on risk–benefit analysis and a careful consideration of the older person's preferences (Downey, Livingston, and Stopeck, 2007).



— FIGURE 4-3 — Age-specific incidence of selected cancers.



— FIGURE 4-4 — Mean age of diagnosis and death for selected cancers.

TABLE 4-2 CANCER TREATMENT ISSUES RELATED TO AGE

DISEASE	AGE-RELATED CHANGES	UNRESOLVED ISSUES
AML	<ul style="list-style-type: none"> <li>• Decreased sensitivity to chemotherapy secondary to increased prevalence of <i>MDR1</i></li> <li>• Unfavorable cytogenetic profiles</li> </ul>	<ul style="list-style-type: none"> <li>• Reversal of <i>MDR1</i></li> <li>• Role of low-dose cytarabine</li> <li>• Supportive care</li> </ul>
Non-Hodgkin lymphoma, large cells	<ul style="list-style-type: none"> <li>• Decreased duration of complete response, possibly secondary to increased circulating levels of interleukin-6</li> </ul>	<ul style="list-style-type: none"> <li>• Use of chemotherapy in higher doses</li> <li>• Biological treatment</li> <li>• Alternative regimens</li> </ul>
Breast cancer	<ul style="list-style-type: none"> <li>• More indolent course, secondary to higher prevalence of a well-differentiated hormone-receptor rich, slowly proliferating tumor(s) and to a hormonal and immunologic milieu that is unfavorable to tumor(s)</li> </ul>	<ul style="list-style-type: none"> <li>• Value of radiotherapy after lumpectomy</li> <li>• Primary hormonal treatment</li> <li>• Value of adjuvant chemotherapy</li> <li>• Value of lymph node dissection</li> <li>• Use of epirubicin or liposomal doxorubicin in lieu of doxorubicin</li> </ul>
Colorectal cancer	<ul style="list-style-type: none"> <li>• Decreased tolerance of fluorinated pyrimidines</li> </ul>	<ul style="list-style-type: none"> <li>• Alternative forms of adjuvant therapy</li> </ul>
Lung cancer (non-small cell)	<ul style="list-style-type: none"> <li>• Reduced tolerance of combined-modality treatment in stage III</li> </ul>	<ul style="list-style-type: none"> <li>• Alternative approaches</li> </ul>
Ovarian cancer	<ul style="list-style-type: none"> <li>• Decreased response to cytotoxic chemotherapy</li> </ul>	<ul style="list-style-type: none"> <li>• Alternative forms of treatment</li> </ul>

AML, acute myelogenous leukemia; *MDR1*, multiple drug resistance gene. Reproduced with permission from the NCCN v.2.2007 Senior Adult Oncology Guideline Clinical Practice Guidelines in Oncology. Copyright © National Comprehensive Cancer Network, 2007. Available at <http://www.nccn.org>. Accessed November 7, 2007. To view the most recent and complete version of the guideline, go to <http://www.nccn.org>.

## ■ End-of-Life Care

The physician's concern with the patient's functioning continues throughout the course of the chronic disease. Elderly patients will die. In many cases, death is not a reflection of medical failure. The approach to the dying patient will often raise difficult dilemmas. No simple answers suffice. Perhaps the best advice is not to take on the whole burden. Too often the dying patient is treated as an object. Ignored and isolated, the patient may be discussed in the third person.

Physicians must come to terms with death if they are to treat elderly patients. Often the patients are more comfortable with the subject than are their physicians. Fleeing from the dying patient is inexcusable. Dying patients need their doctors. At a very basic level, everything should be done to keep the patient as comfortable as possible. One simple step is to identify the pattern of discomforting symptoms and arrange the dosage schedule of palliatives to prevent rather than respond to the symptoms.

Patients need an opportunity to talk about their death. Not everyone will take advantage of that chance, but a surprising number will respond to a genuine offer made without time pressure. Such discussions are not conducted on the run. Often several invitations accompanied by appropriate behavior (eg, sitting down at the bedside) are necessary.

Some physicians are unable to confront this aspect of practice. For them, the challenge is to recognize their own behavior and get appropriate help. Such help is available at various levels: help for the physician and for the patient. Groups and therapy are readily available to assist doctors to deal with their feelings. Patients of doctors who fear death need the help of other caregivers. Often other professionals (nurses, social workers) who are working with these patients already can play the lead role in helping them work through their feelings. But the active intervention of another caregiver is not justification to ignore the patient.

The rise of the hospice movement has created a growing cadre of persons and settings to help with the dying patient. The lessons coming from this experience suggest that much can be done to facilitate this stage of life, although the formal studies done to evaluate hospice care do not show dramatic benefits.

Patients should be encouraged to be as active as possible and as interactive as they wish. Even more than in other aspects of care, the unique condition of the dying patient necessitates that the physician be prepared to listen carefully to the patient and to share in decision making about how and when to do things.

Medical care has evolved in such a way that special exemptions are made for the period at the end of life. Hospice care was created to reverse the overuse of technology and denial of dying (see Chap. 15). It can be viewed as both a success and a failure. On the one hand, it is still probably used too little and too late, only after more drastic measures have been tried. At the same time, it has led to serious reconsideration of how medicine handles the process of dying. It has spawned the concept of palliative care, an idea that many aspects of support and comfort can be applied



coincident with active treatment (Morrison, 2004). It has forced a reassessment of how pain is managed, with more attention to proactive treatment in adequate doses.

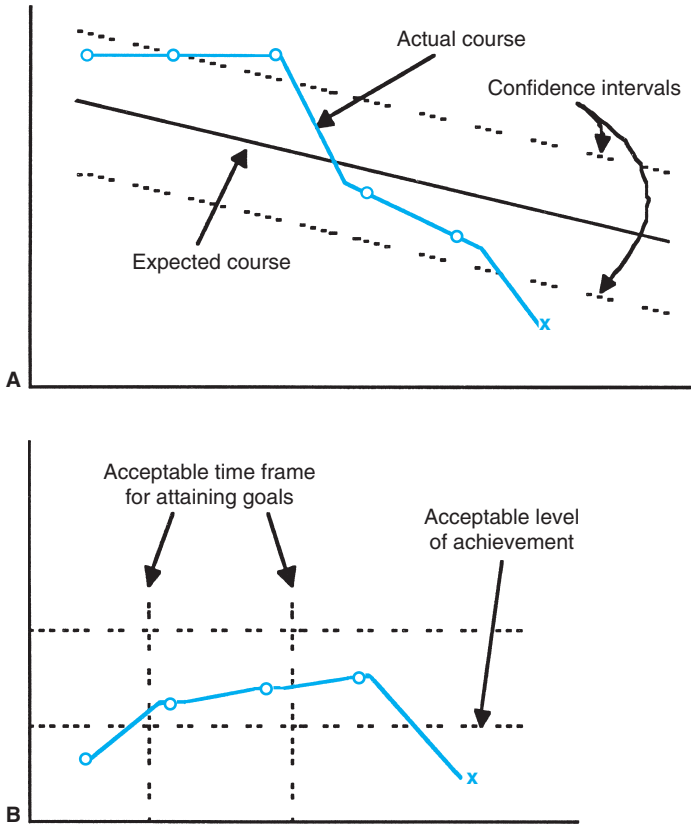
## SPECIAL ISSUES IN CHRONIC DISEASE MANAGEMENT

### Clinical Glide Paths

Providing effective chronic care relies on a longitudinally oriented information system that is sensitive to change. Each clinical encounter with a chronically ill patient is essentially a part of a continuing episode of care; it has a history and a future. Caring for a chronically ill patient, especially one with multiple problems, demands an enormous feat of memory as the patient's list of problems is unearthed and the history, treatments, and expectations associated with each are reviewed. Clinicians caring for such patients (often under enormous time pressures) may find themselves either overwhelmed with large volumes of data from which they must quickly extract the most salient facts or, alternatively, relying on inadequate data from which to reconstruct the patient's clinical course. Moreover, because patients live with their disease 24 hours a day, 7 days a week, they are best positioned to make regular observations about its progress. Such patient-constructive involvement responds to another principle of chronic care. These goals can be achieved using a simple information system that can focus the clinician's attention on salient parameters.

One approach to organizing clinical information and actively involving patients in their own care is the clinical glide path. The underlying concept is based on landing an airplane. Basically, the goal is to keep the patient within the expected trajectory to avoid the need for dramatic midcourse corrections. An expected clinical course (with provision for confidence intervals) is created. Ideally this clinical trajectory would be derived from a large statistical database that shows how similar patients have done previously. However, in the absence of such a database, the expected clinical path can be based on the clinician's experience and intuition. A separate glide path is used for each chronic problem. For each condition, the clinician selects one (or at the most two) clinical parameters to track. Ideally these should reflect how the problem manifests in that patient. The parameter can be a sign or a symptom, or even a laboratory value. The data on this parameter are collected regularly, several times a week or even daily. In most cases, the patients can provide the information, having been taught to make careful, consistent observations. These are recorded on the equivalent of flow sheets, which can be entered into a computer program that produces a graphic display. The key to this monitoring is the early warning. Observations falling outside the confidence intervals prompt strong exception messages. Any pattern of deviation is the cue for action and early intervention to assess the patient's condition and to

take appropriate action. These cases should be seen quickly and with enough time to evaluate the reasons for the changes in status. Figure 4-5 shows a hypothetical example of such a clinical glide path. The patient's progress (marked with diamonds) is within the confidence interval (which indicates a path of gradual



— FIGURE 4-5 — Clinical glide path models. In this model (A), the expected course (solid line) calls for gradual decline. The confidence intervals are shown as dotted lines. Actual measures that are within or better than the glide path are shown as o. When the patient's course is worse than expected, the o changes to an x. The design shown uses confidence intervals with upper and lower bounds, but actually only the lower bound is pertinent. Any performance above the upper confidence interval boundary is very acceptable. The design of the glide path can also take another form, (B). It may be preferable to think in terms of reaching a threshold level within a given time window (eg, in recuperating from an illness) and then maintaining that level.

decline) until the last observation (noted with a star), which falls outside the confidence interval and hence should trigger a warning.

Patients (or their caregivers) can be trained to make systematic observations about salient clinical parameters and to report meaningful changes (determined by established protocols) to their clinicians. Even better, they can enter such observations into a simple computerized data system that has been programmed to notify clinicians when the patterns exceed predetermined algorithms. Routine data are not actionable, only meaningful changes.

The clinician's task is then to evaluate the meaning of such a change. The patient should be seen quickly (either by a physician or another clinician) to have the findings analyzed. The basic approach addresses three questions:

Is the data accurate? Has there been a real change?

Has the patient adhered to his/her prescribed regimen?

Has there been an intervening event (eg, infection, change in diet)?

If the answers to all three questions are negative, then a full assessment is warranted to determine the reason for the deviation.

The glide path approach meets several needs for chronic care. (1) It helps to focus physicians' attention on salient parameters. It provides an indication of early problems in time to make midcourse corrections. (2) It provides a means to involve patients more actively in their care. They learn about what is important and assume greater responsibility. (3) It is a basis for reapportioning time and effort to focus attention where an intervention is likely to produce a greater impact.

It is important to distinguish the clinical glide path approach from clinical pathways. The latter specify an expected course with specific milestones and dictates what care should be provided at specific junctures. This approach works well in very predictable situations such as postoperative recovery and even some instances of rehabilitation, but most of chronic care management is not as predictable. The glide path method specifies what data should be collected, not what actions should be taken. Its underlying premise holds that when clinicians can be aided in focusing their attention on a patient's salient parameters, they will be able to manage the chronic problems better.

Nursing home care has never attracted a great deal of physician enthusiasm, but this need not continue to be the case. If we can implement a new form of record keeping that provides better information to staff and demands better performance from them, we would see an improvement in morale and hence a more attractive atmosphere in which to practice.

## ■ Targeting and Tracking

Case management has received a lot of attention, although its efficacy has yet to be established. One of the problems in assessing the benefits of case management

has been the multiple ways the term has been used. (For a discussion of case management, see Chap. 15.)

Focusing attention on the management of specific problems has become a consistent theme in the effort to improve the management of chronic illness. Disease management is most commonly used by health plans, which use the available administrative data from encounters, drug records, and laboratory tests to identify all enrollees with a given condition. Protocols can then be applied to look for errors of both omission and commission. In some cases, potential complications can be flagged and checks built in to try to avoid untoward events such as drug interactions.

A more active approach to disease management uses case managers for patients who are determined to need special attention, either because they have a diagnosis that suggests high risk of subsequent use or their history indicates problems in controlling their disease(s). These case managers work with the patients to be sure that they understand their regimens. They encourage the patients to raise any questions early. They telephonically monitor the course of the illness using parameters like those described above. They may make home visits to ascertain how the patients are doing and to ensure that they can function effectively in their natural habitats. The positive reports from trials of this approach have encouraged many replications.

Another variation on disease management being practiced in a few managed care organizations is group care. Here patients with a given disease (sometimes a more heterogeneous cluster of patients is assembled) are brought together for periodic sessions that include health education and group support, as well as individual clinical attention. It has proven more efficient to use groups in this way. The same sessions can draw upon specialists to see problematic cases more efficiently.

Particularly in the context of managed care, there is a strong incentive to try to identify high-risk patients in order to attend to them before they develop into high-cost cases. Various predictive models have been developed to identify such cases. One widely used model is the probability of repeat admissions (Pra). (See Chap. 3.)

This tool uses an eight-item questionnaire to flag older patients who are most likely to have two or more hospital admissions in the next several years (Boult et al., 1993; Pacala, Boult, and Boult, 1995). A modification of this method has been developed to use administrative databases as well. A similar approach is being developed to identify those at high risk for needing long-term care. Once these patients have been targeted, an intervention is needed to change the predicted course. The Pra model does not specify what actions should be taken; it was initially developed as a method for identifying those in need of a comprehensive geriatric examination.

Other efforts have sought to target high-risk groups. An analysis of the Medicare Current Beneficiary Survey identified a model that could identify older persons at risk of death or functional decline (Saliba et al., 2001). Another index can identify older adults who have an increased risk of death 1 year after hospitalization (Walter et al., 2001).

Interventions have also been developed to address those at highest risk. A meta-analysis of geriatric assessment declared it a substantial boon to care, because it was associated with reduced mortality and improved function (Stuck et al., 1993). Another meta-analysis suggests that home visits to basically well older persons can prevent nursing home admissions and functional decline (Stuck et al., 2002).

Function has proven to be an important predictive risk factor for both subsequent use of expensive services and or outcomes in general. Poor functional status in hospital patients predicts later mortality over and above the effects of burden-of-illness measures.

### ■ Minimum Data Set for Nursing Homes

The field of postacute care has evolved into at least three separate silos: inpatient rehabilitation, skilled nursing facilities, and home health care. Each has developed its own set of measures, which have subsequently been used for prospective payment. Nursing homes use the minimum data set (MDS). Rehabilitation uses a variant of the function improvement measure (FIM). Home health uses the outcome and assessment information set (OASIS). This inefficient parallelism has precluded good comparisons of the relative effectiveness of these different approaches. A new universal assessment tool for postacute care, CARE, is being tested.

The Omnibus Budget Reconciliation Act of 1987 (OBRA 1987) produced many changes in the way nursing homes were regulated. Perhaps none was as influential as the requirement that all nursing home residents covered by federal funds be assessed regularly using a standardized form, the MDS, for nursing home resident assessment and care screening. This information is designed to be completed by a nurse, but it draws on data from a number of disciplines.

The MDS summarizes a number of facets about each resident, including functional levels, cognitive and behavioral problems, special care needs, skin condition, nutritional status, and psychosocial well-being (the last not very well).

In addition to serving as a basic data set, problems identified trigger more detailed required documentation, called resident assessment protocols (RAPs), in 18 areas. [Table 4-3](#) lists the RAPs.

The MDS is intended to provide a basis for developing better plans of care and for assessing the changes in functional levels over time. It can also prove a useful tool for physicians. It is a compact source of information about various aspects of each nursing home resident. If the pertinent parameters for goals determined to be achieved in the care plan were systematically charted in a flow sheet, it would be possible to see progress at a glance or to recognize the need for a change in the plan of care. Physicians can play a key role in helping nursing home staff to see how such information can be used to improve care, not just to meet external mandates for better documentation.

TABLE 4-3 RESIDENT ASSESSMENT PROTOCOL (RAP) TOPICS

Delirium	Cognitive loss/Dementia
Visual function	Communication
ADL functional/Rehabilitation potential	Urinary incontinence
Psychosocial well-being	Mood state
Behavior problem	Activities
Falls	Nutritional status
Feeding tubes	Dehydration/Fluid maintenance
Dental care	Pressure ulcers
Psychotropic drug use	Physical restraints

ADL, activity of daily living.

However, several important shortcomings of the MDS must be acknowledged. The MDS was designed to be a means of recording judgments. These judgments inevitably pass through several hands. The persons with the most direct opportunity to observe behavior are the nurses' aides, who then communicate their observations to the nurses completing the forms. The overall reliance on observations means that, in effect, all nursing home residents are being assessed as though they were cognitively impaired. This limitation is especially severe, because the MDS purports to measure critical elements of quality of life. Assuming that one can truly infer another person's emotional state, the degree to which they are engaged in meaningful activities or whether they have real social relationships seems like an act of hubris. Even using observations to determine a person's cognitive capacity seems to require heroic assumptions. It may be possible to detect extremes of behavior, but no one would want to argue that such an approach is the best way to assess many of these critical domains. Nonetheless, the MDS does not use specific questions put to those patients who can respond. Work is currently underway to test methods to assess quality of life among nursing home residents. Many, including those who are cognitively impaired can be interviewed directly. The challenge comes in how to gather information on those who cannot respond reliably. Proxy use works poorly at the individual level, although the mean values correspond well with those obtained from residents and thus can be used to assess the performance of nursing home as a whole. The new version of the MDS contains specific questions to pose to nursing home residents.

The MDS has also been used as the basis for assessing the quality of nursing home care. A set of quality indicators has been developed on the basis of MDS information. These are now being nationally normed, although more work is needed on risk adjustment to allow for valid comparisons among nursing homes that may have quite different case mixes.

## ■ Outcome and Assessment Information Set (OASIS)

The federal government has also prescribed a data system for home health care. OASIS is intended to play much the same role in this venue that MDS does in the nursing home, providing both a consistent information base for quality assessment and serving as the basis for better care planning.

### ROLE OF OUTCOMES IN ASSURING QUALITY OF LONG-TERM CARE

Quality of care remains a critical, if elusive, goal for long-term care. As we consider steps for resource allocation, we might first address the question of whether we are spending our current funds most wisely. There is at once a growing demand for more creativity and more accountability in long-term care. It may be possible to reduce the regulatory burden, increase the meaningful accountability, and make the incentives within the system more rational. Progress in long-term care and chronic care will require not only more innovation and creativity, but also accountability. Outcome monitoring (and ultimately outcome-based rewards) allow both to coexist.

Before we can talk about how to package care or how to buy it cheaper, we need a better understanding of what we are really buying. One hears more and more about the value of shifting attention from the process of care to the actual outcomes achieved in acute care. These arguments apply at least as strongly to long-term care.

Two basic concepts must be kept in mind when discussing outcomes.

1. The term outcomes is used to mean the relationship between achieved and expected.
2. Because outcomes rely on probabilities, it is inappropriate to base assessments of outcomes on an individual case. Outcomes are averages and are always judged on the basis of group data.

**Table 4-4** summarizes the reasons for looking toward outcomes as the way to assess and assure quality.

Nonetheless, clinicians frequently balk at being judged on the basis of outcomes. This discomfort can be traced to several issues.

1. Virtually all of clinical training addresses the process of care. Clinicians are schooled in what to do for whom. They reasonably believe, therefore, that if they do the right thing well, they have provided a quality service. They do not like to discuss clusters of patients, preferring to review their care one patient at a time.
2. Many factors can affect the outcomes of care that are out of the clinicians' control. They have difficulty with the concept of probability and prefer to either be responsible or not.

TABLE 4-4 RATIONALE FOR USING OUTCOMES

1. Outcomes encourage creativity by avoiding domination by current professional orthodoxies or powerful constituencies
2. Outcomes permit flexibility in the modality of care
3. Outcomes permit comparisons of efficacy across modalities of care
4. Outcomes permit more flexible responses to different levels of performance, and thus avoid the “all-or-none” difficulties of many sanctions. At the same time, outcomes have some limitations
5. Outcomes necessitate a single point of accountability; all the actors—facility operators, agencies, staff, physicians, patients, and family—contribute to them. Under this approach the role of the provider includes motivating others
6. Outcomes are largely influenced by the patient’s status at the beginning of treatment. The easiest and most direct way to address this issue is to think of the relationship between achieved and expected outcomes as the measure of success
7. Outcomes must also take cognizance of case mix. Predicting outcomes necessitates information about disease characteristics (eg, diagnosis, severity, and comorbidity) and patient’s characteristics (eg, demographic factors, prior history, and social support)

3. Outcomes are by their nature post hoc. Often, a long period can elapse between the time of an action and the report of its success. It is thus too late to intervene in that case.
4. Outcomes indicate a problem but offer no solution. Outcomes do not often point to specific actions that must be taken to correct the problems.

Hence, introducing outcomes, however rational, has not been easy. Making clinicians comfortable with an outcomes’ philosophy will require substantial training and new incentives. Physicians need to be trained to think in terms of both condition-specific and generic outcomes. They need access to data systems that can display the outcomes of their care for clinically relevant groups of patients under their care and compare them with what are reasonable outcomes for comparable patients receiving good care. [Table 4-5](#) summarizes the key issues in outcomes measurement and its applications.

Outcomes should be used as the basis for quality assurance in long-term care. The outcome approach can be used in several ways.



TABLE 4-5 OUTCOMES MEASUREMENT ISSUES

ISSUE	COMMENTS
Need outcome measures that are both clinically meaningful and psychometrically sound	Use combination of condition-specific and generic measures Usually better to adapt extant measures than to develop measures de novo
Outcomes are always post hoc	Expand outcomes information systems to include data on risk factors. These data should be useful in guiding clinicians to collect information that will identify potential problems. Use these data to create risk warnings to flag high-risk cases
Every physician has all the tough cases	Need to include a wide variety of case-mix adjusters for severity and comorbidity Ask clinicians in advance to identify potential risk adjusters Collect almost any item that a clinician might want to see Test the ability of the potential risk factor to predict outcomes and discard if it has little predictive power
Because no two clinicians see the same cases, comparisons are unfair	Use risk adjustment Create clinically homogeneous subgroups; use risk propensities groups of patients with same a priori likelihood of developing the outcome
Cannot control for selection bias; patients may receive different treatments because of subtle differences	Adjust for all clinically identifiable differences Use statistical methods (eg, instrumental variables) to adjust for unmeasured differences

**TABLE 4-6 EVIDENCE-BASED RECOMMENDATIONS DERIVED FROM ASSESSING CARE OF VULNERABLE ELDERLY (ACOVE)**

TOPIC	RECOMMENDATION	LEVEL OF EVIDENCE
Venous thrombosis prophylaxis	Hospitalized patients at high risk for venous thrombosis should receive DVT prophylaxis (pharmacological or sequential or intermittent compression)	Strong
Endocarditis prophylaxis	Patients at moderate to high risk should receive antibiotic prophylaxis	Weak
Central venous catheter infection precautions	Patients with new temporary central venous catheter should receive maximum barrier precautions	Moderate
Indwelling bladder catheter	Catheters should be avoided whenever possible and removed as soon as possible	Weak
Delirium evaluation	Suspected delirium should be evaluated	Moderate
Mobilization	Patients should be ambulated within 48 h of admission unless they are receiving intensive or palliative care	Moderate
Falls	Falls should be investigated to ascertain prodromal symptoms and evaluate medications	Weak
Aspiration pneumonia	Patients who are tube fed should have a plan to reduce the risk of aspiration pneumonia, including elevating the head of the bed	
Preventing ventilator-associated pneumonia	Patients who are mechanically ventilated should have a plan to reduce the risk of pneumonia, including avoiding supine position and using the semirecumbent position	Moderate

Time for antibiotic therapy	Antibiotics should be administered to patients admitted with pneumonia within 4 h of admission	Moderate
Oxygen therapy	Patients with CAP with hypoxia (O <sub>2</sub> saturation < 90%) should receive oxygen	Weak
Changing parenteral to oral antibiotics	Patients with CAP should be switched to equivalently bioavailable oral antibiotics as soon as possible; evidence of a successful switch should include documentation of clinical improvement, toleration of the drugs, and hemodynamic stability	Strong
Discharge assessment	Hospital discharge assessment should include level of independence, need for home health services, and patient and caregiver readiness for discharge	Weak
Preoperative care	Preoperative evaluation for elective major surgery should include a pulmonary review of symptoms and chest auscultation, test for diabetes mellitus, assessment for risk factors for delirium	Weak
Preoperative antibiotics	Patients undergoing major elective surgery should receive prophylactic antibiotics 1 h before incision that are discontinued within 24 h after surgery	Strong
Anticoagulation	Patients who have a hip fracture or have undergone total hip replacement should be started on anticoagulation preoperatively on the evening after surgery	Strong
Postoperative mobilization	Patients who were ambulatory prior to major surgery and are not in intensive care should be ambulated by postoperative day 2	Moderate
Perioperative diabetes control	Diabetic patients undergoing major surgery should have their blood sugar below 200 on the day of surgery and the first two postoperative days	Moderate

**TABLE 4-6 EVIDENCE-BASED RECOMMENDATIONS DERIVED FROM ASSESSING CARE OF VULNERABLE ELDERS (ACOVE) (Continued)**

TOPIC	RECOMMENDATION	LEVEL OF EVIDENCE
Comprehensive palliative care plan	Vulnerable elders with metastatic cancer, oxygen-dependent pulmonary disease, NYHA class II or IV congestive heart failure, end-stage liver disease, end-stage renal disease, or dementia should have a documented plan for managing pain and other symptoms, spiritual and existential concerns, caregiver burdens and needs for practical assistance, and advance care planning	Weak
Gastrostomy tube placement	Careful discussion is needed	Weak
Advance care plan documentation	All vulnerable elders should have a plan for a surrogate decision maker in their outpatient charts	Weak
COPD and smoking	Patients with COPD should be actively urged and assisted to stop smoking	Strong
COPD and passive smoking	Patients with COPD should not be in environments where people smoke	Moderate
Screening for hypoxemia	Patients with COPD who do not use supplemental oxygen and have postbronchodilator $FEV_1 < 50\%$ should be assessed annually for oxygenation status	Strong
Rapid-acting bronchodilator	COPD patients (GOLD > I) should be prescribed a short-acting bronchodilator and taught how to use it properly	Weak
Long-acting bronchodilator	Patients with moderate to severe (GOLD stage II-IV) COPD with symptoms not controlled by as-needed bronchodilator or who have two or more exacerbations in the prior year should be prescribed long-acting bronchodilators	Moderate

Inhaled corticosteroids	Patients with severe to very severe (GOLD stage III-IV) COPD who had two or more exacerbations requiring antibiotics or oral corticosteroids in the past year should be prescribed inhaled steroids (in addition to long-acting bronchodilators), if not taking oral steroids	Strong
Performance scores in breast cancer	Physical and psychosocial status should be evaluated in women with breast cancer	Moderate
Comorbidities in breast cancer	Comorbidities should be evaluated	Moderate
Evaluation of estrogen and progesterone receptors	Estrogen and progesterone receptor status should be evaluated in locally invasive breast tumors	Strong
<i>HER2/neu</i> receptor status	<i>HER2/neu</i> receptor status should be evaluated in locally invasive breast cancer when chemotherapy is contemplated	Strong
Staging bone scan for locally invasive early breast cancer	In the presence of bone pain, elevated alkaline phosphatase, tumor size > 5 cm, or positive lymph nodes, radiographic bone imaging should be done	Weak
Lobular carcinoma in situ	If there is only lobular carcinoma in situ, no further surgical resection is indicated	Weak
Locally invasive cancer	Patients with early-stage breast cancer (I, IIA/B, T3N1M0) who undergo lumpectomy should discuss radiation therapy	Strong
Adjuvant chemotherapy	In a patient with locally invasive breast cancer and 4+ positive nodes and a life expectancy of 5+ years, adjuvant chemotherapy should be offered	Strong
Adjuvant chemotherapy for <i>HER2/neu</i> positive breast cancer	Patients with normal cardiac function and a life expectancy of 5+ years with locally invasive cancer and positive nodes, or who have metastatic cancer, who have <i>HER2/neu</i> receptor overexpression should be offered trastuzumab	Strong

TABLE 4-6 EVIDENCE-BASED RECOMMENDATIONS DERIVED FROM ASSESSING CARE OF VULNERABLE ELDERLY (ACOVE) (Continued)

TOPIC	RECOMMENDATION	LEVEL OF EVIDENCE
Aromatase inhibitors	Patients with advanced ER-positive breast cancer with bone metastasis and without extensive visceral involvement should be offered endocrine therapy	Strong
Performance score for patients with colorectal cancer	Physical and psychosocial status should be evaluated in women with colorectal cancer	Moderate
Pretreatment carcinoembryonic antigen level	Patients with a newly diagnosed colorectal cancer should have a pretreatment CEA level to assess prognosis	Moderate
Pretreatment CT scan	Patients with newly diagnosed colon or rectal cancer who are candidates for elective primary tumor resection and have an elevated or unknown CEA should have a CT scan of the abdomen and pelvis to guide treatment plans for surgery and adjuvant treatment	Weak
Preoperative ultrasound or MRI for rectal cancer	Newly diagnosed rectal cancer patients with normal CEA and candidates for elective resection of the primary tumor should have pelvic imaging by ultrasound, MRI, or CT to improve staging	Moderate
Preoperative total colonic examination	Patients who have new colorectal cancer and are candidates for potential cure should have a preoperative total colonic examination to look for synchronous carcinomas and polyps	Weak

Adjuvant therapy for stage III colon cancer	Patients with stage III colon cancer should receive adjuvant chemotherapy within 4 months of surgery	Strong
Preoperative neoadjuvant therapy for stage II and II rectal cancer	Patients with stage II or II mid-low rectal cancers who are candidates for surgery should receive preoperative neoadjuvant chemotherapy and radiation	Strong
Postoperative adjuvant therapy for stage II and II rectal cancer	Patients who undergo surgical resection for stage II or III rectal cancer and did not receive neoadjuvant therapy should receive postoperative adjuvant chemotherapy, radiation therapy, or both	Strong
Postoperative surveillance	Patients with greater than stage I undergo surgical resection for a cure should be followed every 6 months with a history and physical and CEA levels for the first 2 years and annually for years 3 through 5	Strong
Colonoscopy after surgery	Patients who undergo colorectal cancer resection for cure should have a colonoscopy within 3 years after surgery	Weak

Wenger and Shekelle, 2007

CAP; community-acquired pneumonia; CEA, carcinoembryonic antigen; COPD, chronic obstructive pulmonary disease; CT, computed tomography; DVT, deep vein thrombosis; GOLD, Global Initiative for Chronic Obstruction Disease; MRI, magnetic resonance imaging; NYHA, New York Heart Association.

Data compiled from Wenger NS, Roth CP, Shekelle P, ACOVE Investigators: Introduction to the assessing care of vulnerable elders-3 quality indicator measurement set. *Journal of the American Geriatrics Society*. Oct; 55 Suppl 2:S247-S52, 2007.

1. As reflected in the OBRA 1987 regulations (which, in turn, were stimulated by the Institute of Medicine's 1986 report), there is already growing national interest in increasing the emphasis on outcomes in regulatory activities. Outcome measures can be substituted for most of the current structure and process measures. It is appropriate to continue regulation in areas such as life safety. Concomitant with an outcomes' emphasis would be the reduction of regulatory burden. It is important to recognize, however, that it is not appropriate to dictate structure, process, and outcome at the same time. Such a policy removes all degrees of freedom and stifles creativity at the point when we want to encourage it. Under an outcome-regulated approach, providers whose patients do better than expected are rewarded and are less worried about their style of caregiving, whereas those whose patients do relatively poorly are investigated more closely.
2. Outcomes can be incorporated into the payment structure to link payment with effects of care. Payments, either in the form of bonuses and penalties or as a more fundamental part of the payment structure, can be used to reward and penalize good and bad outcomes, respectively. (eg, an outcome approach might use a factor reflecting the overall achieved/expected ratio for a patient as a multiplier against the costs of care to develop a total price paid for that period of time; or one might use a similar ratio to weigh the amount of money going to a given provider from a fixed pool of dollars committed to such care.) Such an approach must be viewed carefully within the context of our present case-mix reimbursement scheme for nursing homes, because the latter indirectly rewards deterioration in function. An outcome approach to payment is compatible with a case-mix approach that is used on admission only.
3. An outcomes approach can be incorporated into the basic caring process. Where the information base used in assessing patients and developing care plans is structured, the emphasis on outcomes can become a proactive force to guide care. Optimally, the information used to assess outcomes will come from the clinical records and will be the same information used to guide care. Using available computer technology, it is now feasible to collect such data, translate them into care plans, and aggregate these data for quality assurance at minimal additional cost. The great advantage of such a scheme is its potential both to provide a better information base with which to plan care and to reinforce the creative use of such information to achieve improvements in function. Much of the current efforts going into more traditional regulatory activities might be redirected to this effort, with assessors used to validate the assessment and to focus more intense efforts on the miscreants.

We have generally good consensus on the components of outcomes, which include elements of both quality of care and quality of life; but we are less clear



about how to sum them to produce composite scores. The gerontological literature consistently cites the following categories of outcomes:

- Physiologic function (eg, blood pressure control, lack of decubitus)
- Functional status (usually a measure of activities of daily living [ADLs])
- Pain and discomfort
- Cognition (intellectual activity)
- Affect (emotional activity)
- Social participation (based on preferences)
- Social relations (at least one person who can act as a confidant)
- Satisfaction (with care and living environment)

To these must be added more global outcomes, such as death and admission to hospital.

Work is already available with nursing home residents to show that these factors can be predicted with sufficient accuracy to be used in a regulatory model. There is similar work to show that there is reasonable consensus across a variety of constituencies about the relative weights to be placed on them for different kinds of patients (eg, different levels of physical and cognitive function at baseline).

The outcomes approach offers significant assistance with a recurrent problem in regulation—the development of standards. This approach may avoid many of these difficulties by relying on empirical standards. Rather than arguing about what is a reasonable expectation, the standard can be empirically determined. Expectations can be derived from the actual outcomes associated with real care given by those felt to represent a reasonable level of practice. This could include the entire field or a designated subset. Under this arrangement, providers would be comparing their achievements to each other's past records, with the possibility that everyone can do better.

## TECHNOLOGY FOR QUALITY IMPROVEMENT

Ideally, one would like to see a measurement approach that

- Can cover the spectrum of performance
- Is easy and rapid to administer
- Is sensitive to meaningful change in performance
- Is stable within the same patient over time
- Performs consistently in different hands
- Cannot be manipulated to meet the needs of either the provider or the patient

The solution to this challenge is to create an assessment approach that incorporates the features designed to maximize these elements.

To cover the broad spectrum sought and still be relatively quickly administered, an instrument should have multiple branch points. These permit the user to focus on the area along the continuum where the patient is most likely to function and to expand that part of the scale to measure meaningful levels of performance. Branching can also ensure that the assessment is comprehensive but not burdensome.

By using key questions to screen an area, interviewers can ascertain whether to obtain more detailed information in each relevant domain. Where the initial response is negative, they can go on to the next branch point. Reliability is more likely to be achieved when the items are expressed in a standardized fashion tied closely to explicit behaviors. Whenever possible, performance is preferred over reports of behavior.

One cannot expect to totally avoid the gaming of an assessment. If the patient knows that poor performance is needed to ensure eligibility, they may be motivated to achieve the requisite low level. One can use some test of ripeness bias, such as measures of social desirability, but they will not prevent gaming the system or detect all cheating.

## ■ Computer Technology

Clinical medicine seems headed inevitably toward electronic medical records. This step could represent a major advance in the care of older people, if the opportunity is properly harnessed. Simply reproducing the current unstructured information set in a more legible and transmissible format will not suffice. Structured information provides the vehicle for assuring a more systematic evaluation and follow-up of cases. By distinguishing between missing and normal values, it can provide the structure to focus clinicians' attention on salient items.

Computer technology can dramatically reduce redundancy. Properly mobilized, computers can provide the structure needed to assure a comprehensive assessment with no duplication of effort. Because they are interactive, they can carry out much of the desired branching and can even use simple algorithms to clarify areas of ambiguity and retest areas where some unreliability is suspected. Similar algorithms can look for inconsistency to screen for cheating.

Data stored on computers can be aggregated to display performance across patients by provider (eg, physician, nursing home, or agency). Data on a patient can be traced across time to look at changes in function and, in turn, can be aggregated.

The next important step in the progression is to move the focus from a single point of care to the linking of related elements of care. In an ideal system, patient information would be linked to permit tracing changes in status for that individual as they move from one treatment modality to another. Thus, hospital admission and discharge information, long-term care information, and primary care

information would be merged into a common computer-linked record, which allows one to trace the patient's movements and status.

Finally, it would be desirable to have data on the process of care as well as the outcomes. This combination would permit analyses of what elements of care made a difference for which patients.

Such an approach to assuring quality is within our grasp if we are prepared to invest in data systems and to commit ourselves to collecting standardized information. It necessitates a shift in some of our fundamental paradigms from thinking about whether we did the right thing to deciding if it made any difference after all.

Two basic changes in thinking are necessary in order to establish an outcome-based philosophy, both of which are difficult for clinicians.

1. Thinking in the aggregate, using averages instead of examining each case; outcomes do not work well for individual cases because there is always a chance that something will go wrong, and life does not provide a control group.
2. Attributing responsibility to the whole enterprise rather than placing blame on an individual; a pattern of poor outcomes will mandate closer inspection of the process of care, but outcomes per se are a collective responsibility.

Computerized records greatly facilitate the task of monitoring the outcomes of care. Ideally, such a record system should be proactive, directing the collection of clinical information to encourage adequate coverage of relevant material. Long-term care is actually ahead of acute care in this regard, with the federal requirement for computerized versions of the MDS. Unfortunately, most of the systems in use are simply inputting mechanisms. They do not begin to tap the real potential of a computerized information system. Because long-term care depends heavily on poorly educated personnel for so much of its core services, the availability of an information support system, which can provide feedback and direction, is especially appropriate.

Computerization can provide both the flexibility and the brevity sought by using branching logic to expand a category when there is reason to explore it more thoroughly. It can avoid duplication by displaying data already collected by others while still permitting the second observer to correct and challenge earlier entries. More important, it can display information to show change over time, thus permitting both the regulators and the caregivers to look at the effects of care.

Once the data are in electronic form, they are easily transmitted and manipulated. It is not hard to envision a large set of data derived from these systematic observations that would permit calculations of expected courses for different types of long-term care patients. These could then be compared to individual patients' courses to assess the potential impact of care on outcomes.

The computer's ability to compare observed and expected outcomes extends beyond its role as a regulatory device. It could be a major source of assistance to

caregivers. One of the great frustrations in long-term care, especially in the trenches, is the difficulty in sensing whether the caregiver is making a difference. Because so many patients enter care when they are already declining, the benefits of care are often best expressed as a slowing of that decline curve. Without some measure of expected course in the absence of good care, those who render care daily may not appreciate how much they are accomplishing and thereby may forgo one of the important rewards of their labors.

To display information about the change in patient's condition over time, a simple task for a computer, will assist the long-term caregiver to think more in terms of the overall picture, rather than a series of separate snapshots in time. Given the computer's ability to translate data into graphics, it is a simple procedure to develop pictorial representations of the changes occurring for a given patient or group of patients and to contrast those with what might be reasonably expected.

Again the effort is directed toward changing perceptions about older persons, especially those in long-term care. For too long, long-term care has worked in a negative spiral—a self-fulfilling prophecy that expected patients to deteriorate—served to discourage both care providers and patients. Such an attitude is hardly likely to attract the best and the brightest in any of the health professions. As noted earlier in this chapter, nursing home patients are among the most responsive to almost any form of intervention. Any information system that can reinforce a prospective view of long-term care, especially one that can display patient progress, represents an important adjunct to such care.

Assessing care of vulnerable elders (ACOVE) has also made a number of recommendations about steps in providing better care, but none are supported by strong evidence (Wenger and Shekelle, 2007). These recommendations include

- All patients should be able to identify a physician or clinic to call for medical care and know how to reach them.
- After a new medication is prescribed for a chronic illness the following should be noted at follow-up:
  - Medication is being taken as prescribed.
  - Patient was asked about the medication (eg, side effects, adherence, availability).
  - Medication was not started because it was not needed or changed.
  - If a patient is seen by two or more physicians and new medication is prescribed by one, the other(s) should be aware of the change.
  - If a patient is referred to a consultant, the referring physician should show evidence of the consultant's findings and recommendations.
- If a diagnostic test is ordered, the following should be documented at the next visit:
  - Result of test specifically acknowledged.
  - Note that test was not needed or not performed and why.
  - Note that test is pending.

- If a patient misses a scheduled preventive visit there should be a reminder.
- When patients are seen in an emergency department (ED) or admitted to hospital, the continuity physician should be notified within 2 days.
- Patients discharged from hospital and who survive 6 weeks should have some contact with their continuity physician who should be aware of the hospitalization.
- When patient is discharged to home from hospital and receives new chronic disease medication, the continuity physician should document the change in medication within 6 weeks.
- When patient is discharged to home or to a nursing home from hospital and tests are pending, the results should be available within 6 weeks.
- When patient is discharged to home or to a nursing home from hospital, there should be a discharge summary in the continuity physician's records.
- If a patient does not speak English, the interpreter or translated materials should be used.

## SUMMARY

In many respects, geriatrics is the epitome of chronic disease care. New paradigms are needed, which recognize the changing role of patients their own care, the need to think differently about the payoff horizons for investments in care, and the tracking of the course of disease to identify when intervention is needed. With geriatrics and chronic disease in general, the benefits of good care may be hard to discern, because they represent a slowing of decline. This effect is invisible unless there is some basis for forming an expected clinical course against which to compare the actual course.

Physicians caring for older patients need to think in prospective terms. They will enjoy their practices more if they can learn to set reasonable goals for patients, to record progress toward these goals, and to use the failure to achieve progress as an important clinical sign of the need for reevaluation.

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