

Chronic care: the unmet challenge

SPECIAL ARTICLE

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ABSTRACT Chronic disease is a demographic reality across the world and health care systems need to readjust their approach to care accordingly. Such a transformation will require rethinking almost every aspect of care as we know it and the roles of health care practitioners will need to change, as many tasks can now be accomplished by others. Concurrently, patients must become active and productive partners in their care. Time concepts must also be shifted from events to episodes, wherein success over the long term will best be measured by comparing actual clinical courses to what would have occurred in the absence of good care. The philosophy of care should reflect a willingness to invest in care at the front end in expectation of later benefits. Information technology is central to these changes, both in the sharing of information about clinical status and to alerting caregivers to early signs of clinical change. These necessary developments will not come easily.

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INTRODUCTION

Although the importance of chronic care has become widely recognised, little has been done to change the way medical care is organised and practised to respond to this challenge. Ironically, despite all the technical advances in medicine over the last decades, the actual administration of health care has changed very little in the last century. Patients appear spontaneously, they are treated for a finite period—be it an office visit, an emergency room encounter, or a hospital stay—and then disappear until they re-emerge for another encounter. This pattern is inappropriate and insufficient in the face of the clinical realities of chronic disease.

The centrality of chronic disease has become an established fact in the United States and other developed countries, accounting for over two thirds of health care spending in the United States and over 95% of health costs for older people.¹ Its relevance is no longer limited to the developed world; the World Health Organization has recognised its importance in all countries.²

functional limitations and disability, these spheres do not neatly overlap. Among the 120 million non-institutionalised Americans reporting a chronic condition in 1996, 31 million also had a disability, but another 7.6 million had a disability without a chronic disease. Likewise, of the 12.3 million with a functional limitation, 0.6 million did not have a chronic disease.³ When people with three or more chronic illnesses are considered, the overlap becomes much greater.

Defining a chronic illness is not as easy as might be expected. An arbitrary duration of treatment and follow-up can be assigned, but many chronic diseases have periods of remission and exacerbation. However, some general characteristics do pertain. Chronic diseases last a lifetime and therefore accumulate with age (although it could be argued that, with the development of transplantation surgery, some diseases and conditions can actually be cured). Chronic diseases are generally progressive, although their courses can feature ups and downs. They are also life-shaping and may have different meanings in different cultures and traditions.

Although chronic disease is closely related to

The goals of chronic disease care can be

summarised as follows:

1. Manage the disease to achieve the best possible reduction of the extent and frequency of exacerbations.
2. Prevent (or at least minimise) the transition from impairment to disability and from disability to handicap.
3. Encourage the patient to play an active role in managing his/her disease but avoid allowing the disease to become the dominant force in the person's life.
4. Provide care in a culturally sensitive manner.
5. Integrate medical care with other aspects of life without medicalising those aspects.

Although no defined science of chronic disease care yet exists, some principles have evolved:

1. Move from encounters to episodes of care: care should follow the patient. The patient's condition should be tracked over time and observations should not be limited to those few times when the patient has contact with a medical professional. The timing of interventions should be based on changes in status.
2. Patients must play a more active role in their care: patients should be the primary monitors of their status, reporting changes or untoward events to health professionals. Patients therefore need to both understand and comply with their treatment regimens. They must play a more active role in making decisions about their own care, and must then share the responsibility for the consequences of these decisions.
3. The structure of formal care-giving may need to evolve: the nature and training of people providing various services may change but the locus of ultimate responsibility is likely to continue to rest with physicians. Inter-professional collaboration will be important but the nature of that collaboration will vary.
4. The nature of communication is changing: more reliance will be placed on technology to monitor and warn of changes in patients' clinical status. Structured information systems will be used to collect salient information and better focus clinicians' attention on it. Broader, faster access to timely, pertinent data by authorised people will be essential.
5. Emphasis must be placed on function as the ultimate outcome: physiological measures will

continue to be important, but these are often transient. Survival is no longer the ultimate consideration. The ultimate evidence of clinical success will be the sum of smaller successes, namely the effect on patient function.

6. Success is defined both by slowing the rate of decline and improving the clinical trajectory. In the context of chronic disease, where decline is generally expected, improvement is no longer the primary criterion—slowing the rate of decline may constitute a major achievement.

NEW DEFINITIONS

In the world of chronic disease, familiar terms assume new meanings. Prevention focuses less on avoiding conditions than on managing their consequences. This does not mean that efforts to reduce risks should be abandoned. Immunisations, efforts to reduce smoking, and the like should continue, but the emphasis should shift to providing better primary care in an effort to avoid functional catastrophes. Good care should reduce the rate of hospitalisations and emergency visits, which are clinically devastating and economically costly, by preventing exacerbations of the underlying conditions. The most preventable problems are iatrogenic: over-medication or inappropriate medication, excessive zeal in labelling, or sentencing patients to a term in bed may produce untoward consequences.

Patients' roles must also necessarily change. They must become active partners in their care. The idea of presenting passively to the physician for examination and instruction will no longer suffice. Patients themselves are the only ones who experience chronic diseases 24 hours a day, 7 days a week, and they are in the best position to observe and report changes in their condition.

In order to become actively involved in making decisions that will affect the courses of their lives, patients will need good information about the consequences of alternatives. They will need help with structuring the stages and components of these decisions and with sorting out which specific outcomes they want to maximise. Once patients become joint decision-makers, they must also be prepared to share responsibility for the consequences of those decisions.

As monitors of their own clinical conditions, patients will require structured tools to most efficiently observe and communicate important information. They will also need to have appropriate access to health care professionals in order to provide this feedback. In some cases, this may simply involve a way to summarise observations at the time of the next encounter. At other times, it will mean knowing how to get access to the system in an emergency, or how to initiate a contact before the next scheduled encounter.

As the name implies, time plays a different role in chronic disease, which pays little attention to the artificial conventions of health care encounters. The processes of chronic disease continue regardless, and the idea of assigning arbitrary dates for revisits is anachronistic. Such appointments are, at best, based on an educated guess about the patient's future clinical status. The actual clinical course constitutes a better guide. Patients who continue on their expected course can be seen less frequently, but those who deteriorate more rapidly than expected need to be accommodated sooner.

Likewise, at a time when clinical encounters are brief and shrinking, it no longer makes sense to expect that all encounters should be of equal length. Less time is needed for patients who are staying on track, leaving more time for those whose clinical conditions need to be re-evaluated. Furthermore, much of the contact time with the former group can be given over to other personnel, leaving physicians free to concentrate on those patients who need more attention.

There is growing evidence that nurse practitioners can perform many of the functions traditionally played by primary care physicians.^{4,5} At a time when the supply of primary care physicians is dwindling and the need for such people is increasing, some substitution seems imperative.⁶ Likewise, when nurses are also in short supply,⁷ many nursing tasks can be performed by lesser trained personnel. In many cases, all that is needed are competent primary care skills combined with an ability to remain aware of the impact of several simultaneous conditions. In other cases, the underlying nature of the dominant condition may make attention from a specialist paramount. However, many specialists are reluctant to move far from their organ system.

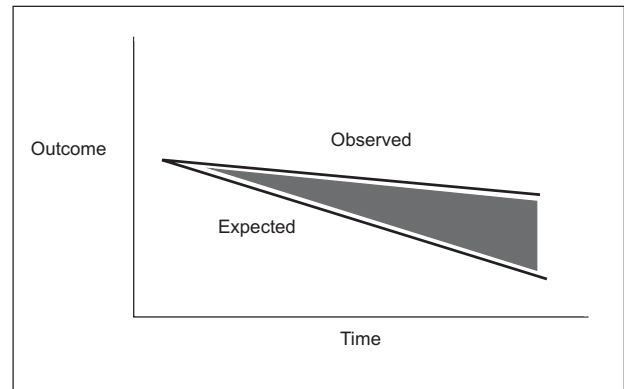


FIGURE. General model of clinical outcomes observation

A promising compromise may be to pair the specialist with a nurse practitioner; the former can treat the organ and the latter can attend to the person.

Another implication of time in chronic disease management is the pay-off horizon for care investments. Under current payment schemes, there is little incentive to provide intensive services in the expectation of future clinical dividends. For example, the principles of geriatric evaluation and management are based on evidence that spending substantial effort at one point in time will prevent later use of expensive hospital and nursing home care.⁸

NEW APPROACHES

Expectations must change under the aegis of chronic disease. The concept of cure must yield to the emphasis on management with the goal of preventing exacerbations. Success must be redefined to recognise that the most frequent clinical course involves decline over time. Good care consists of slowing the rate of that decline, but such an achievement is invisible unless there are some ways to capture the expected clinical course in the absence of that good care. Thus, the key to evaluating chronic care is comparing the actual to the expected course. As shown in the FIGURE, the benefits reflected in the shaded area would not be apparent unless there was a means to display the expected course.

A key element in the delivery of modern chronic care will be better information systems. At present, clinicians must confront both too little and too much information when they see a patient. Salient information can be lost in a sea of irrelevant data. The multivolume chart is a strong signal that it will

be hard to find a clear indication of the reasons for the current visit or the clinical history that preceded it. Under greater pressure to practise efficiently, clinicians need timely and focused information that will direct their attention to the salient data. As much as airline pilots, clinicians need warnings when things are not going according to plan. As in modern shipping and manufacturing practices, clinicians need 'just in time' information. The goal of an information system should be to provide the right content and amount of information at the right time.

Clinical protocols, based on well-validated studies, may prove useful in managing some aspects of chronic disease, but much of this care involves working with several diseases simultaneously. Protocols work best when they address a single predictable event. In these cases, such as care pathways for surgical recovery, they are extremely helpful to both practitioners and patients and their families in defining expectations. A variation on the concept of the clinical guideline or protocol is the clinical glidepath. Based on the assumption that most practitioners will know what to do if they are aware of the problems, the clinical glidepath is analogous to the information systems used to land an airplane. These systems alert the pilot when a plane is drifting out of its preplanned trajectory so that adjustments can be made in order to produce a smooth landing—they allow for minor course corrections to avoid major disturbances. Likewise, in clinical practice, by defining a limited number of salient clinical variables for each chronic condition and monitoring them over time, comparing the observed findings to the predicted clinical course, the clinician can determine when a patient is drifting off his clinical glidepath and intervene quickly to prevent the unwanted exacerbation. Patients can collect and transmit most of the clinical observations needed to monitor clinical glidepaths on their own, giving them an active role in their own care.

Structured data systems can further assure that the relevant information is recorded. By providing fields for items that address issues that are otherwise often ignored, such as function and quality of life, structured approaches can increase the likelihood that clinicians will attend to them. Computerised flow sheets can display changes in status over time, which can readily be transformed into graphs. Data

that relate treatment and outcomes can be merged. Patient histories can be taken by computer before the patients see the clinicians. Computerised prescribing can incorporate fail-safe procedures to safeguard against drug-drug interactions or drug-disease interactions.

New strategies to improve chronic disease care are already being tested. A number of approaches fall under the general rubric of 'disease management', and these approaches are usually layered onto the existing care. Additional personnel (usually nurses) contact patients to ensure adherence to clinical regimens. Some of these functions are directed at specific populations, such as patients with congestive heart failure discharged from hospital⁹; others include all patients with a given diagnosis. At the other end of the continuum are strategies designed to encourage self-care.¹⁰ Patients are taught skills and strategies to increase their sense of self-confidence and empowerment. A middle path seeks to create more effective partnerships between patients and their clinicians, enabling each to play a more effective role in the care process—but in coordination.

IMPROVING LINKAGES BETWEEN ACUTE AND LONG-TERM CARE

Most long-term care (LTC) is related to chronic disease. Historically, LTC has been torn between the so-called medical and social models of care, but effective LTC must rely on coordinating the medical and social aspects of care. The former are usually depicted as focused on achieving some set of clinical goals, while the latter generally address supportive measures that meet assessed needs. This discrepancy is unproductive. The first step in maximising coordination is developing a set of shared goals. Collaboration and discussion among all parties are necessary to develop these mutual goals, which should reflect elements of both approaches.

In many systems, payment for LTC is administered separately from that of acute care, impairing potential coordination. Merged payment may facilitate coordination, but it will not assure it; more fundamental changes in practice patterns are needed. Case management may help to coordinate care, but unless it plays a proactive, hands-on role, it simply adds another level of bureaucracy.

An important principle of LTC is the need to recognise the distinction between the site of service and the nature of the services provided. Too often, care is defined by where it is provided. Thus, home care is seen as an entity distinct from nursing home care. In truth—especially given the evolution of technology—the same patients can be served as well in various locations. Patient-centred care should never be defined by the location of that care. Freed of such limitations, we can develop new packages of care that combine medical and social elements more creatively and more effectively.

An overarching theme that must be constantly borne in mind when assessing approaches to LTC is the need to focus on outcomes over process. Crucially, outcomes should be defined in terms of the contrast between observed and expected results.

THE FUTURE OF CHRONIC CARE

Despite a strong research record that has demonstrated a number of effective strategies for providing chronic-care elements, few have been systematically adopted.¹¹ Various reasons have been given for this failure. For example, the fee-for-service payment system is incompatible; but while changes have been suggested in the approaches to payment—such as specific incentives for better outcomes, or clustering payments into episodes of care (eg hospital and post-hospital care)—managed care has done little to improve the situation.^{12,13}

Disease management may ultimately prove successful on a broad scale, however. The Internet has made possible a range of consumer-directed information to foster self-care, some of it capable of being individualised to the characteristics of specific users. A variety of information systems have also been developed to allow clinical tracking at a distance. Computerised medical records and ordering systems provide more structured information bases. Mobile computing allows better supervision of non-professional home care workers and linkages among separated workers within a care system. Importantly, geriatric nurse practitioners are increasingly assuming a variety of roles previously filled exclusively by physicians.

CONCLUSION

While the story of chronic disease management continues to be written, some observations can be offered now. Chronic disease is here to stay. It is worth investing in better ways to deliver such care, because chronic disease is likely to remain a dominant force for the foreseeable future. More must be done to bring health care systems into alignment with the pervasive reality of chronic disease. We cannot afford to continue to behave as though we still live in a world of acute illness. This transition will not be easy; it means giving up familiar (and often rewarding) practices. While there is good scientific evidence to show that better chronic disease care is possible, the challenge is to implement this knowledge while building upon it. Managed care does not seem to be the answer to bringing about the reforms that many had hoped for. Financial incentives for better chronic care are likely to be needed and, certainly, financial disincentives must be eliminated.

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