What pervades social interaction is that the person with AIDS or HIV infection is expected to manage the awkward and difficult emotions that may arise.⁸

Finally, living with a chronic disease requires a different view of the self and the meaning of the illness and one's life. When AIDS was an acute illness, the diagnosis was delivered as a death sentence. Wills were written, funeral plans made, and possessions distributed to friends and family. Many long-term survivors have described the reorganization their lives had to undergo as they realized that if, indeed, they were going to die, it might not be anytime soon. In some respects, the uncertainty of chronic illness is as difficult to live with as the knowledge that you will soon die.

BELIEFS ABOUT NORMAL LIFE

All societies hold beliefs about what the normal life course should be. Anthropologist Gay Becker observes that in the United States, the life course is generally viewed as a linear progression of events from birth to death in a predictable sequence. Life is an orderly process. Chronic and life-threatening illnesses challenge this view of continuity and order. Life is no longer predictable. During an acute crisis, a person's life is suspended. As the crisis subsides, the person must make sense of it to reestablish continuity and normality. Becker says, "Management of a serious chronic illness that has frequent ups and downs entails a continual reworking of identity." Many HIV-positive people suddenly realized they have a future, if limited, where there

had been none. The energy required to reorganize one's identity to move forward into the future, and the disappointment, frustration, and depression that can occur when the process must be repeated after a crisis, should not be underestimated. One consequence of chronic illness is that the responsibility for all aspects of management—physical, mental, and social—increasingly falls on the shoulders of those who have the illness. In the absence of a crisis, it is easy to forget that people with an illness are still working hard to care for themselves and to resume what could now constitute a normal life.

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Individualized stepped care of chronic illness

The routine care of people with chronic illnesses often fails to follow evidence-based guidelines or to achieve optimal outcomes.^{1,2} Because of the high prevalence and costs of chronic illness care^{3,4} and the key role of primary care physicians in managing chronic illness, enhancing care and outcomes in primary care settings is a public health imperative.

There are important general issues about how chronic conditions are effectively managed.^{1,5,6} Identifying these generalities is essential if the potential advantages of primary care of chronic illness are to be realized. Evidence-based guidelines for diverse chronic conditions identify similar elements of patient care (table).⁷⁻¹² These elements include a well-defined care plan, patient education, scheduled follow ups, outcome and adherence monitoring, the

targeted use of specialist consultation or referral, and the use of stepwise treatment protocols. Despite evidence that these elements of chronic illness care improve patient outcomes, they are often inadequately organized and delivered.¹

PROBLEMS IN CHRONIC ILLNESS CARE

The diagnosis and treatment of specific diseases are over-emphasized relative to developing a treatment plan with patients, patient education, setting a follow-up schedule, and managing the consequences of treatment in a patient's daily life.

The initial assessment is given greater emphasis than monitoring adherence and outcomes. In general, it is dif-

Michael Von Korff
Center for Health
Studies
Group Health
Cooperative of Puget
Sound
Seattle, WA
Bea Tiemens
Trimbos Institute
Utrecht, Netherlands

Correspondence to:
Dr Von Korff
vonkorff.m@ghc.org

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Summary points

- Efforts to improve the care of chronic illness require effective systems capable of implementing those treatments on a population basis
- Despite evidence that patient outcomes are improved by implementing clinical guidelines through organized practice systems, how to accomplish the key elements of good patient care in routine practice remains unclear
- Limited professional resources is a substantial barrier to ensuring essential services
- Under stepped care, simpler interventions are tried first, with more intensive interventions reserved for when a good outcome is not achieved
- Stepped care provides a framework for achieving professional support for chronic illness that is cost-effective and is based on patients' observed response to treatment

difficult to predict patient outcomes and treatment response in chronic disease. Finding the "right" treatment for a particular patient can depend as much on monitoring treatment adherence and response as it does on a comprehensive diagnostic evaluation.

Physicians focus on presenting problems and illness crises while neglecting preventive follow up. Faced with competing demands for time and attention,^{13,14} physicians neglect preventive health follow up and services that may help avert complications.

Failures in treatment adherence and lifestyle change are attributed to problem patients rather than system deficiencies. Chronically ill patients often do not carry out prescribed treatments or achieve desired changes in diet, exercise, and other health behaviors.¹⁵⁻¹⁸ It is more productive to organize practice systems and implement approaches to patient care that improve patient follow-through on treatment plans.^{19,20}

Although a collaborative approach is needed to treat chronic illness, the specific roles of primary care physicians, specialists, allied health professionals, and patients in chronic illness care remain unclear.^{1,5}

PROVIDING EFFECTIVE CARE FOR CHRONIC ILLNESS

Improving the care of patients with chronic illness depends on reforming systems for and approaches to chronic illness care and implementing specific clinical guidelines. The chronic illness care model of Wagner and coworkers provides a systems approach to improving care.¹ Decision support (for example, clinical guidelines), practice design (that is, defining provider roles and organizing care to ensure active follow-up), self-management support (such

as patient education), and clinical information systems (such as care registries and reminders) are elements of effective systems for the care of patients with chronic illness.

Enhanced collaboration between patients and physicians improves patients' outcomes.⁵ Collaborative management of chronic illness involves setting goals and developing a care plan with patients, training and support for self-management, and active follow up to monitor success and modify care as needed.⁵ Care management services using structured protocols and active follow up have produced beneficial effects for a range of chronic conditions.²¹⁻²⁶ Specialty consultation services can improve patients' outcomes when the focus is on implementing treatments based on guidelines, rather than patient assessment alone.^{27,28} Randomized trials of consultation services consisting of "assessment only" interventions have not proved successful.²⁹⁻³¹ The evidence suggests that when care that is based on protocols is implemented, outcomes for patients with chronic diseases can be improved when self-management training and support are combined with the right level of active follow-up and support.

A fundamental problem in organizing the care of patients with chronic illness, then, is providing the right level of support. However, professional resources for the various elements of this care are limited—the need for these services seems far greater than the professional resources that are available and the ability of patients and insurers to pay for the services.

Stepped care has been advocated for managing diverse chronic conditions in ways that initially rely on less expensive interventions.³²⁻⁴⁶ Stepped-care protocols are sequential clinical guidelines for assigning treatments to patients based on observed outcomes. Stepped-care principles, however, have broader implications for the organization of cost-effective practice systems and the delineation of patient and physician roles in collaborative approaches to chronic illness care.

Patients with arthritis benefit from exercise in a therapy pool

AP Photo/Murac Haynes

Generic elements of chronic illness care included in evidence-based guidelines for 5 chronic conditions

Elements	Rheumatoid arthritis ⁷	Depression ⁸	Asthma ⁹	Diabetes mellitus ¹⁰	Heart failure ^{11,12}
Treatment plan	Yes	Yes	Yes	Yes	—
Patient education	Yes	Yes	Yes	Yes	Yes
Scheduled follow-up	Mentioned	Yes	Yes	Yes	Yes
Outcomes monitoring	Yes	Yes	Yes	Yes	Yes
Adherence monitoring	Yes	Mentioned	Yes	Yes	Yes
Stepped therapy	Yes	Yes	Yes	Yes	Mentioned
Specialty consultation and referral	Yes	Yes	Yes	Yes	Yes

WHAT IS INDIVIDUALIZED STEPPED CARE?

Stepped care provides a framework for the care of patients with chronic illnesses that uses limited resources to their greatest effect on a population basis. Stepped care is based on three assumptions: different people require different levels of care; finding the right level of care often depends on monitoring outcomes; and moving from lower to higher levels of care based on patient outcomes often increases effectiveness and lowers costs overall.

The use of stepped care has been advocated for many chronic conditions, including hypertension,^{32,33} diabetes mellitus,³⁴ nicotine dependence,³⁵⁻³⁷ high cholesterol levels,³⁸ asthma,³⁹ bulimia,⁴⁰ gastroesophageal reflux,⁴¹ back pain,⁴² alcohol dependence,⁴³ and depression.⁴⁴⁻⁴⁶ Donovan and Marlatt⁴³ defined stepped-care processes as “the least costly, least intensive, and least restrictive (that is, requiring the least total life-style change for the individual) treatment judged sufficient to meet the person’s needs and goals should be attempted initially before more costly and restrictive treatments are attempted.” Although stepped

care is guided by the response to treatment, tailoring the care based on severity, clinical status, and patient preferences is appropriate,³⁷ so first-line treatment is not always the least intensive, least restrictive, or least expensive regimen. Initial and subsequent treatments are selected according to evidence-based guidelines in line with patient goals, treatment preferences, and clinical status. Patient adherence, treatment response, and outcomes are actively monitored and treatments modified as needed to achieve the best possible outcome for each patient.

ORGANIZING STEPPED CARE

In stepped care, the intensity of professional care is augmented for patients who do not achieve an acceptable outcome with lower levels of care. A stepped-care model (figure) defines four levels of professional support for managing chronic disease.⁴⁵ In this scheme, acute and chronic care use evidence-based guidelines, and both use collaborative management. The level or intensity of care is guided

Individualized stepped care: a scheme for managing chronic illness in primary care

Acute (episodic) care		MANAGEMENT CONTINUUM	Chronic care	
Goals	<ul style="list-style-type: none"> Control disease Decrease symptoms Prevent disability Prevent chronicity 	EVIDENCE-BASED PROTOCOLS GUIDING CLINICAL MANAGEMENT AND LEVEL OF CARE	<ul style="list-style-type: none"> Prevent complications Prevent relapse Minimize disability 	GOALS
Level 1	<ul style="list-style-type: none"> Recognition and diagnosis with screening and diagnostic tools Watchful waiting with active follow-up for subthreshold illness 	FOR ALL PATIENTS AT EACH STEP	<ul style="list-style-type: none"> Monitoring patient status to guide long-term management Preventive care 	Level 1
Level 2	<ul style="list-style-type: none"> Treatment by the primary care physician 	Collaborative Management: Shared problem definition, goal setting and care plan + Self-management training & support + Active following-up	<ul style="list-style-type: none"> Self-management with low-intensity support 	Level 2
Level 3	<ul style="list-style-type: none"> Specialty consultation in support of primary care management 		<ul style="list-style-type: none"> Lower intensity care management services 	Level 3
Level 4	<ul style="list-style-type: none"> Referral to specialty setting for more complex or intensive intervention and/or to refine care plan 		<ul style="list-style-type: none"> Higher intensity care management services 	Level 4

Figure adapted from Tiemens.⁴⁵

An example: stepped care for depressive illness

Many depressed patients in primary care have subthreshold illness that does not benefit from active treatment.⁴⁸ For these patients, watchful waiting (level 1 of acute care) may be a preferred option.⁸ Other patients show complete remission of depression when treated by their primary care physician without specialist or the support of a care manager (level 2 of acute care).^{27,28} Some depressed patients, however, continue to have symptoms after initial treatment. When identified by an assessment of depression outcomes at a follow-up visit, these patients may benefit from specialist consultation and brief intervention designed to augment primary care treatment without transferring responsibility to specialty care (level 3 of acute care).^{27,28} Among patients requiring specialist involvement in acute care, a few who continue to show a poor outcome at follow-up may require more intensive specialty care than practical in the primary care setting.⁴⁶ Responsibility for these patients may be appropriately transferred to specialty care (level 4 of acute care), either permanently or until a care plan that can be implemented in primary care is more fully developed. At the lowest level of chronic care, a plan for monitoring depression severity and relapse is needed⁸ (level 1 of chronic care).

Patients actively treated for depression benefit from training and support in implementing pharmacologic and behavioral treatments^{27,28} (level 2 of chronic care). Patients requiring higher levels of support may benefit from care management services that ensure ongoing follow-up and adaptation of care^{26,46} (levels 3 and 4 of chronic care). In particular, an important subset of patients may require maintenance medication or maintenance psychotherapy long term to prevent relapse.⁸ These patients, in particular, may require some form of care management to assist them in carrying out these interventions.

by observed outcomes. Active follow-up is used to determine the level of care each patient requires over time.

For both acute and chronic care, screening for specific conditions and diagnostic, preventive, and outcomes monitoring services are included in the lowest level of care (level 1) and applied to all patients in the target population. Patients appropriate for active treatment (level 2) may be managed initially with a first-line treatment plan implemented in primary care and combined with low-intensity self-management training and support (such as educational counseling and proactive telephone follow up from a practice nurse). Patients who do not show a favorable response or who require greater support may be appropriate for level 3, in which specialist consultation with a specific time limit and/or limited care management services are offered in the primary care setting. Finally, more complex and difficult to treat patients, identified by a lack of response to lower intensity care, may be appropriately managed by a specialist or care manager, possibly with responsibility transferred to specialty care temporarily or permanently (level 4). For some patients with severe illness or complex treatment needs, a higher level of care (level 3 or 4) may be the appropriate first step in care.

This increasing intensity of professional services is consistent with existing practice patterns and norms in primary care.⁴⁷ Important differences exist between this stepped-care approach and existing community standards for referral. Individualized stepped care assumes higher levels of coordination between specialist care, care management services, and primary care than generally exist.

Collaborative management implies that the primary care team, specialist-consultant, and care manager (when needed) work together to provide the level of professional support needed for effective self-management and to achieve an acceptable outcome, no more and no less. Each member of the team fulfills a clearly defined and differentiated role in the patient's care, rather than functioning as a multidisciplinary team that is coordinated by meeting frequently to discuss individual cases. Primary care physicians, the care manager, and the specialist-consultant may not have formal case conferences but may communicate informally as needed to develop, adapt, and implement care plans for individual patients.

CONCLUSIONS

Individualized stepped care is an approach in which simpler, less restrictive, less intensive, or less expensive interventions, or a combination, are tried initially, followed by care based on guidelines for patients who have an inadequate response. Care is guided by the patient's response to treatment and by a schedule for preventive maintenance, not by diagnosis alone. Stepped-care principles provide a framework for organizing and allocating the limited professional resources available for decision support, self-management support, and active follow-up in the care of chronic illnesses.

Stepped care may allow primary care physicians to transcend the gatekeeper role. However, this broader responsibility for coordinating care needs to draw on different members of a treatment team (the patient, the care manager, and the specialist-consultant) as the needs of patients emerge. The primary care team provides continuity and support for patients adapting to the changing demands of chronic illness. The care manager and specialist-consultant provide targeted services to ensure that patients achieve the best possible outcomes. At all levels of stepped care, supporting the patient's role in self-management is essential: the patient is an integral part of the team.

Stepped care draws on the strengths of primary care to care for patients with chronic illnesses without compromising the primary care physician's core responsibilities in both acute and chronic illness care. It emphasizes general capabilities in chronic illness care, such as treatment planning, patient education, active follow up, and outcomes monitoring. As primary care becomes better organized to provide these general care services for patients with chronic illness, the strengths of primary care for managing chronic illness may come to the fore.

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