

Culture and Medicine

Emotional dimensions of chronic disease

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Advances in research and the delivery of health care have reduced mortality from disease and extended life expectancy in developed countries. We are living longer, but are we necessarily living better? Those who would have died from their condition may now survive but there is the emotional cost of long-term treatment and medical surveillance to consider (for example, the patient who has had a liver transplant must then continue immunosuppression treatment). Such patients must cope with a chronic condition and yet the emotional dimensions of these conditions are frequently overlooked when medical care is considered. Concepts such as the “sick role” and “illness behavior” have helped us understand the impact of disease and are familiar to most clinicians. Yet challenges still exist in the recognition and management of the psychological and social dimensions of chronic illness.

CHRONIC MEDICAL ILLNESS

Mental illness developing from chronic disease

Patients with chronic conditions often have to adjust their aspirations, lifestyle, and employment. Many grieve about their predicament before adjusting to it. But others have protracted distress and may develop psychiatric disorders, most commonly depression or anxiety. A prospective study of general medical admissions found that 13% of men and 17% of women had an affective disorder.¹ The proportion of patients with conditions such as diabetes or rheumatoid arthritis who have an affective disorder is between 20% and 25%.² Among patients admitted to the hospital for acute care and among patients with cancer, rates can exceed 30%³ compared with a prevalence of depression in the community of about 4%-8%.⁴

It can be difficult to diagnose depression in the medically ill. Physical symptoms such as disturbed sleep, impaired appetite, and lack of energy may already exist as a result of the disease. Sometimes treatment for a medical condition (for example, the use of steroids) may affect the patient's mood, as may the disease process itself (for example hypoxia and infection in a patient with chronic respiratory disease may have a direct cerebral impact on mood). The functional limitations imposed by the disease may result in “understandable” distress, and some clinicians find it difficult to conceptualize such distress as a depressive disorder.⁵ Indeed, the distinction between an adjustment reaction and a depressive illness is often not clear. Clarification of the diagnosis may be aided by examining the patient's risk factors for depression—that is, whether they have a history of depression, a major functional disability, or pain. Other risk factors include adverse social circumstances, such as unemployment or financial strain, and a lack of emotional support.⁶ In elderly people

Summary points

- The emotional dimensions of chronic conditions are often overlooked when medical care is considered
- It can be difficult to diagnose depression in the medically ill but diagnosis and treatment are essential
- Doctors may be well equipped for the biomedical aspects of care but not for the challenges of understanding the psychological, social, and cultural dimensions of illness and health
- Clinicians can play an important part in helping their patients to maintain healthy coping skills
- Clinicians should reflect on the emotional dimensions of their work, including how professional development and training may enhance professional satisfaction and patient care, and the important role that relationships and outside activities have in providing balance

in particular, there are clear links between physical illness, disability, and depression⁷ and increased use of hospital and medical outpatient services.⁸

Despite these difficulties, it is essential to diagnose and treat depression in patients with chronic conditions. Even mild depression may reduce a person's motivation to gain access to medical care and to follow treatment plans. Depression and hopelessness also undermine the patient's ability to cope with pain and may exert a corrosive effect on family relationships.⁶ Although the patient with an incurable medical illness who commits suicide may seem to some people to have acted rationally, most of the patients who commit suicide are also suffering from a depressive illness.⁹ Furthermore, the development of depression in people with a medical illness has been linked to adverse physical outcomes and substantial increases in disability.¹⁰ Patients who become depressed after a cerebrovascular accident have been found to have an increased risk of dying¹¹ and to make significantly less recovery on measures of activities of daily living.¹² The clinical course of heart disease is also influenced by depression, and 9 out of 10 studies have found an increase in mortality from cardiovascular disease among depressed patients.¹³ It is not clear to what extent the identification and treatment of depression might improve the outcome in such cases.

The process of diagnosis is often complex, as is the treatment. Antidepressant drugs may aggravate the patient's medical condition, there is the potential for drug interactions, and the presence of impaired renal, hepatic, or gastrointestinal function may alter drug metabolism.¹⁴ Thus, selecting an antidepressant requires careful assessment of the risks and benefits.¹⁴ However, antidepressant drugs are effective in people who are medically ill,¹⁴ and

antidepressants are tolerated in up to 80% of patients with cancer without adverse effects.¹⁵ The optimal treatment of depression in patients with chronic conditions also involves using a combination of cognitive and supportive psychotherapies that incorporate awareness of the grief and loss that are consequences of the disease process.

Chronic disease superimposed on mental illness

The development of a chronic medical condition in patients with a pre-existing mental illness may lead to an exacerbation of their symptoms and bring about a deterioration in their functioning. There may be delays in diagnosing medical conditions in patients with chronic psychotic conditions because these patients may fail to give their symptoms priority or they may have an impaired capacity to communicate their symptoms.

Ethical issues can arise in considering the capacity of such patients to accept or decline treatment. Psychiatrists have a valuable role in assisting patients to understand the medical issues they face and in evaluating their capacity to make informed decisions.¹⁶

The physical consequences of mental illness merit attention in their own right. After an episode of major depression the risk of myocardial infarction increases fourfold to fivefold when other medical factors are controlled.¹⁷ Depression in women has been associated with decreased bone mineral density.¹⁸ Thus, depressive episodes may contribute to the development of medical conditions that have a chronic course.

Physical symptoms as an expression of emotional dysfunction

The development of new symptoms in a patient whose condition had previously been stable may indicate that the patient is emotionally distressed. The exacerbation of an established illness, such as the development of pseudo-seizures in a patient with epilepsy, may indicate adjustment difficulties, depression, or complex social or relationship problems. The key symptoms of the so-called somatoform disorders are physical complaints, excessive fear of physical illness, or the excessive and unwarranted pursuit of medical or surgical treatments.¹⁹ Despite their frequency in general medical practice, these problems can be some of the most difficult for doctors to manage, and doctors report finding patients with these disorders among the most difficult to help.²⁰ A doctor's use of effective patterns of communication²¹ can reduce the risk of chronic morbidity and disability.²²

ISSUES AFFECTING CLINICIANS

Patients with chronic medical conditions may provoke feelings of anxiety and professional inadequacy; they may also become an emotional burden on the clinician who is



A group of breast cancer survivors crosses a ceremonial finish line after a fundraising walk

exposed to the cumulative suffering and losses experienced by patients and their families. Counterbalancing these feelings may be the sense of fulfillment derived from providing consistent and unflinching care and the deep appreciation expressed by patients. The number of patients coping with chronic conditions seems to be growing because of improvements in treatments and increases in survival times, particularly for conditions such as HIV infection and some malignancies.

Maintaining the patient's hope

For patients and their families, hope is an integral part of coping. The clinician has a key role in engendering realistic hope. Maintaining hope is key for long-term survivors of HIV infection²³ and long-term survivors of breast cancer.²⁴ Healthy coping, however, differs from the popular notion of "positive thinking." It implies the capacity to tolerate and express concerns and emotions not just the ability to put anxieties aside. Being able to discuss the anxieties, uncertainties and fears, losses and sadness that usually accompany severe illness is generally helpful, despite the pressure commonly exerted by family and friends for the patient to always "keep a positive outlook."²⁵ "Positive thinking" may represent an attempt to avoid confronting the distress of chronic illness, and doctors who care for these patients and their families are not immune to such patterns of coping. A study of women with breast cancer found that those who sought alternative treatments had higher levels of psychological morbidity²⁶; the pursuit of such treatments might thus indicate the patient's distress rather than their well-being.²⁷

Moving towards the terminal phase

Recognizing that the condition has progressed and that the patient is approaching the terminal phase of their disease may be distressing for staff who have known the patient well. In some cases the patient may be reluctant to discuss the need to change treatment goals or the possi-

bility of death, but in others it is the doctor's avoidance that limits the chance for the patient to raise these issues.²⁸ Staff may be reluctant to relinquish more aggressive treatments. It is worth remembering that health professionals' appraisals of treatments that they would accept are different from appraisals made by patients with cancer.²⁹ Patients with a chronic illness sometimes report a surprisingly high level of satisfaction with their quality of life.³⁰ Also, clinicians may underestimate the quality of life maintained by patients with chronic illness and by elderly patients.³¹ Patients may attach greater importance to their mental health than their doctors do; doctors may focus on their patients' physical limitations.

Treatment issues

Adverse effects of treatment

The side effects of some treatments, for example those caused by steroids, may lead to frustration and anger; these feelings may be mediated by an emotional reaction to changes in the patient's body and symptoms but may also be the direct result of the effect of the treatment on the patient's mood. The clinician may experience guilt about such side effects. Additionally, patients who are angry, demanding, or resentful may engender powerful feelings of rage in staff.³²

Compliance

Although adherence to prescribed treatments may improve the course of a disease, the clinician cannot promise the patient that "being good" will be rewarded; in some diseases, such as diabetes, impairment may still occur. Young patients, in particular, may test limits and challenge the status and knowledge of the staff caring for them. Compliance may be poor even in patients who have had an organ transplanted. There may be conflict between a patient and a clinician about the proposed treatment. In chronic fatigue syndrome, for example, evidence has emerged about the benefits of cognitive therapy³³ and the importance of exercise.³⁴ If patients and their families are resistant to these approaches, long-term care may be adversely affected.

Psychosocial aspects of care

Psychosocial interventions are increasingly being incorporated into routine medical care, and these approaches seem to be effective. In patients with rheumatoid arthritis, the use of interventions to manage stress has resulted in significant improvement on measures of helplessness, dependency, coping, and pain.³⁵ Comparatively simple interventions that allow patients with asthma and rheumatoid arthritis to express the psychological impact of their disease and other stress have significantly improved symptoms in these patients.³⁶ The families of patients who are chronically ill tend to be more depressed and are more

likely to have other psychological symptoms.³⁷ Clinicians should be aware of this hidden morbidity among carers.

HOW CAN HEALTH PROFESSIONALS COPE?

Recognizing of the cost of caring

Clinicians who treat patients with a chronic illness must not ignore their own needs. Clinicians may be exhausted by the emotional needs of their patients. When the clinical course is stormy or the patient rejects treatment or commits suicide the sense of professional isolation and despair may be intense. There is strong socialization against members of the medical profession discussing their own distress for fear of appearing weak. At least half of the physicians in one study reported high levels of emotional exhaustion.³⁸

Factors that shape responses

Confronting feelings of helplessness and the limitations of the medical treatments available may elicit a range of responses from health professionals. These responses may include rejecting and withdrawing from the patient, blaming the patient for failing to recover, or taking excessive personal responsibility for the patient's failure to recover. Both under- and over-treatment of the patient may ensue. Such problems are illustrated in the widespread debate over the care of dying patients and doctors' responses to "incurable" suffering.³⁹

Health professionals do not work in a vacuum. Medical care is increasingly provided in a complex clinical and ethical landscape of public scrutiny and economic accountability. The technological complexity of medical treatment in areas such as transplantation surgery and intensive care, for example, brings clinicians face to face with complicated ethical issues on prolonging the end of life or allocating resources. Demands are made for "evidence-based care," but in many areas evidence is either unavailable or limited, causing further concern among clinicians.

Education and training

The responses made by health professionals to difficult clinical situations depend on their training and life experiences.⁴⁰ The clinical experiences of junior doctors rotating through a range of specialty attachments and participating in specialist training programs frequently fails to provide them with the experience of treating patients over a long period. Short-term contact with patients with severe chronic illnesses in hospital settings may provide junior doctors with a distorted perspective on the course of such illnesses, the role of medical treatments, the needs of patients, and their own potential responses. Surveys of medical graduates show that they are aware of these deficiencies in their training.⁴¹

Doctors may be well equipped for the biomedical aspects of care but the challenges of understanding and

responding appropriately to the psychological, social, and cultural dimensions of illness and health need to be addressed.⁴² Many clinicians also feel that providing emotional support for families is a source of stress.⁴³ Medical education must include information on the emotional aspects of diseases and their impact on the patient, the patient's family, and the clinicians treating them. Communication skills are vital. Clinicians who feel that they have received insufficient training in communication and management skills have significantly higher levels of distress than those who feel they have sufficient training.⁴⁴

Team membership and use of external resources

When a clinician is part of a multidisciplinary team it is possible to discuss difficult clinical problems, share the burden of care, and gain access to the specialist skills of other staff and agencies. Non-governmental agencies and volunteer support groups can provide social support, education, and advocacy for patients with chronic physical and mental illnesses. Clinicians have a key role in linking patients with such groups. These organizations can counteract the social isolation and stigma experienced by many patients with chronic illnesses.

Self-care

Working excessively long hours is not conducive to providing high quality health care, and clinicians should consider exerting control over their clinical work and setting their own priorities.⁴⁵ Clinicians should reflect on the emotional dimensions of their work, including how professional development and training may enhance professional satisfaction and patient care, and the important role that relationships and activities outside of work have in providing balance. Physicians cannot provide excellent clinical care if they fail to nurture themselves physically, emotionally, and spiritually.⁴⁶

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How to deal with medically unknown symptoms

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The term medically unknown symptoms covers various symptoms and diagnoses that change with the advance of medical knowledge.¹ Included in this term are illnesses such as fibromyalgia, chronic fatigue syndrome, irritable bowel syndrome, environmental sensitivities, and chemical intolerances (sometimes referred to as multiple chemical sensitivities). Although the acceptability of these symptoms as real depends on the cultural and medical climate in which they are seen, patients will continue to appear in physicians' offices with these types of complaints. Denying that patients have these symptoms will only make their problems worse.

Controversy exists over whether medically unknown symptoms are psychologic, physiologic, or both. Proponents of somatization would place medically unknown symptoms in the realm of psychologic disorders.¹⁻⁴

ENVIRONMENTAL SENSITIVITIES SYNDROME

Environmental sensitivities may best be considered a multisystem, multisymptom syndrome. The most widely used definition suggests that both environmental sensitivities and multiple chemical sensitivities are characterized by recurrent symptoms referable to multiple organ systems

and occurring in response to exposure to many chemically unrelated compounds at doses far below those established in the general population to cause harmful effects. To date, no single widely accepted test of physiologic function has been shown to correlate with symptoms.⁵

Ongoing debate in medical circles over the definition that should be applied to this clustering of medically unexplained symptoms has produced various labels. These range from multiple chemical sensitivities⁵⁻⁷ to environmental hypersensitivity syndrome,^{8,9} total allergy syndrome,¹⁰ environmental illness,¹¹ idiopathic environmental intolerance,¹² and environmental sensitivities (the last currently in use by the Nova Scotia, Canada, Environmental Health Center), just to name a few. The definitions are either narrow or so nonspecific that almost anyone could be included under their label.

In 1995, the province of Nova Scotia reported that 3% of its population was chronically affected by environmental illness.¹³ In a population study, Meggs and coworkers found that 33% of the US population reported chemical sensitivities, with 4% being affected on a daily basis.¹⁴ Recent statistics place the prevalence of environmental illness, diagnosed by a physician, at 6% of the California population. A further 16% report being "allergic or unusually sensitive to everyday chemicals."¹⁵

TRADITIONAL WESTERN MEDICINE VERSUS CLINICAL ECOLOGY

Western medicine seeks to practice evidence-based medicine.^{16,17} This is not the case for physicians who are clinical ecologists and practice environmental medicine. These physicians advocate the avoidance of a wide range of chemicals and the use of nonvalidated tests and treatments.^{18,19} Clinical ecologists think that the symptoms triggered by perfumes or other chemicals are physical and that environmental sensitivities are pathophysiologic.¹⁸ They think that personal observations and experience are all that are necessary to diagnose and treat people with medically unknown symptoms.¹⁸ Their theories and practices have been condemned by most medical societies. Relying on personal experience alone may result in incom-

Summary points

- The term medically unknown symptoms covers a multisymptom, multisystem, and multifactorial problem that has yet to have a widely accepted definition
- Medical practice traditionally involves making a clear diagnosis before intervening and before healing may occur
- Standard appointment times are not long enough for patients with medically unknown symptoms to tell their story
- Poor communication exacerbates the chronicity of the condition
- Patients respond better if physicians listen with respect, acknowledge their experience, and reassure them