From the Director

Over the last century, the success of public health and biomedicine in the industrialized world has wiped out most of the acute diseases that once brought swift and painful death. People live longer today. Yet for many, this means living longer with manageable, but often incurable illnesses, such as heart disease, diabetes, or cancer. These diseases are now what will be responsible for most of our deaths.

In 1999 the Centers for Disease Control and Prevention reported that chronic diseases were responsible for the deaths of 1.7 million Americans annually—or 70 percent of all deaths in the United States. The medical costs alone totaled more than $400 billion—or more than 60 percent of total medical care expenditures. Moreover, these chronic illnesses can corrode the quality of people’s lives. They can often lead to or exacerbate chronic mental illness—most notably, depression in all its forms, from the truly clinical to depressed mood and reduced productivity and enjoyment of life.

Many of the deaths could be prevented and the quality of people’s lives could be improved if we invested more in prevention, treatment, and better disease management. There are a number of innovations that have already been clinically proven and others in the pipeline.

Some of these measures emerge from addressing the contribution of health behaviors, including smoking, diet, and exercise, which we discussed in our last issue of Exchange. Still other interventions come from understanding the role psychology and culture play in chronic illness, which is the topic for this issue.

CHC researchers are among those shedding light on the complex interplay between mind, body, culture, and disease. CHC research helps confirm that psychology and culture pervade
Establishing The Mind-Body Link

Though it is not hard to find those who believe intuitively in the link between mind, body, and disease, intuition is not enough to change the way medicine is practiced. (Nor should it be.) Convincing a skeptical medical culture of the need to incorporate psychosocial factors into disease prevention, treatment, and management demands that we present scientific evidence—clear biological cause and effect. If we can establish, for example, that shame over-stimulates the body’s production of the inflammatory proteins that play a role in a wide range of illnesses, we might be able to overcome the resistance of a medical culture that has long focused solely on biomedical techniques for treating illness.

Shame, Self-Acceptance, and Disease

Health psychologist Margaret Kemeny is among those establishing mind-body links. An expert in psychoneuroimmunology, Kemeny has focused on the connection between psychology and immunology for the last 20 years. In her earlier work, Kemeny had helped establish that stressful experiences and individual’s psychological response to stressful events can alter the immune system and affect the course of certain diseases, such as HIV infection. But psychological responses to stressful events are quite varied and can include anxiety, shame, guilt, anger and depression, among others. Kemeny wanted to determine which of these was most likely to lead to immune changes, particularly those related to inflammation. While inflammation is a necessary bodily response to injury and infection, chronic inflammation can damage tissue and lead to a variety of chronic medical conditions, such as autoimmune disease and cardiovascular disease.

As one example of her research, Kemeny and her colleagues conducted a study that asked people to write about various events in their life, focusing on those that made them feel bad about themselves, after which she measured the level of inflammatory proteins in their saliva. She discovered that writing about such events induced feelings of shame and other emotions, and also caused the release of inflammatory proteins, in comparison to a control group. Those who reported the most shame showed the greatest increase in these important but problematic substances. She subsequently found that exposure to these kinds of stressful events was less important than whether or not the person responded with negative thoughts about the self and negative self-conscious emotions such as shame.

This has some important implications for a broad range of diseases. For example, in another study, Kemeny and her colleagues found that HIV-positive men who were sensitive to rejection showed more rapid deterioration in their physical condition and shorter survival than those who were less sensitive to rejection, even if they did not experience depression or other forms of mood disorders. Based on a growing body of research, Kemeny believes that views of the self may be important, yet quite understudied, predictors of health. So what are the implications of this research for improving health? This is not yet known. “We believe that the key is not promoting an inflated sense of oneself but instead maintaining self-acceptance, being able to accept the good and the not-quite-so-good in ourselves” says Kemeny. She intends to determine whether self-acceptance is protective when one is experiencing threats to one’s sense of self and then to measure whether...
We believe the key is maintaining self-acceptance, being able to accept the good and the not-quite-so-good in ourselves.

CHC researchers discover:

- How shame affects immunological disease
- How stress affects diabetes
- How depression affects multiple sclerosis
- How perceived community standing increases the risk of ill health

David Mohr

cognitive/behavioral interventions (restructuring the way people think about relevant issues) will improve self-acceptance and tamp down on the body's tendency to produce these dangerous inflammatory proteins.

Measuring the Physical Effect of Stress and Depression

Psychologists Elissa Epel and David Mohr are both examining the relationship between stress and depression and physical illness. Epel's research has helped establish the links between stress-induced cortisol levels, obesity, and the disease states associated with obesity. Her recent work measures whether stress reduction techniques can bring about measurable physical improvements for diabetics. Mohr's research found that lower quality of life, as measured by stress and depression, affected the course of multiple sclerosis (MS). Mohr's team established that moderate and chronic life stresses increased the risk of brain lesions associated with MS. Both are testing interventions to reduce stress and depression levels and have been able to demonstrate the impact on disease symptoms (see page 7).

Social Status and Disease

Feelings of stress or depression or the ability to accept one’s self all may be affected by social relationships and, more specifically, by social status. Psychologist Nancy Adler has pioneered much of the work on the connection between social status and health.

Adler and others have drawn clear links between perceived social status and health. One study, for example, demonstrated that people who place themselves low in terms of their community standing were between 60%–70% more likely to get a cold when exposed to the virus than those who placed themselves high on the scale.

That work on adults demonstrated that subjective social status might be a pathway to the onset of disease. Now, Adler and her colleagues have begun to trace the path backwards chronologically. In a recent study, Adler found that the MacArthur Scale effectively measured the connection between adolescents’ perception of social status and obesity and depression. Adler has now begun to explore doing similar studies in ever-younger children. “This measure (the MacArthur Scale) captures something powerful related to health,” says Adler. “Understanding the determinants of subjective states may reveal new ways to intervene to improve people’s physical and emotional health throughout their lives.”

November 2002
Emotion, Culture and Disease Management

The medical community typically views disease management as a biomedical regimen that implies drug treatments and the monitoring of a few key physical indicators, such as weight, blood pressure, and glucose levels.

But psychosocial factors have a profound effect on people's ability to comply with a medication, diet, or exercise regime. Anything from depression to conflicting cultural beliefs about illness to communication gaps with providers can undermine effective disease management. CHC researchers have begun to pinpoint just what role psychosocial factors play in the management of chronic illness.

Acceptance and Coping

Through a series of studies, including a landmark piece on asthma with her UCSF colleagues, nurse researcher Patricia Benner has identified what she calls “links between an emphasis on responsibility for self-care, and an over-attraction of self-control and responsibility in preventing asthma episodes for persons with asthma.

Assuming that one has more control over one's health than is possible may cause a sense of moral responsibility for becoming ill that, in turn, can create a sense of helplessness that diminishes self-care. By contrast, a militant rejection of the illness may come as a strong folk version of “mind over matter” that prevents people from making any concessions to the demands of the illness. Either unrealistic expectations for preventing illness, or militant rejection of the demands of the illness, may cause the person to manage their illness less effectively. Says Benner, “The challenge for providers is to figure out how to help a person come to terms with the realistic possibilities of illness prevention, and the demands of self-care during an illness episode without conveying false expectations of ‘perfect management.”

Trying to come to terms with the demands of illness is part of what is known as “coping,” something that has long been the focus of psychologist Susan Folkman’s research. Now Folkman and social psychologist Judy Moskowitz have begun adding an entirely new dimension to how we understand coping.

After a five-year study of 253 men who were caring for their partners with AIDS, Folkman and Moskowitz realized that, in the midst of this crisis, many caregivers showed high levels of “positive affect”—pride, for example, in their role and joy at their ability to express love in ways they may not have been able to do before. Folkman and Moskowitz hypothesized that such emotions are coping mechanisms, essential for keeping people effectively engaged in the process of managing disease.

Having reviewed previous studies for what they reveal about positive affect—and having replicated their own study with a different population—Moskowitz now intends to explore how positive affect affects emotional adjustment, immunity levels, and the social consequences of the disease “Perhaps this can help all patients understand that it is okay to feel these positive emotions—and to seek them out—in the face of chronic disease,” she says.

Just as positive emotions may be beneficial, psychologist Larry Fisher knows well the dangers of depression—both clinical and sub-clinical—in coping with illness. He has conducted extensive research on people with diabetes, most recently focusing on the interplay among depression, disease management, and family dynamics.

“Poor family relationships and depressive symptoms are intertwined among both patients and their spouses, and depressive affect disrupts regular disease management behaviors,” Fisher says. He describes observing one couple where the patient withdrew from a heated dis-
Poor family relationships and depressive symptoms... disrupt regular disease management behaviors.

CHC researchers:

- Illustrate the impact of “positive affect” and family relationships on coping with serious illness
- Establish that cultural beliefs about illness affect disease management
- Identify communication gaps between older Americans and health care providers

Illustration with his wife about disease management by falling asleep, indicating that the stressful nature of the interaction made it difficult for the patient to work with his wife to manage the disease collaboratively. Fisher is now testing an intervention for couples who are wrestling with a chronic disease.

Cultural Beliefs Change the Process

Fisher’s work has shown him the importance of patients’ cultural beliefs. “Our research has also indicated that different cultures approach disease and family communication about disease in different ways, so culturally specific interventions need to be part of clinical practice.” Anthropologist Gay Becker would certainly agree. Her work has consistently demonstrated that different cultural beliefs have an enormous influence on how people respond to illness.

Becker is currently part of a research team that is studying how four different cultural groups—African-Americans, Latinos, Filipino-Americans, and Cambodian-Americans—cope with chronic illness. She tells the story of an elderly Cambodian woman impaired by shortness of breath, wheezing, and tightness in her chest. She frequently awakens at night with nightmares and difficulty breathing. Many years earlier, her baby died in childbirth. She believes she is having difficulty sleeping because her child is a ghost trying to return. Although this woman has poorly controlled asthma, she thinks nightmares— not asthma—are the problem, and that her physician does not understand.

Becker’s team has begun to identify a number of distinctive cultural factors that affect illness management. Such differences argue strongly for culturally sensitive interventions if we truly want the interventions to succeed.

Understanding and Managing Disease among the Elderly

Older people also have a distinct set of physical, cultural, and emotional concerns. One of the most overlooked of these concerns is hearing loss. In recent studies, nurse researcher Margaret Wallhagen and her colleagues discovered that hearing loss not only contributes to the deterioration of a person’s mental health, social functioning, and physical activity but also affects the spouse’s psychosocial well-being.

Many people are embarrassed by their hearing loss or hearing aids. Unfortunately, isolation resulting from this embarrassment can lead to depression and lack of exercise, which negatively affect physical health and quality of life. This is especially true for people with chronic conditions—from which seniors suffer in much larger numbers than the general population.

The failure of the health delivery system to adequately recognize hearing loss exacerbates the problem. Insurance does not typically pay for hearing aids; most providers receive only minimal training about this condition’s implications. “I would like this work to heighten the awareness of the impact hearing loss has on successful aging,” Wallhagen says.

A recent study of physicians and their elderly patients more directly documented the communication gap between physicians and older Americans. Anthropologist Judith Barker and her colleagues found that physicians consistently underestimated the difficulties patients experienced in their everyday functioning, in particular around such things as bladder control and struggling to walk upstairs. These may seem to be minor issues, but they can often lead to severe depression.

“If, as a physician, you don’t understand these issues, you may miss some important cues,” says Barker. “And if patients can’t communicate effectively with their doctors, they may miss an opportunity to improve their quality of life.”
Creating More Effective Interventions

Soberly, rigorous research is pressing the medical community to change the interventions they use to manage illness.

As medical director of UCSF's Osher Center for Integrative Medicine, physician Bradley Jacobs uses many mind-body techniques in his internal medicine practice and has published reviews on their effectiveness. In one large study of people undergoing surgery for colorectal problems, one group received guided imagery and music twice daily from the 2-3 days before their operation through the six days following. Compared with those who did not receive the guided imagery and music, this group needed less pain medication after surgery, reduced the time to their first bowel movement, and had less anxiety. As a result, says Jacobs, both Kaiser and Blue Shield now supply guided imagery tapes as an option for all their surgical patients.

In many ways, argues Jacobs, the techniques reflect simple common sense. "Angry men die earlier from cardiac disease," he says. "Stress brings on chest pain. And there is a wide range of techniques to reduce anger, depression, and stress." He cites cognitive behavioral therapies that can change the way people react or think about their illness or symptoms, as well as stress-reduction techniques that range from yoga or martial arts to behavioral techniques for reducing workloads or making lifestyle changes.

Using Behavioral Therapy to Reduce Physical Risk Factors

Psychologist Elissa Epel recently provided stress reduction techniques to a group of older military veterans with Type II diabetes. Her goal was to see if by using a combination of cognitive restructuring and physical relaxation, she could reduce stress and depressive symptoms and, in turn, reduce abdominal obesity.

"For diabetics, abdominal obesity is particularly vicious," says Epel. "First, obesity increases insulin resistance, which predisposes people to diabetes and, second, once you have diabetes, abdominal obesity is likely to increase so it feeds into a downward spiral." Working with a group of retired veterans, Epel and her colleagues found that reducing stress and depressive symptoms clearly led to reduced abdominal obesity and a healthier cortisol rhythm.

The men engaged in daily meditation and relaxation exercises for three months, choosing from a wide range of potential techniques. For the cognitive restructuring, Epel and her colleagues met with small groups twice a week for three months to address how these men thought about problems in their life, including their disease. One example of a common negative thought was: I can't control my diabetes, which means I am a weak person. The groups helped them understand that they could indeed manage the controllable aspects of the disease—and helped supply the tools to do so.

"What was fascinating," says Epel, "was that most of these men were not interested in the traditional diet or exercise interventions. They'd been hearing that from their doctors for decades. But when we framed what we were doing as stress reduction, that was more interesting to them, as a new way to help themselves and their health. And after doing a relaxation exercise, when they saw nearly immediate improvements in their blood pressure, they were surprised and impressed. Hearing that relaxation reduces blood pressure is much less powerful than actually experiencing and seeing the changes on oneself."

Over a six-month period, the treatment group showed a reduction in abdominal fat, had healthier cortisol levels, and reduced anxiety. Epel notes that she still needs to do a long-term follow-up to see
“Hearing that relaxation reduces blood pressure is much less powerful than actually experiencing the changes on oneself.”

CHC researchers:

- Test mind-body techniques in everyday medical practice
- Use stress reduction to reduce risks for diabetics
- Reduce complications for heart patients by providing a sense of control
- Stave off the progression of MS by treating depression
- Heighten the quality of life for patients and families suffering through terminal illness

if the results will hold, but she believes they will based on similar attempts with other diseases. “I believe studies that help understand the psychological issues inherent in coping with diseases are one of the most important contributions psychology can add to the discussion of how to help people with long-term illness,” says Epel.

Working With Families

Like Epel, Larry Fischer is testing an intervention for patients with Type II diabetes, though his focus will be on reducing depression by working with the patients and their spouses. This is based on his earlier work that demonstrated that a couple’s emotional state has a significant impact on diabetes management. Fischer will test a one-day couples workshop that works on problem solving, communication, respect for different belief systems, understanding of the disease, and the need to verbalize. Spouses will speak first in different groups about their roles; then the groups will come back together and, finally, the couples will speak with each other individually.

“Marital quality affects the pervasiveness of the disease,” says Fisher.

“Given what we hear from patients and spouses about their fears and their feelings of helplessness—and our observations of couples’ difficulty in dealing with this ‘thing’ that takes up so much of their lives—communication and understanding become crucial for disease management.”

A Sense of Control

Abating feelings of helplessness in both patients and families has been a large part of Kathy Dracup’s work with heart patients. “We know that psychological adjustment in the early phases after a cardiac event, especially a sense of perceived control, affects future complications and compliance with medical and exercise regimens,” says Dracup, Dean of the School of Nursing.

Dracup has focused on decreasing the anxiety of patients immediately following surgery, as well as providing patients and families with the tools to recognize symptoms early and to do CPR if necessary. She has completed a number of studies that measure the effectiveness of giving patients’ confidence that they can control the effects of their disease.

“In one study, we found that the combination of a family presence, education, and an orderly environment significantly decreased anxiety, depression, and hostility immediately following the procedure and improved psy-

Kathy Dracup

Addressing the Course of Disease—and Beyond

Psychologist David Mohr has also tested a number of interventions for treating emotional symptoms in chronic or terminally ill patients. After studies indicated that stress contributed to the risk of new brain lesions in multiple sclerosis patients, Mohr compared the effectiveness of three widely used depression therapies for multiple sclerosis patients who were also suffering from major depressive disorder.

continued on back page
all the stages of chronic disease and that there is an interactive, ongoing link between the disease and psychological factors and cultural beliefs.

This implies that prevention, treatment, and management tools for chronic illness must not be limited to biomedical approaches. For many people, the inclusion of psychological and cultural factors could make the difference between experiencing a devastating downward spiral or an empowering climb toward improved quality of life. Helping provide the latter is one of the most important goals of our work.

**Nancy Adler**

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**Interventions continued from page 7**

“While there was some difference in the three treatments, the study confirmed that depression is treatable for MS, which in turn can affect underlying immune processes known to be responsible for disease exacerbation,” he says.

Another study points to the importance of addressing emotional responses to terminal illness. Mohr worked with couples where one spouse had terminal cancer. He found that helping couples communicate about dying and helping the patient understand that they had a caregiver role as well resulted in significant reductions in anxiety about dying, reductions in depressive symptoms for the caregiver, reduced conflict, and increased closeness.

These results raise an important point about the role health care and health care providers play in helping patients cope with chronic or terminal illness. Health care services are more than the amelioration of acute biologically based symptoms; health care providers can utilize social and psychological knowledge to lessen suffering and improve the quality of life for individuals and families living with disease, even the terminally ill.”