A NEW MODEL FOR TREATING THE CHRONICALLY ILL

The Four-Phase Model (Fennell, 1993, 1995a, 1998, 2001, 2003a, 2003b, 2003c), a method for assessing and treating the chronically ill, addresses the heterogeneity that characterizes chronic conditions. Although phase or stage models are not in themselves new, this particular model offers a robust, flexible, and comprehensive systems approach and applies it specifically to chronic illness. This approach does not separate chronic illness into a number of separate conditions, but it regards certain factors common to all forms of chronic illness as sharing characteristics that can make the Four-Phase Model a particularly efficacious approach.

Chronic conditions represented by the overall term chronically ill include:

- Physiological diseases that most of the medical profession considers chronic illness. These include, but are not limited to, conditions such as diabetes, rheumatoid arthritis, multiple sclerosis, lupus, cystic fibrosis, Sjogrens syndrome, chronic fatigue syndrome (CFS), fibromyalgia (FM), and scleroderma.
- A group of conditions that encompasses diseases where the successes of current treatment have extended the patient’s life so that the patient lives with the disease in much the same way a patient in the first category does. These include HIV/AIDS, various cancers and kidney diseases, heart disease, stroke, and orthostatic disease.
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- A group of conditions for which the Four-Phase Model may provide useful intervention, including addictions, depression, posttraumatic stress syndrome (PTSD), situations involving intractable pain, and postrape and abuse conditions.

Whereas each condition may have specific medical treatments associated with it, which may differ from those associated with other chronic illnesses, the Four-Phase Method addresses what I consider to be the distinctive characteristics of chronicity that make all chronic conditions particularly difficult to assess and treat successfully with current approaches.

NECESSARY PARADIGM SHIFTS

I believe that in order to evaluate and treat individuals with chronic illness appropriately, it is important to adopt a systemic approach. First, it is necessary to acknowledge the intimate interplay that exists between the individual’s mind and body. Next, the individual, the individual’s family, clinician, workplace, social network, and the overarching community must be seen as dynamic, interactive, interdependent factors within an organic whole (T. Wilson & Holt, 2001). The Four-Phase Model considers that a person’s body and mind and his or her family, friends, clinicians, colleagues at work, and community at large are essential contributors to a total environment where changes that occur in one part of the system affect all other parts.

The model described in this book addresses several factors often missed in current approaches to care for the chronically ill. It recognizes the existence of the previously mentioned nested set of systems that a patient inhabits and calls attention to several conceptual dichotomies that frustrate successful patient care. It examines the phenomenon of chronicity and the varieties of traumatization that can be experienced by the chronically ill. The approach assumes that patients who successfully navigate the four phases will achieve integration rather than cure. Because of this changed goal, clinicians engage in a shift of viewpoint and undertake new activities. In addition to ensuring that their patients receive standard medical care, clinicians following this model seek to provide palliation for their patients, guide them toward strategies for dealing with their life situation, and engage with them in discussions of the philosophical or spiritual dimensions of their situation.
The new model defines four broad phases experienced by the chronically ill—crisis, stabilization, resolution, and integration. For each phase, the model describes the events and responses that typically occur in each context of the patient’s life—that is, within the physical and psychological self and within the family, clinical setting, workplace, community, and culture at large—and identifies methods of assessment and treatment for that phase. Each phase also addresses the changing experiences of the clinician and provides direction so that clinicians may best incorporate these changing experiences.

The model recognizes that patients may move backward as well as forward among the phases because lapses of insight or new crises of illness or life situation may return the patient to experiences characteristic of earlier phases (Berg, Evangelista, & Dunbar-Jacob, 2002; Chin, 2002; Prochaska, Norcross, & DiClemente, 1994; Sutton, 1997). After patients and clinicians have negotiated the four phases once, however, they have learned to anticipate the experience of relapse in their illness or untoward new experience; and after the initial shock, they know better how to deal with it (DiClemente, 1991). Whereas they must again use the techniques of earlier phases to address the new issues, the time spent moving into resolution and integration diminishes.

Empirical investigation has demonstrated the validity of the four discrete phases. Outcomes demonstrating clinical efficacy have not been completed (Jason, Fennell, Taylor, Fricano, & Halpert, 2000; Jason, Fricano, et al., 2000; Jason et al., 1999; Van Hoof, Coomins, Cluydts, & de Meirleir, forthcoming-a, forthcoming-b).

THE FOUR-PHASE MODEL AND OTHER PHASE THEORIES

The Four-Phase Model takes the increasingly popular construct of stage theory and revises and expands it to define four phases of adaptation that occur in chronic illnesses. The phases are locations along a passage that patients must navigate on the way to defining a new self and a new life. The model describes the events of chronic illness and the responses to it that typically occur at each phase of the illness experience in the context of the individual’s life; that is, the model addresses the physical-behavioral manifestations, the psychological manifestations, and those relating to the social-interactive sphere.
It is important to recognize that for those suffering a chronic condition, the alteration in their lives is imposed (Chin, 2002). The Four-Phase Model maps a process that, for the most part, individuals do not enter into willingly. This fact distinguishes the model significantly from stage theories that focus on intentional change in the psychological sphere alone (Prochaska, DiClemente, & Norcross, 1992).

Moreover, throughout this process, individuals suffering chronic conditions are subject to experiences in their physical condition or in their social interactive life over which they have little or no control (Onega & Larsen, 2002). It is primarily in their psychological life that these individuals have experiences and can engage in activities somewhat similar to those of stage models such as Prochaska’s Transtheoretical Model of Behavioral Change (TTM; Prochaska, DiClemente, & Norcross, 1992; Prochaska & Velicer, 1997a, 1997b; Prochaska et al., 1994).

Once individuals experience the physical and psychological crisis of illness onset, as well as the social responses this sets in motion, their ability to stabilize usually depends on skilled intervention, which recognizes that certain protocols are more successful during crisis and others during stabilization. When intervention ceases at stabilization, however, or does not address the systemic responses of the individuals’ social and work world, many of the chronically ill cycle back from stabilization into crisis again and sometimes simply from crisis to crisis (Chin, 2002). In part, this response expresses the individual’s own desire to deny the intolerable aspects of chronicity and the ambiguity of chronic illness and return to the former self and way of life. But, in part, it also occurs because of the individual’s response to the social pressure of family, friends, and the workplace to return to the precrisis self. Informed clinicians may facilitate movement out of this relapse cycle into the resolution phase by helping patients learn to understand and develop tolerance for chronicity and ambiguity, to grieve for their losses, and to begin constructing a new and meaningful existence in all the domains of their life—the physical, the psychological, and the social/interactive.

Although the phases are sequential, this model, like some others, recognizes that patients may move backward as well as forward; they may exhibit signs of more than one phase simultaneously; and later crises, whether disease-related or otherwise, may propel patients back into Phase 1 (Berg et al., 2002; Prochaska et al., 1994; Sutton, 1997). When patients have successfully progressed through the four phases once, however, the knowledge they gain during
the first passage makes it possible for them to process subsequent crises more swiftly and efficiently. This phenomenon has been noted in other stage models (DiClemente, 1991). Patients more quickly understand what is happening to them, know techniques to help improve their situation, and have the skills to seek and utilize necessary clinical help.

Several decades ago, stage theories became a useful method of organizing information in different fields into typologies, categories, or hierarchical constructs (Erikson, 1959; Kohlberg, 1959; Kübler-Ross, 1969; Piaget, 1952). Such frameworks have had a variety of applications (N. D. Weinstein, Rothman, & Sutton, 1998): They help researchers understand how individuals use medical services (Rakowski et al., 1992), they aid in the adoption of preventive behavior (Blalock et al., 1996), and they suggest how to stop unhealthy behaviors (Brownell, Marlatt, Lichtenstein, & Wilson, 1986; DiClemente, 1991; Prochaska, DiClemente, & Norcross, 1992; Prochaska & Velicer, 1997a; Prochaska et al., 1994). By helping to organize research that might seem unrelated or contradictory when not conceptualized from a stage framework, such models offer important heuristic contributions to scientific and social disciplines. In addition, the models suggest new areas and domains of inquiry, as theorists and investigators use these templates to make more precise, targeted predictions (K. S. Berger & Thompson, 1995).

Among stage-theory models, one type posits a pattern of discrete, sequential stages, where each stage contributes to an invariant developmental sequence. The stages progress hierarchically, with each succeeding stage considered a qualitative advance over the preceding one. The new stage is thought to combine aspects of the previous stage with the current stage’s new aspects in a more specialized manner (Rest, 1973).

The Four-Phase Model belongs to a second type, which employs stages as a method for arranging information into specific categories. The model employs the term phase rather than stage because it does not regard the phases as discrete entities, and patients do not necessarily pass through them only once. Phases can, in fact, recur and may overlap, resulting in more than one phase occurring concurrently (Fennell, 1993, 1995a, 1998, 2001, 2003a, 2003b; Jason et al., 1999; Kübler-Ross, 1969).

The Four-Phase Model posits that when coping with the change imposed by a chronic illness, patients and their families progress through phases, similar in nature to those postulated by Kübler-Ross for individuals experiencing the death of a loved one, as they learn to negotiate the illness experience. The
model offers a robust design for understanding how all the elements of change in chronic syndromes operate in both the short and the long term.

Like other stage theories that have argued that matching intervention to stage provides the best outcomes (DiClemente, 1991; Prochaska, DiClemente, & Norcross, 1992; Prochaska & Velicer, 1997a; Prochaska et al., 1994), this model indicates what may be expected over time and indicates the best times and ways to intervene to improve the patient’s quality of life. Conversely, interventions attempted at the wrong time may prove less effective and may undermine the possibility of the same interventions being effective at a later phase when the patient would ordinarily be responsive to such interventions (Berg et al., 2002; Woods, Haberman, & Packard, 1993).

Finally, the overall goal of the Four-Phase Model is integration of the illness into the patient’s life, not a cure in the traditional sense. One distinctive aspect of integration as the final phase is that integration is not a conclusion. Stage models that deal with dysfunctional or addictive behaviors conclude when participants cease using the substance or exhibiting the behavior. But chronic illness patients never leave the phases. The process of maintaining themselves, ideally in the integration phase, is ongoing. It does not reach an end.

Phase 1 of the Four-Phase Model is characterized by crisis. Individuals move from the actual onset of the syndrome to an emergency stage. Its severity typically forces sufferers to seek some form of relief. This relief may take the form of medical, psychological, or spiritual help, but sometimes individuals simply resort to a self-administered anodyne in the form of alcohol or drugs. The task of the individual, the family, and the clinician (if present) during this phase is to cope with the hurt, loss, and potential trauma of the new illness.

Phase 2 is characterized by the search for stabilization. Patients continue to experience chaos and dissembling about the illness, but often their symptoms have plateaued and they feel a degree of control returning to their lives. Now their struggle is to fit their condition into their lives. The task of the individual, family, and clinician in the second phase is to initiate stabilization and the restructuring of life patterns and perceptions.

It is my clinical experience that without sustained guidance from a clinician, most patients find themselves either perpetually in crisis (Phase 1) or in an endless loop between the first two phases. Each plateau of stabilization recalls the precrisis “normal” life. Patients want to deny that a permanent change has occurred, and frequently those around them in their home and work life
want to deny it as well. The potential trauma, stigma, and loss patients suffer as ill individuals offer no incentive to accepting the illness as a permanent condition and learning to cope with it. When they first plateau in their physical symptoms or develop some *modus vivendi* with them, patients can feel a false sense of relief and are usually anxious to return to life the way it used to be. Often, they are also receiving pressure from others to return to former life patterns and activities. This may encourage them to behave in ways that promote a relapse, but equally often patients suffer relapses because that is the nature of their condition or because of a crisis totally unrelated to the illness. With clinical support and guidance, however, patients can be helped to learn from their relapse experiences (Berg et al., 2002; Prochaska, DiClemente, & Norcross, 1992; Prochaska et al., 1994) and, by doing so, make the very important transition into Phase 3.

Phase 3 is characterized by *resolution*. Patients may experience a plateau of symptoms or suffer relapse, but they have learned how the illness behaves and how the world responds. They realize in a very deep way that their condition is chronic—that it will not end in the foreseeable future. The task of the third phase is for patients to develop meaning in their lives and create a new self as they work to accept the chronicity and ambiguity of the chronic illness experience.

Phase 4, the final phase, is characterized by *integration*. Patients may experience recovery, continued plateau of symptoms, or periods of relapse. But they have now integrated aspects of their preillness self with the person each is now. The task in this phase is to continue to find ways to express a new “personal best”; to reintegrate or form new supportive networks of family and friends; to find other vocations, activities, or appropriate employment if they are able to work; and to locate the illness experience within a larger philosophical or spiritual framework. In the most complete integration, patients have validated the realities of their illness, stabilized and restructured their lives, developed meaning, and come to experience a complete life in which illness is only one aspect (Fennell, 1993, 1995a, 1998, 2001, 2003a, 2003b).

Whereas theories of health behavior change are most typically psychological in focus (Prochaska et al., 1994), the Four-Phase Model does not confine itself to the psychological aspects of adjustment to illness (Fennell, 1993; Kübler-Ross, 1969). In each separate phase, it addresses factors proceeding from the physical-behavioral and social-interactive domains, as well as the psychological, and considers problems associated with stigma and illness.
traumatization. It also examines factors that arise from social and cultural influences (McCahon & Larsen, 2002). Increasingly, researchers in medical family therapy (Doherty, McDaniel, & Hepworth, 1994) and others, such as Wellard (1998) and Henderson (1997), are moving in this direction.

No person exists solely as an illness. At the same time that individuals are navigating the process of an illness—which in chronic illness usually means for the rest of their lives—they are also moving through the developmental and maturation arcs that occur in every life. Simultaneously, they carry out continually changing patterns of activity that include self-care, school, job, care of others, and many other activities. In addition, the personal energy process, which shifts over time and with regard to influences other than health, intersects with the chronic illness experience. These developmental and activity processes are discussed in greater depth in subsequent chapters.

It is also essential in the Four-Phase Model to consider external social and cultural issues because they have a profound impact on the experience of chronic illness. Poverty, violence, discrimination, lack of social support, multiple homes or schools, learning disabilities, and abuse are issues that can make it extremely difficult to negotiate a chronic illness experience as well. Nonetheless, in a fashion similar to the TTM model, the four-phase structure allows clinicians to identify those places and times when it is possible to make meaningful interventions that can permit a patient to escape from an endless loop through successive crises (Prochaska, DiClemente, & Norcross, 1992; Prochaska & Velicer, 1997a; Prochaska et al., 1994). Although the effectiveness of matched interventions and the lack of efficacy of mismatched interventions have yet to be demonstrated empirically, my clinical experience and that of the people trained in this approach initially support the assertion.

Some factors provide positive support for patients. Patients may have always been physically robust before the illness and have had strong recuperative powers. Patients may be psychologically hardy and adaptable. They may enjoy a positive and supportive environment in the form of family, friends, self-help groups, church groups, community organizations, civil rights organizations, and feminist groups. All these social elements can help to integrate those with chronic illnesses into meaningful life with other people.

Some of the salient literature on adaptation to chronic illness focuses primarily on the patient’s response to the initial diagnosis (Greer, Morris, & Pettingdale, 1979). The Four-Phase Model describes the experience of the chronically ill over time without being confined to a unidirectional process.
Increasingly, others are paying attention to changes that occur in patients as they continue to live with a chronic illness (Henderson, 1997; J. Lewis, 1999; Rolland, 1987; Wellard, 1998). But even these analyses describe a trajectory for the unidirectional process, whereas the Four-Phase Model incorporates instances of relapse, overlap of phases, and return to crisis. Wellard suggests that the trajectory model may be an error resulting from the deeply ingrained preference of clinicians for achieving cures. In contrast, J. Lewis (1999) suggests that the HIV patients undergoing her “status passages” may move back to a prior status if they experience a remission in symptoms, but at the present time her conception appears applicable only to this specific illness.

Unlike most change theorists, who posit an eventual end to the adjustment process and an end to relapses (Brownell et al., 1986; N. D. Weinstein et al., 1998), the Four-Phase Model views chronic illness as a cyclical experience (Fennell, 1993, 1995a, 1998, 2001, 2003a, 2003b). Even though patients have successfully achieved the psychological and social integration goals of Phase 4, it is possible that relapses or untoward life experiences may return them to an earlier phase. Other stage theorists describe a similar spiral phenomenon in the relapsing behavior of addicts, but their model suggests that relapers do not cycle endlessly and do not necessarily regress back to the beginning (Brownell et al., 1986; Donovan & Marlatt, 1988; Prochaska, DiClemente, & Norcross, 1992; Prochaska et al., 1994). Instead, they postulate that the addicts learn from their mistakes and can apply different strategies during subsequent attempts to end their addiction (Prochaska, DiClemente, & Norcross, 1992; Prochaska et al., 1994). The Four-Phase Model posits similar learning from past mistakes in the movement through the phases but also asserts that chronic illness patients are never immune from the possibility of being thrown back into a prior phase or into crisis. Following one successful navigation of the four phases, however, such revisitations to earlier phases tend to be partial and of shorter duration than the original progression.

Each different population uses the Four-Phase Model in a different way. For patients and their families, the model helps them to organize a narrative of their experience. Narratives appear to be a very useful coping tool (Neimeyer & Levitt, 2001; Nochi, 2000). The understanding that the narrative gives can reduce fear and anxiety for both patients and their families. The unknown becomes more known and, through the descriptive structure of the phase narrative, patients make sense of their distressing experiences. As ambiguity and chaos diminish, patients gain a degree of coherence about their experiences.
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They have a method of validating their experiences, stabilizing and structuring their responses, developing meaning for their experiences, and ultimately developing a full, complete life. The narrative offers roles for patients and their families to assume, giving them a positive framework within which to construct new lives.

For the empirical investigator, the Four-Phase Model provides a template that reconciles diverse phenomena into an integrated, unified construct, potentially permitting a better understanding of the widely divergent experiences of patients with chronic illness. Prochaska, DiClemente, Velicer, and Rossi (1992), authors of the most popular and arguably the most thoroughly researched theory of stage-based behavioral change, have lamented the lack of research on other forms of behavioral change and an analysis of how these forms resemble or differ from their own. Fortunately, the investigation of stage/phase approaches seems to be increasing (Rolland, 1994; Wellard, 1998).

One commentator has noted that clinicians begin working with methods that seem right and valuable—if they do no harm—before they have empirical evidence that demonstrates the efficacy of their approach. He comments that scientific evidence rarely precedes policy and practical developments in the real world (Heather, 1992). Another commentator added that there was no evidence for the effectiveness of Miller’s groundbreaking article on motivational interviewing, only a conceptual framework and a practical set of counseling strategies that made sense and could be put into practice immediately (Stockwell, 1992).

In a review article, Prochaska and colleagues allude to the large number of individuals suffering from the problems they address (Prochaska, Velicer, Fava, Rossi, & Tsoh, 2001). With half the population of the United States suffering with at least one chronic illness (Hoffman, Rice, & Sung, 1996), it seems that research resulting in best practice in this area would be of great benefit.

For the clinician, the Four-Phase Model has three specific applications:

1. The model includes phase-specific assessment steps and interventions to help patient and family meet the tasks at hand (Prochaska, DiClemente, & Norcross, 1992; Prochaska & Velicer, 1997a; Prochaska et al., 1994; Woods et al., 1993).

2. It also integrates the assessment steps and interventions into a broad collection of spiritual and philosophical traditions, such as Buddhism and Jungian psychology, as well as with more contemporary therapies.
Finally, this phase model provides a framework for using the therapist’s or clinician’s countertransference experiences.

UNDERLYING ASSUMPTIONS OF THE MODEL

Most of the assumptions of this model are neither novel nor original. The model draws on a variety of approaches and philosophies in clinical care and employs a systems approach.

Body-Mind Integration

The model uses a holistic paradigm based on the concept that body and mind are integrated and that all illnesses involve both soma and psyche to greater or lesser extents. This holds true whether the illness is heart disease, lupus, or multiple sclerosis and whether the initial presentation is of physiological symptoms or of psychological ones. The Four-Phase Model assumes that there are psychological components to physical illnesses and physiological components to illnesses defined as psychological. Clinicians review each patient from the perspective of both body and mind, regardless of the symptoms that brought the patient to the clinician initially and despite the focus of the clinician’s primary training. Those trained to treat psychological disease consider physiological problems, whereas those trained to treat physical disease examine for psychological factors. All providers must then ensure that treatment covers whatever is necessary for the entire body-mind system (Doherty et al., 1994; T. Wilson & Holt, 2001).

Throughout this book, the term clinician is used to cover a broad range of health care practitioners including medical doctors, psychiatrists, psychologists, medical/clinical social workers, counselors, therapists, and others, rather than repeatedly listing the array of practitioners who might function in a particular context. In some instances where only one or two disciplines would be able to perform the function mentioned, either the particular specialty or the term clinician may be used.

The Patient-Family System

The patient is not only an individual body-mind system, but also part of a family (Woods et al., 1993). It is important to note here that the concept of
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family includes both the patient’s biological and marital relatives and any individuals whom the patient considers as his or her family. To be effective, clinicians include the patient’s family, however constructed, both in assessment and in treatment. The physiological and psychological symptoms that the patient experiences have a direct impact on the family, and the family’s response has, in turn, a direct impact on the patient (Beardslee, Versage, & Gladstone, 1998; Bull & Jervis, 1997; Doherty et al., 1994; Falicov, 1988; Henderson, 1997; Nicassio & Smith, 1995; Travis & Piercy, 2002; Yeheskel, Biderman, Borkan, & Herman, 2000).

The Patient-Family System in the Community and Workplace

Chronically ill patients and their families are inextricably involved in larger communities, particularly in their various places of work. All the mutual interactions that occur between patients and their families also take place among patients, their families, and their larger communities and workplaces. A patient’s illness may disrupt work schedules for both patient and family members and may result in lost income, conflicts in relationships both at home and at work, and overall stress. Coworkers, employers, or others in the community may respond in ways that multiply negative social, psychological, and physiological symptoms (Lubkin & Larsen, 2002; Roessler & Sumner, 1997; Satcher, 1992; Satcher & Hendren, 1991; Scambler & Hopkins, 1990; Ware, 1998).

In addition, patients diagnosed with the same chronic illness may have widely varying experiences because they differ from one another as to income level, class, ethnicity, race, sexual orientation, education, and other demographic issues (Anderton, Elfert, & Lai, 1989; W. F. Auslander, Thompson, Dreitzer, White, & Santiago, 1997; Blum, Potthoff, & Resnick, 1997; Heijmans & de Ridder, 1998; Henly, Tyree, Lindsey, Lambeth, & Burd, 1998; J. Lewis, 1999; Penninx et al., 1999; Scambler & Hopkins, 1990; Siegel, Raveis, & Karus, 1997; Woodgate, 1998).

The Patient-Family System and the Clinician

Patients and their families are embedded in the health care system most noticeably through the person of their primary clinician. The clinician is an active part of the health care system, which in turn is an integral part of the patient’s family and community system. Along with providing or failing to provide appropriate treatment for the patient, the clinician also defines the
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The patient’s condition both for the patient and for the community at large. This definition dramatically affects how the patient will think about himself or herself and how the world will respond to the patient (Anderton et al., 1989; Doherty et al., 1994; Nicassio & Smith, 1995; Scambler & Hopkins, 1990; Tait, Chibnall, & Richardson, 1990).

Embedded Systems and Holistic Assessment and Treatment

Because the different systems interact and have impact on one another, assessment and treatment that focus on the patient alone, apart from all the other systems, may be more susceptible to failure. Each system can reduce, magnify, and sometimes even create symptoms in the patient or in individuals associated with the patient. Patients with difficult problems often have a correspondingly profound effect on the clinicians, their workplaces, and their communities. Problems can continuously transmute and multiply unless clinicians use a systemic holistic approach (Doherty et al., 1994; Nicassio & Smith, 1995).

Many contemporary approaches to medical problems consider themselves holistic. The Four-Phase Model uses this term more inclusively than is sometimes the case. Holistic in this model includes more than the body-mind continuum or the importance of philosophical or spiritual factors, though these are obviously important. In addition, this model examines the practical institutions and worlds that affect a patient. It takes into consideration, in both assessment and treatment, a broad range of economic and cultural issues from lost wages and what treatments health maintenance organizations (HMOs) will cover to destructive or misleading attitudes projected by the national media.

Poverty and the Socially Disadvantaged

The poor and disadvantaged suffer disproportionately from chronic illness (Lubkin & Larsen, 2002; Hardin, 2002), yet they have far fewer resources than middle-class people have to help deal with the illnesses. Some middle-class individuals suffer a drastic reduction in income because of their chronic illness and are forced to deal with issues of poverty and lack of access to health care in addition to their illness. Health expenses are the leading cause of personal bankruptcy in the United States, and although many people are devastated by the expenses of catastrophic acute illnesses, many others become impoverished because of chronic illness (Jacoby, Sullivan, & Warren, 2001; Warren, Sullivan, & Jacoby, 2000). Even if poor patients have access to
medical care, the services they need may not be available to them. Language and cultural issues may raise further barriers to adequate assessment and treatment. Lack of education may also make some therapies difficult because many interventions require a level of verbal communication that depends in large part on patient and clinician sharing class, educational, and sociocultural backgrounds.

Increasingly, communities are beginning to experiment with new methods of delivering necessary services and support to the chronically ill (Jason, Fennell, & Taylor, 2003); and as chronic illness becomes more widely recognized, public clinics such as CURE, run by Johns Hopkins in East Baltimore, are developing methods of dealing with this patient population. Clinics and public social services recognize the importance of language and cultural assumptions and attempt to get input and assistance from other members of the patient’s community. The Four-Phase Model emphasizes the necessity for clinician and patient to form a strong bond that can take place only if clinicians understand or learn about the cultural imperatives in their patients’ lives.

CONCEPTUAL DICHOTOMIES

The model presented in this book assumes that previous clinical and scientific approaches have often created conceptual dichotomies in patient care (Riska, 2000; Thornton, 1998; Walter, 2000). These include mind as opposed to body, clinical approaches and realities as opposed to empirical constructs and related findings, illness as opposed to disease, professional activity as opposed to personal involvement, and clinician as opposed to patient.

Such dualistic thinking has plagued the culture of health care since the Enlightenment. In the Cartesian split of mind from body, physiological, observable, and material things became acceptable objects of medical investigation, whereas psychological, nonobservable, and immaterial things were not (S. L. Baumann, 1997; Bendelow & Williams, 1995; Epstein, Quill, & McWhinney, 1999; Gamsa, 1994; Kirmayer, Robbins, & Paris, 1994; Stuart & Noyes, 1999; Vaughan, 1994). The division included in the province of mind everything moral and character-related, leaving medicine to examine only those things connected with the physical being. The actual and observable could be viewed as real, or legitimate, whereas nonmaterial processes “existing only in the mind” were unreal, and hence not legitimate medical
issues. Although in the past 25 years, the health care profession in general and behavioral medicine in particular have made great strides in understanding the interaction of mind and body, the cultural assumption that the two are distinct still subtly or openly persists in much clinical practice.

**Body-Mind**

Much as the Age of Reason and the Enlightenment helped to establish rigorous scientific analysis, this particular distinction has sometimes served to obscure what actually happens in clinical situations with actual illnesses.

In the seventeenth century, scientists arrived at a territorial agreement with the Church whereby the human body would belong to the province of science, and the less determinable mind and immortal soul would be the province of the Church. Scientists at first regarded the parts assigned to the Church as things that were unknowable by reason, and hence not necessary to their pursuits, and more subtly as things of lesser or diminished importance. What occurred in the mind or soul belonged in the realm of imagination or fancy, whereas physical things were real and could be investigated objectively. Measurable physiological symptoms came to be the only reliable indicators for disease, at least those treated by doctors who were men of science. As scientific and materialist thinking began to dominate cultural conceptions, most people came to share these attitudes, especially about health. Any health issue thought to proceed from a person’s mind or soul was in some fashion imaginary or willed, unlike conditions with clear physical causes and symptoms. Inevitably, an imagined or willed illness seemed to many to indicate a failure in the patient’s character, if it was not intended fraudulence.

Even after the late nineteenth century, when psychological conditions began to be acceptable as areas of scientific medical study and treatment, they continued to be regarded with suspicion by many in the medical community. Even today, measurable chemical changes in brain chemistry make mental conditions more acceptably medical than conditions for which there are no physical markers. Finally, there is always the possibility that nebulous or irregular symptoms are imagined and may indicate malingering or some other character flaw.

A somewhat negative evaluation of psyche persists in the term *somatization* (Epstein et al., 1999; McCahill, 1995; Stuart & Noyes, 1999). A patient with a psychological condition who manifests physiological symptoms is conceived as having consciously or unconsciously created them from the arena of
psyche, whereas a genuinely sick person is the innocent victim of physical symptoms caused by completely mechanical or external and undesired agents. Medical personnel frequently determine that patients who manifest intermittent or hard-to-measure physiological symptoms that do not immediately fit into a standard diagnostic category are psychologically ill and creating their physiological symptoms, or somatizing. This is not to say that somatization is without merit as a clinical description. But despite the desire of clinicians to remain objective and nonjudgmental, for some, a somatized physical symptom is not in the same category as a real physical symptom (Salmon, Peters, & Stanley, 1999).

Chronic illnesses expose the deep flaws of the body-mind split, which is one reason they can make observers so uncomfortable. Despite the fact that today many people, even or especially those in health care, acknowledge that body and mind are inextricably intermixed, the Cartesian split still exists, dividing body from mind and permitting unfortunate and damaging judgments to flourish.

Disease-Illness

A growing dichotomy in the health care field is the one between disease and illness. Everyday language tends to use these two terms interchangeably, but it is useful to distinguish them in a way that will help illuminate an aspect of clinical treatment (Anderton et al., 1989; Durban, Lazar, & Ofer, 1993; Epstein et al., 1999; Ridson & Edey, 1999; White & Lubkin, 1995).

The traditional medical community diagnoses and treats disease. That is, the patient has identifiable physical symptoms (pain, rash, fever, swelling, etc.) that clearly fit established causes (virus, bacteria, physical trauma) for defined sicknesses or conditions (flu, measles, broken leg), and the medical practitioner attempts to return the patient to his or her previous, “normal” state.

Increasingly, however, a growing number of care providers who must deal with more intractable or long-term conditions are seeking to treat “illness” in addition to disease. That is, they try to treat the patient’s psychological and social experience and the overall experience of suffering as well as the defined disease. This approach, it can be argued, treats the entire person. It considers the individual’s various life experiences in addition to his or her medicalized body. It includes the individual’s family system, work situation, and community setting (T. Wilson & Holt, 2001). Within the illness framework, clinicians use the patient’s cultural and philosophical or spiritual context, as well as social context, to evaluate that individual’s experience of
illness. By examining the patient’s total experience, the clinician greatly enhances the effectiveness of treatment.

**Empirical-Clinical**

It has been argued that a gulf separates the people who investigate the causes and treatments of chronic illness and those who actually treat the chronically ill. The disconnect and lack of communication that can exist between empirical investigators and clinicians mean that important new information and understanding about treatment is poorly distributed. This division grows wider as some protocols that have not been empirically investigated have become increasingly popular. This has created even greater distance and, to a certain extent, greater distrust between those who investigate chronic illnesses and those who treat them (Irvine, Phillips, Fisher, & Cloonan, 1989; Ivanoff, Robinson, & Blythe, 1987; Kontz, 1989; Singer, 1995).

**Professional-Personal**

People educated traditionally in the provision of medical care are usually trained to hold themselves apart emotionally from their patients so that they will be able to make objective, clear assessments and provide effective care. The underlying assumption is that emotional engagement with patients clouds the clinicians’ judgment and thereby damages or destroys their effectiveness. Even those who receive psychological training are urged to maintain distance from their patients for the same reasons (Collins, 1994; Durana, 1998; Durban et al., 1993; Hirschauer, 1991; Lang, 1990; Levinson et al., 1999; Ridson & Edey, 1999).

Traditional training often includes discussion of *countertransference*. Clinicians are informed about reactions they may feel in response to patients’ issues or experiences, but until relatively recently, they were instructed that having these feelings—that is, experiencing countertransference—was rare and not to be indulged or encouraged. Even today, training in the physiological or psychological domain of medicine tends to assume that emotional distance is the clinicians’ most desirable stance (Collins, 1994; Counselman & Alonzo, 1993; Durban et al., 1993; Hirschauer, 1991; Lang, 1990; Levinson et al., 1999; Mitrani, 1993; Ridson & Edey, 1999; Roter et al., 1997). Some change is occurring in this area, which can only be applauded. Many clinicians are now taught that personal reactions to patients do occur regularly and that clinicians should acknowledge and manage their personal feelings.
Not surprisingly, therefore, some patients complain that their providers are impersonal, cold, distant, unfeeling, and fail to communicate with them well (Armstrong, 1987; Barnett, 1998; Lang, 1990; Roberts, 2000). They assert that the providers do not understand them or relate to them or care for them in the broad emotional sense of the term care. As a consequence, the patients often do not trust the providers or believe that their treatment will be effective. Patients with chronic problems, who continue to experience symptoms regardless of treatment, often manifest their distrust of and lack of relationship with medical practitioners by shopping for clinicians, going from one to another in an attempt to find someone who will help them and make them feel cared for (Marbach, 1999; Schlesinger, Druss, & Thomas, 1999).

Americans expect clinicians to care for their patients, not simply to assess and treat them, and most traditional medical providers claim that they do care for their patients in addition to maintaining the objectivity demanded by their training (A. O. Baumann, Deber, Silverman, & Mallette, 1998; Harder, Kelly, & Dunkelblau, 1997; Lang, 1990; Roberts, 2000; Roter et al., 1997). Medical personnel say that they strive to act in a warm, caring manner but that it has become increasingly difficult in the current health care environment, where economic market concerns, over which they have decreasing control, continuously shorten the time they may devote to any individual patient (Gordon, Baker, & Levinson, 1995; Harder et al., 1997; Levinson et al., 1999; Ware, Lachicotte, Kirschner, Cortes, & Good, 2000). Health maintenance organizations seek to increase productivity—health care professionals seeing more patients in the same time frame—and, at the same time, they require increased substantiation and documentation of examinations and procedures. In determining how best to serve patients, doctors often feel they have no choice but to focus on measurable assessment and treatment activities rather than on forming relationships with patients, an activity often perceived as time consuming (Fishman, 2001).

Patients continue to insist, however, that they want a personal relationship. When asked, for example, why they seek alternative medical care, most patients include their perceptions that the alternative practitioners are caring and courteous (Hastings Center Report, 2000; Kelner & Wellman, 1997; Neuberger & Woods, 1995).

Another result of restraining personal response to remain “objective” is that patients turn into examples of their disease. They cease to exist as individual human beings of the same sort as the medical practitioner (Levinson et al.,
A New Model for Treating the Chronically Ill

Although this may be necessary to help the health care provider endure the horrible news that an assessment may bring, the pain or suffering the necessary treatment may require, or even the annoyance or anger the patient may stimulate in the clinician, separating the patient into a category apart from the medical practitioner ultimately hurts the patient. The patient becomes a different “class” of person from the clinician, one whose pain, suffering, confusion, and terror are not of the same kind or quality as the clinician might feel.

The Four-Phase Model encourages clinicians to consider their own individual natures and their own subjective responses in both assessment and treatment of the chronically ill. The approach asserts that part of clinicians’ role is to monitor their own and their patients’ subjective needs continuously and to seek to employ these observations and understandings to broaden their assessment and enhance treatment. The more clinicians review their own inner experience and harness their reactions positively, the more they can increase their relatedness with patients and hence their effectiveness (Emanuel, 1995; Howe, 1995; Lazare, 1987; T. Lewis, Amini, & Lannon, 2000). Clinicians must, of course, bear in mind the issues of appropriate boundaries between practitioner and patient and, in some instances, legal issues.

Clinician-Patient

The dichotomy between clinician and patient grows out of the division encouraged between the clinician as a professional and as a feeling individual (Harder et al., 1997; M. Rosenberg & Molho, 1998). All too often this distinction can transmute into the notion that there is an intrinsic difference between those who provide care and those who receive it. The distinctiveness of the clinician is reflected in behavior both on and off professional duty. Some have explained this separateness by arguing that in addition to medical providers’ needing to remain objective, they also need to develop and maintain a strong, separate ego to carry out their work. Given the life and death decisions they make, professionals in the health care world, even nurses and technicians, have an aura of special powers. This tends to keep medical providers elevated above patients and isolated from them (Fugelli, 1998; Loewe, Schwartzman, Freeman, Quinn, & Zuckerman, 1998; Mitrani, 1993).

Patients and the public at large have helped to establish medical practitioners on a higher, separate plane because the public wants to believe that their
medical providers will always be able to rid them of pain, suffering, and danger. When the medical world fails, as it often must, people generally prefer to blame the patient rather than the doctor and medical science. They prefer to assume that if they were sick, their better attitudes or behavior, in conjunction with the doctor’s skill or the pill’s efficacy, would produce a cure in them and that failure lies in the patient, not the doctor (Ax, Gregg, & Jones, 1998; Ballweg, 1997; M. S. Bates & Rankin-Hill, 1994; M. S. Bates, Rankin-Hill, & Sanchez-Ayendez, 1997; Epstein et al., 1999; Kirmayer et al., 1994; McCahill, 1995; Morse, 1997; Stuart & Noyes, 1999; Thorne, 1990; Turk & Rudy, 1991).

Not only does this separation damage individual relationships between care provider and patient, but it also hurts the general community (Barshay, 1993; M. S. Bates et al., 1997; Ware, 1998). It leads to unrealistic expectations about prognoses in illnesses and harmful judgments of the chronically ill. In addition, the distance between medical provider and recipient can be further exacerbated by a perception that lack of a caring relationship between clinician and patient is economically motivated (Barnett, 1998; M. S. Bates, 1990; DiMatteo, 1998; Safran et al., 2000; Ware et al., 2000).

At the same time that medical treatment has succeeded in curing an increasing number of acute conditions, the number of chronic illnesses among all age groups has soared. In addition, improved medicine has turned some previously acute conditions into chronic ones (Do Rozario, 1997; Heinzer, 1998). With the average life span in developed nations extending into the 80s and some people living well beyond that, more and more of the general population will eventually experience chronic illness, including health care providers (Barshay, 1993; Elliot, 1996; McReynolds, 1998). All parts of the population will be affected. Children who were ill will survive and become providers. Clinicians who have worked as medical professionals will experience chronic illness and disability and receive care from others, especially in their old age (Barshay, 1993; Counselman & Alonzo, 1993; Durban et al., 1993; Elliot, 1996). One way or another, most people not only will experience a chronic illness, but also will have to help care for someone who is chronically ill. Without doubt, this will increase their understanding of what clinicians are trying to achieve with the chronically ill. Those who receive care and those who provide it will become increasingly interchangeable.

In today’s world, the upper-, middle-, and lower-class divisions in health care are collapsing into one increasingly overburdened health care system,
and this, too, is bound to affect the quality of care adversely. Yet, it is possible that this very collapse may also help to heal the split between clinician and patient (Casey, 1999; Rauber, 1998; Rosenbaum, 2000).

THE PHENOMENON OF CHRONICITY

The following dichotomies position chronicity in the contemporary cultural context.

Acute versus Chronic Illness

In the history of modern Western medicine, the focus has been on acute diseases, that is, on conditions that have a single clear cause, a specific onset, identifiable symptoms, usually a single treatment, and ultimately a cure (Lubkin & Larsen, 2002). Until about 75 years ago, Americans did not have to consider chronic illnesses very closely because people simply did not live long enough. It is true that in the past some people spent a great part of their lives as “invalids,” either with recognized conditions such as gout or dropsy or with unspecified ones, such as often disabling “female complaints.” But for most of the population, those who fell sick either recovered—with or without medical assistance—or they died. The same was true for those who were injured. This is no longer true. For the first time ever in history, people are living long enough so that chronic disease is becoming common.

Americans have, as yet, a cultural intolerance of chronic illness. This proceeds in part from Western culture’s enduring philosophical split between body and mind. In part, it results from the cultural assumption of health as a normative state and illness as a disruption of the normative (Thornton, 1998). But it also comes about because medical practitioners frequently do not actually observe the ebbs and flows, the relapses and remissions, of chronic illness (M. S. Bates et al., 1997; Epstein et al., 1999; Kane, 1996; Robinson, 1990; Rood, 1996). It is hard to understand the appearance and disappearance of symptoms, especially when clinicians do not actually see them, and it is particularly frustrating, and thus hard to credit, that symptoms keep changing over time. The chronically ill individual often has to report on his or her condition, rather than the symptoms being patently obvious to the clinician or
accessible via clinical tests. But self-reporting is subject to question if unac-
companied by other “hard” data. For the most part, only those symptoms ob-
erved by the clinician during a medical visit are considered real and then
only because they can be observed by the trained, objective clinician. Self-
reporting is also suspect because it is tainted by the patient’s psychological
reactions (M. S. Bates et al., 1997; Heijmans & de Ridder, 1998; McCahill,

Chronic illnesses, moreover, frequently do not have single clear causes.
They do not exhibit simple beginnings, middles, and conclusions. Instead, pa-
tients go through cycles of relapse and remission. Chronic illnesses are also
frequently hard to treat (Ax et al., 1998; M. S. Bates et al., 1997; Epstein et al.,
1999; Mayer, 1999). When a condition does not fit into an acute framework, the
system tends to regard it as psychologically based, inorganic, and potentially
not legitimate medical business (Ax et al., 1998; Ballweg, 1997; M. S. Bates &
Rankin-Hill, 1994; M. S. Bates et al., 1997; Epstein et al., 1999; Gamsa, 1994;
Kirmayer et al., 1994; Komaroff et al., 1996; Mayer, 1999; McCahill, 1995;
Reis, Hermoni, Borkan, & Biderman, 1999; Stuart & Noyes, 1999). Calling an
illness psychological is sometimes simply a way to assert that the illness may
not really exist and may, in fact, be an issue of character (Ax et al., 1998; Ball-
weg, 1997; M. S. Bates & Rankin-Hill, 1994; D. W. Bates et al., 1993; Gamsa,
1994; Kirmayer et al., 1994; McCahill, 1995; Stuart & Noyes, 1999).

**Illness as Anomaly versus Illness as Normal Life**

In the traditional cultural framework, illness is viewed as unusual or anom-
alous (Thornton, 1998). In reality, members of all families, workplaces, and
communities will experience illness and disability. Illness is just as sure as
death and occurs more frequently, a fact society ignores just as relentlessly as
it ignores death (Fugelli, 1998). Despite the current awareness that health
care is a necessity for everyone and despite the great political debate raging
over appropriate forms of health care insurance, health care issues them-
selves are viewed as something merely possible in life, not as something in-
evitable (Fugelli, 1998; Ware, 1998). Insurance and hospital promotional
materials celebrate their maintenance of *wellness*, not their care of disease.
Because Americans consider illness an anomaly, rather than a fact of normal
life, they are ill prepared to deal with chronic illness either in themselves or
in others.
Given the increasing numbers of people with chronic illness, the culture must come to a new understanding of what is a natural eventuality. Chronic illness needs to become something for which people are emotionally and intellectually prepared and for which they plan, the same way they plan for children or education or retirement. The society needs to develop a language and behavior for open discussion of chronic illness, as well as methods for coping with it (Burckhardt, 1987).

**Static versus Dynamic Disabilities**

Over recent decades, American society has developed a radically new attitude toward people with disabilities, which it has even solidified into law (Remsburg & Carson, 2002). Wheelchair access that is commonplace today would have been unthinkable in 1950. But the culture, including the world of health care research and care provision, still lacks an awareness that many illnesses are disabling and thus create disabilities (Rolland, 1994) and that disabilities can be dynamic as well as static or unchanging.

Consider a man who has lost his leg. Once his initial physiological trauma is resolved, most people think of his situation as being a fairly static one. Day by day, his disability varies little. Except for secondary physical complications or new forms of technology to assist him, the man’s disability will remain the same for the rest of his life.

However, a growing population of the disabled includes what can be called the *dynamic disabled*. These include patients with conditions such as HIV/AIDS, CFS, or FM and, increasingly, patients with lupus, multiple sclerosis, and even cancer. These patients have disabilities, but they are not fixed or static because the patients’ symptoms ebb and flow cyclically as their conditions relapse and remit (Bergquist & Neuberger, 2002; Komaroff et al., 1996; Rood, 1996; Ware, 1999). The manifestation of their disabilities can be said to be dynamic.

Some people have combinations of dynamic and static disabilities, requiring clinicians to maintain awareness of both conditions in one individual. In addition, some disabilities can be worsened by physical or social stressors. Stress, for example, is known to exacerbate the symptoms of lupus or multiple sclerosis (Cannon & Cavanaugh, 1998; Gatchel & Gardea, 1999; Ware & Kleinman, 1992). And even though the stress of external events would not change the disability inherent in the loss of a leg, it could well have a significant effect on intermittent chronic pain suffered by the man who had lost the leg.
Clinical Concerns of Chronicity

Most models of Western care approach illness as though it were acute. Protocols for physical and psychological evaluation tend to stress the presenting problem that the patient is experiencing during the clinical visit (Armstrong, 1987; M. S. Bates, 1990; Gamsa, 1994; MacIntyre, Ford, & Hunt, 1999; Reis et al., 1999). Symptoms that the patient experiences at times other than the clinical visit may be dismissed as unreal. Patients may even be suspected of fabricating or exaggerating symptoms (Ballweg, 1997; M. S. Bates et al., 1997; Gamsa, 1994; Kirmayer et al., 1994; Marbach, Lennon, Link, & Dohrenwend, 1990; Mayer, 1999; McCaill, 1995; Rood, 1996; Stuart & Noyes, 1999). Such a binary model—the patient either exhibiting symptoms (presumed to occur most of the time) or no symptoms (because they are not seen in the office)—will not support any primary clinician trying to provide quality care to chronically ill patients.

The acute model of disease has recovery as its goal (Cameron & Gregor, 1987; Cooper, 1990). Even when recovery is assumed to include a prolonged rehabilitation period and is thus weeks or months away, ultimate recovery is still assumed. When recovery does not occur and, in fact, the patient’s illness is chronically dynamic and continues to proceed through cycles of relapse and remission, it is understandable that clinicians may experience each relapse or the unchanged illness state as representative of patient failure. Frustrated medical providers, if they are convinced that their treatment has been appropriate and should be effective, may come to locate the failure in the patient, who may be seen as resisting care, even sabotaging it (Ballweg, 1997; Barnett, 1998; M. S. Bates et al., 1997; Kirmayer et al., 1994; Kontz, 1989; McCaill, 1995; Rood, 1996; Turk & Rudy, 1991). Again, the clinician may suspect that the patient’s original symptoms were of psychological origin or perhaps simply reveal a defect of character.

This form of clinical response exists on a continuum of disbelief. Within the acute model framework, once the clinician determines that the patient is not recovering, he or she can relegate the problem to the psychological realm. The patient will then fit conveniently into a schema that begins with denial, moves on to resistance, continues to somatization or conversion, and finally arrives at malingering and moral or character failure (Anderton et al., 1989; Ballweg, 1997; Cameron & Gregor, 1987; Kirmayer et al., 1994; McCaill, 1995; Stuart & Noyes, 1999; Turk & Rudy, 1991).
At the same time, patients treated according to an acute model of care have expectations that are not appropriate to a chronic illness (Benet, 1996; Durban et al., 1993; Rood, 1996; Turk & Rudy, 1991). Most people have been culturally trained to expect an immediate, unambiguous diagnosis, followed by a treatment that provides immediate relief, preferably through the administration of a drug. With the medical advances of the past several generations, patients have come to expect medical miracles. When they don’t experience one, they are confused and disappointed. People no longer have cultural expectations of suffering, whether physical, psychological, or social, and they resist and resent any health treatment that requires lifestyle changes. They certainly do not expect to have to change their lives dramatically, let alone permanently (M. S. Bates & Rankin-Hill, 1994; M. Rosenberg & Molho, 1998; Thorne & Patterson, 1998). Understandably, in an acute model of illness, a severely relapsing patient very likely assumes that a relapse after eight years of tenuous improvement is the result of either a personal or clinical failure, when instead it could, in a phase model of chronic illness, be a probability that the patient could plan for.

Although the situation is gradually changing, most clinicians and patients are not yet trained to perform as joint partners in health care (Alonzo, 2000; M. S. Bates & Rankin-Hill, 1994; M. Rosenberg & Molho, 1998; Thorne & Patterson, 1998). Both parties expect that the clinician will find a cause and eventually provide a cure. When both groups are forced to accept new roles in the management of chronic illness—in which the clinician has a decreased level of control and the patient an increased responsibility of management and thus control—the situation can be equally uncomfortable for clinician and patient.

Empirical Concerns Relating to Chronicity

Clinical investigations are also dedicated to an acute model of care. Data are collected from the patient population at a particular point in time, which establish that the patient population has a particular set of symptoms. Even when data are collected several times in a longitudinal study, they still may not capture the characteristic waxing and waning of symptoms in chronic illness. Many patients in a study may not be experiencing all the typical symptoms at any discrete instance of data collection (Armstrong, 1987; Buchwald, Pascualy, Bombardier, & Kith, 1994; Komaroff et al., 1996; McGorry, Webster, Snook,
& Hsiang, 2000; Turk & Rudy, 1991). When the empirical framework takes an essentially binary approach—the simple presence or absence of a set group of symptoms—it does not necessarily capture the chronic illness experience.

Moreover, the acute model fails the empiricist because chronic patients are gathered into one undifferentiated group. Some chronic patients with the same condition offer few usefully similar symptoms or patterns of symptom. The acute model fails to distinguish the distinctly different symptoms and responses that appear in particular phases of chronic illness or disability (Friedberg & Jason, 1998; Jason, Fricano, et al., 2000).

In fairness to the scientific community, as mentioned before, the necessity to develop models of chronic care is fairly recent. At the turn of the century, individuals expected to live 50 or 60 years, assuming that they survived a host of childhood diseases. It was only later in the twentieth century that Americans came to stay alive for such a long time. Thanks to advances in public sanitation, in the pharmaceutical industry, and in technologically driven assessment and surgical procedures, they can expect to live into their late 70s and early 80s.

As the baby boomers, a huge demographic group, continue to age, the percentage of the population with chronic illness can be expected to soar. Furthermore, it is reasonable to assume that members of the aging population will have more than one chronic illness. Thus, it is imperative to develop effective models of chronic care that include protocols for assessment, treatment, and management.

**TRAUMATIZATION OF THE CHRONICALLY ILL**

Research has drawn attention to the effects of cumulative trauma or adversity, which can result in a spectrum of trauma-related disorders ranging from the more benign (i.e., anxiety) to the severe (PTSD; Alonzo, 2000; Dohrenwend, 2000; Fullilove, Lown, & Fullilove, 1992; Turner & Lloyd, 1995). Individuals who repeatedly suffer traumas that may not meet the diagnostic criteria of PTSD in the strict clinical sense (Scott & Stradling, 1994) may Nonetheless experience symptoms that manifest at any point on a continuum of symptomology from severe PTSD to what has been called subclinical PTSD (Blank, 1993; Vrana & Lauterbach, 1994). Cumulative adversity and the possible resulting continuum of trauma disorders can impact the patient’s ability to cope.
with the illness experience, the health care system, and other life domains (Alonzo, 2000). Patients may develop impeded responses to their own symptoms and the utilization of health care because of an accumulated burden of adversity. This has been investigated in certain specific medical conditions such as heart patients and cancer patients (Alonzo, 2000; Alonzo & Reynolds, 1996), but clinically it can also be seen as a response to many chronic conditions, which expose patients to various and repeated traumas.

**Stigmatization**

It also cannot be stated strongly enough that stigma is attached to many chronic illnesses and that this has an adverse effect on the patient as well as those in the patient’s world. The medical community, the media, and the public have at times, depending on the illness, variously trivialized, stigmatized, sensationalized, and minimized chronic illness (Ax et al., 1998; Ballweg, 1997; Brody, 2000; J. Lewis, 1999; Marbach et al., 1990; Scambler & Hopkins, 1990; Schiller et al., 1994; Stuart & Noyes, 1999; Ware, 1998). If a person looks healthy, it is difficult to believe that he or she is actually suffering from any illness. In our culture, we expect an obvious physical sign of illness or disability. Without such evidence, people can become suspicious and conclude that the person merely claims to be ill and may actually be lazy, malingered, and vaguely immoral.

**Evolving Definition of Trauma**

Increasingly, the formal clinical definitions of trauma found in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) are coming under critical scrutiny (Alonzo, 2000; Asmundson et al., 2000; Blank, 1993; Fullilove et al., 1992; Scott & Stradling, 1994; Turner & Lloyd, 1995, Yehuda & McFarlane, 1999). Although there is legitimacy in current definitions, concerns remain, especially in situations concerning, for example, lifelong trauma (Herman, 1999; Mezey & Robbins, 2001). In a paper about survivors of prolonged and repeated trauma, Herman provides strong evidence that current definitions must be expanded to account for a variety of stress-related disorders. As to trauma and CFS, for example, results of a community-based sample study suggest that, in medical practice, when evaluating and treating individuals with chronic fatigue and unexplained somatic
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symptoms, it is essential to consider coexisting psychosocial and psychiatric issues (R. R. Taylor & Jason, 2000). In addition, some biological abnormalities occurring in individuals with PTSD have occurred in individuals with CFS and FM (R. R. Taylor, Friedberg, & Jason, 2001).

Hence, the current definitions may not be inclusive enough to capture what many clinicians and researchers believe to be genuine trauma experiences associated with chronic illnesses or conditions. Traumas can vary widely, and individuals suffer the effects differently. An individual’s history and his or her circumstances at the time of any trauma can further affect the individual’s perception of it. Furthermore, the degree to which patients may be traumatized may depend on what others think, feel, and believe about their particular illness. Some conditions generally elicit sympathy and concern, whereas others arouse strong social condemnation and stigma. And, as discussed previously, the accumulation of trauma or adversity also affects individual responses to chronic illness.

Failure to Diagnose Trauma

Research indicates that PTSD is routinely undiagnosed in clinical settings. Clinicians on the primary care level tend not to consider this problem, and they often do not recognize it or differentiate it from other symptoms (Zimmerman & Mattia, 1999). As a consequence, trauma is underreported and not integrated into treatment plans. This situation is changing somewhat for particular medical conditions. Literature is developing as to medical and surgical events triggering trauma sequelae (Scott & Stradling, 1994; Shalev, Schrieber, & Galai, 1993). For example, heart patients can experience trauma symptoms after treatment (Stoll et al., 2000) and, as a result, fail to pursue life-saving interventions in a timely manner during subsequent heart-health events (Alonzo & Reynolds, 1996). Similarly, acute respiratory distress patients can experience trauma after treatment (Schelling et al., 1998). Women can experience PTSD as a result of giving birth (Ayers & Pickering, 2001) and after complicated abortions (Fisch & Tadmor, 1989). A significant literature is developing about cancer and its treatment and traumatic stressors for survivors (Alter et al., 1996; Cordova, Studts, Hann, Jacobsen, & Andrykowski, 2000; M. Y. Smith, Redd, Peyser, & Vogl, 1999), for women in particular (Hampton & Frombach, 2000), for children (Twombly, 2001), and for family members (M. Y. Smith et al., 1999; Twombly, 2001). Controversial illnesses are also being investigated for their potential traumatic effects,
including HIV-positive patients (Botha, 1996) and CFS patients (Fennell, 1995b, 2001, 2003c).

**Traumas Caused by Illness Onset**

The individual’s recognition that something is very wrong—the moment when he or she actually experiences the onset of the chronic illness—can be as traumatizing as the actual effects of the illness itself. The specific symptoms of the illness may include pain or infection, severe depression, the inability to walk or speak properly, the inability to read or write, or any one of a number of other physical changes. Because all of these symptoms can result in physical, cognitive, emotional, lifestyle, and social changes that cause additional pain and difficulty for patients and their families, it is hardly surprising that the patient’s actually realizing the onset of the illness is frightening, sad, and inevitably accompanied by loss (Alonzo, 2000; Baldwin, 1978; Botha, 1996; Lindy, Grace, & Green, 1987).

**Traumas Caused by Family Response**

Even though patients may gradually come to terms with their chronic illness and learn productive ways to live with it, their families may not. A patient’s changed life may be more than a spouse has bargained for. Parents may simply not want to believe that their chronically ill child is not going to get appreciably better, and children don’t like or know how to relate to the changes in a chronically ill parent. None of these reactions is lost on the patient, and each may cause trauma apart from the actual disease symptoms (Cannon & Cavanaugh, 1998; Fisher & Weihs, 2000; Hayes, 1997; Heinzer, 1998; Pless & Nolan, 1991; Scambler & Hopkins, 1990; Ware, 1998). Some families attempt to shield patients from anything that reminds them of their condition or situation. One researcher refers to this as the *trauma membrane* (Lindy, Grace, & Green, 1981). As part of this shielding, families may discourage patients from seeking treatment or from carrying out treatment protocols because these would remind the patient of the unhappy condition.

**Traumas Caused by Societal Response**

The culture is constructed around an idealized work ethic in which healthy, productive individuals are considered the most socially useful and are valued
Accordingly. Given this, those who are very young, very old, differently abled, or infirm may be loved, indulged, or even admired but are not seen as contributing to the good of society and thus can be actively devalued. People with chronic illnesses are often unable to engage in economically productive work at their former pace. As a result, these individuals, who frequently have no outward signs of illness or disability, may be perceived as simply trying to escape from doing their fair share or engaging in otherwise self-serving victimization (Bartley & Owen, 1996; M. S. Bates et al., 1997; Henderson, 1997; Plehn, Peterson, & Williams, 1998; Pless & Nolan, 1991; Scambler & Hopkins, 1990; Stuart & Noyes, 1999; Tait et al., 1990; Ware, 1998, 1999).

Accordingly, society’s response can be extremely hurtful, and these potentially traumatizing events tend to repeat again and again. Such responses can occur in the workplace, at home among family members, or in any environment or situation where the patient’s chronic illness may become an issue (Bartley & Owen, 1996; Cannon & Cavanaugh, 1998; Fisher & Weihs, 2000; Heinzer, 1998; Ware, 1999; Ware & Kleinman, 1992).

The medical community, the media, and the public at large have at times stigmatized, belittled, or sensationalized chronic illnesses such as CFS (Ax et al., 1998; Ballweg, 1997; Brody, 2000; J. Lewis, 1999; Marbach et al., 1990; Scambler & Hopkins, 1990; Schiller et al., 1994; Stuart & Noyes, 1999; Ware, 1998). It was only a few years ago that the term "yuppie flu" was used to stereotype individuals suffering from CFS (Barshay, 1993). If people “look” healthy, it is difficult to believe that they are actually suffering from any illness. In our culture, we expect to see a scar, a crutch, a wheelchair, or some other obvious physical sign of illness or disability (Bergquist & Neuberger, 2002). In the early 1980s, the media called AIDS the gay plague, thereby stigmatizing anyone with AIDS as a person who engaged in homosexual (and thus immoral) acts (Kitzinger, 1990). Victims were seen as deserving the punishment of the disease (Nisbet & McQueen, 1993; Schiller et al., 1994; Singer, 1994).

**Premorbid and Comorbid Traumas**

It is also important to consider traumatic events that are independent of the patient’s specific chronic illness but may be confused with it or contribute to the manner in which the patient processes the illness. Premorbid traumas are those that occurred before the onset of the chronic illness (Blum et al., 1997;
Ware & Kleinman, 1992). Examples include childhood incest, assault as an adult, active duty in the armed services, time spent in a war zone, torture, natural disasters, car accidents, and so forth.

Comorbid traumas can include developmental transitions and upheavals, such as the birth of a child, the decision to return to work, and the death of a loved one (Alonzo, 2000; Gatchel & Gardea, 1999; Van Mens-Verhulst & Bensing, 1998). But comorbid traumas may also consist of the illness of family members, caregiving responsibilities, divorce, assault, robbery, or any other unusual life event (Lutgendorf et al., 1995; R. R. Taylor & Jason, 2002). It is important to recognize that trauma can result in some individuals from even a positive situation, such as a new marriage, a longed-for pregnancy, or a new job.

Clinicians also need to recognize and help their patients see that chronic illness may lengthen the processing of life changes such as the death of a loved one because the chronic illness often entails slowed decision making, chaotic thinking, short-term memory loss, the inability of perform activities of daily living, or other cognitive and physical impairments. Avoiding or ignoring issues that arise from chronic illness may confuse both patients and clinicians about, for example, the grief the patient feels when a child leaves home or the misery caused by perpetual pain or exhaustion. Those who provide treatment need to help patients define their experiences on all levels. By separating current external events from emotional and physiological responses to chronic illness, clinicians can help mitigate the disruption surrounding transitional upheavals and the mental or cognitive disorientation associated with the changes wrought by chronic illness.

Finally, it is important for clinicians to recognize that although unrelated to the chronic illness, these other traumas are part of the cumulative trauma package.

**Vicarious Traumas**

Those who live, love, and work with the chronically ill can also be traumatized (Hayes, 1997; Rolland, 1994; Scott & Stradling, 1994). Like the patient, these people can experience trauma because of the illness onset, their witnessing of the patient’s suffering, or their own difficulties because of their changed life. They, too, can suffer from society’s judgments and responses to their loved ones. Family members as well as patients have premorbid and comorbid issues. They may be divorcing the newly ill patient, or they may be a
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patient’s child. They may be going through their own developmental crises. They may find that their spouse cannot have children because of a chronic illness. Those associated with the patient also may experience iatrogenic traumatization.

Vicarious traumatization affects clinicians as well (Clark & Gioro, 1998; M. Rosenberg & Molho, 1998). Any clinician can be upset by witnessing the onset of an illness or distressed by the chronic nature of an illness. The inability to cure a patient can produce frustration and despair or anger. It can be argued that all clinicians have their own premorbid and comorbid issues, and all experience countertransference.

Clinicians can also suffer guilt by association and clinical marginalization because of whom they treat (Engel, 1977). Clinicians who treat the poor, the disenfranchised, and the chronically ill report experiences of stigmatization or discrimination by their peers because of treating specific illness groups. One primary care physician reported being warned by her HMO not to take on any more of “those chronically ill patients” (communication to the author). Another physician who was very effective in treating a particular chronic illness group let it be known that she did not want the larger patient community to learn of her effectiveness with these patients. Her HMO had already hinted that she was “misplacing” her efforts and had told the office staff to consider her caseload for such patients closed. Another physician practicing in a popular tourist area was strongly encouraged by local politicians to move his practice elsewhere because he championed the care of a particular group of patients (communication to the author).

Iatrogenic or Clinically Induced Traumas

Iatrogenic trauma is usually associated with a medical response or intervention to a physiological illness (Cuijpers, 1998; Epstein et al., 1999; Kirmayer et al., 1994; McCahill, 1995; Stuart & Noyes, 1999). In addition to including mistakes or unexpected adverse events (e.g., a new illness contracted because of a hospital stay), iatrogenic trauma can also arise from what is normal and appropriate medical care. This kind of medical traumatization may involve the actual treatment itself, and it may also involve frustrating or frightening experiences with the health care system over a period of time (Alonzo, 2000; Alonzo & Reynolds, 1996). This second kind of trauma can affect whether patients continue with medical care or how they respond to it.
In the context of chronic illness, it is also necessary to extend the concept of iatrogenic illness into two other areas. The first is the domain of medical intervention that is not considered procedure-specific, such as informal contact with the patient and the patient interview and assessment (Hampton & Frombach, 2000). The second arena where iatrogenic response is possible is the arena of psychological care (van der Kolk, McFarlane, & Weisaeth, 1996).

All of these potentially traumatizing events interface with one another. They can accumulate over time into a significant clinical concern (Alonzo, 2000).

THE INTEGRATION ASSUMPTION

Unlike medical models that assume an eventual cure, the Four-Phase Model pursues the goal of illness integration. Whether the disease or illness experience is acute or chronic, this model assumes that it needs to be integrated within the ultimate health and quality of life of the patient. Even if a patient is assured of complete recovery and achieves it, the physical and emotional scars of the illness can remain and need to be considered in that person’s ongoing physiological and psychological health maintenance. Where a patient suffers a chronic illness and will never achieve a cure, the necessity of integration is paramount, because the patient should not have to experience clinical and personal failure repeatedly with each relapse or illness change.

Immediate disease symptoms (such as pain and fatigue), auxiliary symptoms (such as emotional suffering and loss), traumatization, and stigmatization all need to be approached with the goal of integration. This model conceptualizes that symptom reduction or elimination is one goal, but not the only goal. It is part of an overall effort that seeks to help the patient integrate symptoms into a meaningful, explanatory narrative framework. This approach shifts the expectations of chronically ill patients from unattainable goals to accessible ones and thus makes it possible for both patients and clinicians to achieve success.

PALLIATION

The treatment tools of palliative care are logical additions to the treatment options for the chronically ill. Traditionally, palliation has been applied
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primarily to the terminally ill and then only to reduce suffering. Medical practitioners do not usually turn to palliation until they have abandoned what are considered active treatment options (Butler, 1996; Marbach, 1999; Stieg, Lippe, & Shepard, 1999).

In current practice, active treatment—treatment aimed at returning the patient’s medicalized body to some state considered *normal*—continues, and technological methods are used to assess and treat organic symptoms that can be measured and quantified until the patient is perceived to be gaining nothing from the treatment and hence to be actively dying (Clifford, 1993). At this point, active treatment is discontinued. For some, palliation is offered, often in the form of hospice care. Finally, the patient becomes an object of “care,” and he or she is treated as a whole person, not only as a medicalized, diseased body (Weissman, 1997; Weissman & Griffie, 1998).

In the Four-Phase Model, palliation is an active treatment option. In chronic disease, palliation bridges the disease-illness and cure-integration dichotomies. At the same time clinicians pursue specific treatment to eliminate or reduce disease symptoms, they can use the treatment tools employed by hospice and pastoral care providers to improve the patient’s overall quality of remaining life. These methods incorporate a variety of auxiliary and holistic approaches, such as family treatment and pastoral care. They are thoroughly acceptable within the hospice setting and have long-established empirical and clinical links with the traditional medical community (Mayer, 1999). Because these methods can distinctly improve the quality of care for chronically ill patients, they might also help eliminate the reasons chronically ill patients seek inappropriate or unproven care.

PATIENT AND CLINICIAN TOGETHER

The Four-Phase Model offers a shared progressive experience for the patient, the family, and the health care provider. The clinician does not treat from outside but is an intrinsic component in the process, which embraces the whole array of embedded issues and worlds the chronically ill patient inhabits. It is a truly holistic, systemic approach. The dichotomy between the patient and the clinician has led to failures in patient care and a great deal of personal suffering (Engel, 1977, 1980; Gallagher, 1999). The chronically ill patient has to negotiate a long and potentially arduous journey to achieve integration
about his or her illness. It can be nearly impossible to make this trip without
the company and guidance of a care provider who may or may not be able to
relate directly to the patient’s personal experience of illness but who is in-
vested in the process.

As patients and their families enter the initial phases of chronic illness,
clinicians using the Four-Phase Model participate with them, first as assessors
and advisors, and then as people who provide treatment. But eventually, if the
clinicians truly grasp the heart of the experience, they accompany the patient
and the family as fellow travelers. The patient progresses, typically encoun-
tering cycles of adversity or suffering and then remission, and the clinician
shares the experience. Instead of trying to dampen intrinsic and necessary
countertransference reactions as undesirable responses, the clinician contin-
ually reacts and feels and pays attention to these responses. By using coun-
tertransference effectively, the clinician can actually enlarge and enhance the
treatment process for everyone concerned.

The Four-Phase Model also uses the countertransference reactions that
proceed from clinicians’ negative experiences, including those encountered
when professionals practice with a socially marginalized clientele. All of the
clinicians’ experiences and reactions become useful, compassion-provoking
raw material, not only in the immediate patient relationship, but also in the
personal and professional growth of the clinician.

When the care provider shares the patient’s journey, the treatment can be
truly effective (Cameron & Gregor, 1987; National Institute of Health [NIH],
1996). This joining with the patient helps the patient, family, and clinician
access the knowledge that suffering is an inevitable part of life but that,
nonetheless, the chronically ill can lead productive, meaningful lives that in-
te grate their experience of suffering.

The previous description is an ideal portrait. But it can and does exist in the
real world, even within the economic constraints of the current HMO environ-
ment. Clinicians who work using the Four-Phase Model must develop relation-
ships with HMOs so that they receive appropriate compensation. They have to
explain the benefits of their approach, which is, among other things, cost effec-
tive in the long run. Using this approach, patients learn skills and arrive at un-
derstandings that reduce their fear, increase their coping skills, and begin to
establish them in a new, satisfying identity that has meaning for them. These
advances reduce their need to turn to the medical system. This is a practical de-
scription, not an ideal. Clinicians using the Four-Phase Model have negotiated
with health insurers, and they are paid for their services. Moreover, although
the journey taken with a chronic illness patient may occur over a significant pe-
riod of time, actual visits with the clinician are usually punctuated, occurring
consistently during the crisis and stabilization phases, sporadically during the
difficult times of the resolution phase, and even less frequently when clinicians
are monitoring patient progress with coping skills.

Similarly, I would argue that if public clinics target interventions for their
chronically ill patients by phase and address all three systems—the physi-
cal/behavioral, the psychological, and the social/interactive—they will
achieve better outcomes more cost effectively. By attending to these systems
in a patient’s life at the appropriate phase, clinics can use their limited re-
sources more effectively. In addition, by intervening with treatments suited
to the patient’s particular phase—a time when they are more likely to be
compliant—clinics can help patients break out of a pattern of repeated crises
that usually require more extensive resources in response.