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## CHAPTER 19

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# MASTERING FAMILY CHALLENGES IN SERIOUS ILLNESS AND DISABILITY

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### A NORMATIVE SYSTEMIC HEALTH PARADIGM

Illness, disability, and death are universal experiences in families. The real question is not “if” we will face these issues, but when in our lives, under what kinds of conditions, how serious they will be, and for how long. With major advances in medical technology, people with formerly fatal conditions are living much longer. Cancer, heart disease, diabetes, and now AIDS are just a few examples. Many children with chronic conditions that were previously fatal or necessitated institutional life are now reaching adulthood, and, with the help of new policies, they are assimilating into mainstream adult life. This means that ever-growing numbers of families are living with chronic disorders over an increasingly long time span and often coping with multiple conditions simultaneously.

The extension of later life has heightened the strain on sons and daughters who must contend with divided loyalties and a complex juggling act between caregiving for aging parents and grandparents, childrearing, and providing financially for the family. They must achieve these ends in a society in which over 50 million were uninsured in 2010 (with projections by the Congressional Budget Office that 23 million will remain uninsured after implementation of current health care reform legislation), and 62% of bankruptcies currently are linked to illness and medical bills (Himmelstein Thorne, Warren, & Woolhandler, 2009). Families are geographically dispersed, most have woefully inadequate coverage for long-term care, and health care disparities continue to increase for minority and lower socioeconomic status populations (U.S. Bureau of the Census, 2009).

Given these changes, how can we best describe the normative challenges of serious illness and optimal family coping and adaptation? We are advancing past stereotypical definitions of “the family” and the view of normal family life as “problem-free” to recognize that all families are challenged by adversity. In the same way, when serious illness strikes, we need to move beyond an outdated, rigid, and often romanticized version of coping.

This chapter provides a normative, preventive model for psychoeducation, assessment, and intervention with families facing chronic and life-threatening conditions (Rolland, 1984, 1987, 1990, 1994a, 1998, 2002). This model offers a systemic view of healthy family adaptation to serious illness as a developmental process over time in relation to the complexities and diversity of contemporary family life, modern medicine, and flawed models of health care delivery and access to care. Before I describe the model, some basic constructs are useful.

First, we need to broaden the unit of care from the medical model’s narrow focus on the ill individual to the family or caregiving system (McDaniel, Hepworth, & Doherty, 2012). Systemically, an effective biopsychosocial model needs to encompass all persons involved in the family unit and caregiving, which in turn can influence the course of an illness and the well-being of the affected person. By using a broad definition of “family” as the caregiving system, we can describe a model of successful coping and adaptation based on family system strengths.

Second, we need to describe the complex mutual interactions among the illness, ill family member, and family system within a normative framework. There is a vast literature describing the impact of chronic disorders on individuals and families. However, the impact of individual and family processes on disease has historically been defined in terms of psychosomatic processes and almost invariably in pathological terms. The definition of a condition as “psychosomatic” is a shame-laden label associated with pejorative cultural meanings that imply family dysfunction and negative influences that exacerbate symptoms and suffering.

The framework presented here describes psychosomatic processes in more holistic, interactive, and normative terms. All illnesses can be viewed as having a psychosomatic interplay in which the relative influence of biological and psychosocial factors varies over a range of disorders and illness phases. In a psychosomatic interplay, psychosocial factors, not just biomedical interventions, can be important influences in well-being and disease course. With this approach, professionals can undercut pathologizing family and cultural beliefs, and help families approach a psychosomatic interaction as an opportunity to make a positive difference. This increases their sense of control and overall quality of life.

Family research in the area of chronic illness, like studies of the individual, has tended to emphasize pathological family dynamics associated with poor disease course or treatment compliance (Campbell, 2003; Martire, Lustig,

Schulz, Miller, & Helgeson, 2004; Weihs, Fisher, & Baird, 2001). This focus on illness-based family systems and so-called “psychosomatic” families has narrowed attention to one end of a continuum of family functioning and does not clarify what constitutes healthy family coping and adaptation to illness. At the other end of the continuum, especially in the popular literature, there has been a focus on the exceptional patient (Siegel & Sander, 2009). Numerous personal accounts highlight the “superstar” patient or family. Although these provide a refreshing relief from descriptions of pathological patients and families, they often err toward superhuman, epic descriptions that leave the average family without a reference point. The average family is vulnerable to double jeopardy. Its members can feel deficient either by noting any similarities with severely dysfunctional families or by not measuring up to the exceptional one. This leaves families with a view of healthy adaptation that is rarely achieved and perpetuates self-judgments of deficient performance, infused with blame, shame, and guilt. The inspirations of the exceptional and the warning signs of dysfunction need to be grounded by descriptions of typical experiences. More recently investigators have shifted attention toward the influences of social support and a range of family processes that enhance coping and adaptation. A growing literature is examining the positive impact of individual and family functioning on health/well-being and, in the context of illness, the quality of life for all family members, as well as disease course and outcome (Carr & Springer, 2010; D’Onofrio & Lahey, 2010; Weihs et al., 2001).

Finally, outdated, rigid, gender-based models of the normal family invariably define a narrow range of roles and strategies for coping with illness and disability. Traditional models of patient and caregiver roles can shackle families—especially the designated female caregiver—in the face of the protracted strains of illness and threatened loss. A broad multigenerational and multicultural conception of the family that evolves over the life cycle (McGoldrick, Carter, & Garcia-Preto, 2011) is essential to constructing a normative model.

The family-centered model described in this chapter views a broad range of family forms and processes as normative and uses as its central reference point the idea of goodness of fit between the psychosocial demands of the illness in relation to family challenges and resources over time. For example, high versus low family cohesion is not viewed as inherently healthy or unhealthy. Rather, the organizing principle becomes relative: What degree of family cohesion will work optimally with this illness now, and how might that change in future phases of the condition?

A basic task for families is to create a meaning for the illness situation that preserves their sense of competency and mastery. At the extremes, competing ideologies can leave families with a choice between a biological explanation or one of personal responsibility (bad things happen to bad people). Families desperately need reassurance that they are handling the illness normally (bad things do happen to good people). Without a psychosocial map,

many families, particularly those with untimely disorders, find themselves in unfamiliar territory and without guides. This highlights the need for a preventive, psychoeducational approach that helps families anticipate normative illness-related developmental challenges over time in a fashion that maximizes a sense of control and mastery.

To create a normative context for their illness experience, families need the following foundation. First, they need a psychosocial understanding of the condition in systems terms. This means learning the expected pattern of practical and affective demands of a disorder over the course of the condition. This includes a time frame for disease-related developmental tasks associated with different phases of an unfolding disorder. Second, families need to understand themselves as systemic functional units. Third, they need an appreciation of individual and family life-cycle patterns and transitions to facilitate their incorporation of changing developmental priorities for the family unit and individual members in relation to evolving challenges of a chronic disorder. Finally, families need to understand the cultural, ethnic, spiritual, and gender-based beliefs that guide the type of caregiving system they construct. This includes guiding principles that delineate roles, rules of communication, definitions of success or mastery, and fit with beliefs of the health care providers. Family understanding in these areas facilitates a more holistic integration of the disorder and the family as a functional family–health/illness system evolving over time.

## FAMILY SYSTEMS HEALTH MODEL

A normative, preventive model has been developed for psychoeducation, assessment, and intervention with families facing chronic and life-threatening disorders (Rolland 1984, 1987a, 1987b, 1990, 1994a, 1998). This model is based on the concept of a systemic interaction between an illness and family that evolves over time. The goodness of “fit” between the psychosocial demands of the disorder and the family style of functioning and resources is a prime determinant of successful versus dysfunctional coping and adaptation. The model distinguishes three dimensions: (1) psychosocial “types” of disorders, (2) major phases in their evolution, and (3) key family system variables (Figure 19.1). A scheme of the systemic interaction between illness and family might look like the diagram in Figure 19.2. Family variables given particular emphasis include (1) the family and individual life cycles, particularly in relation to the time phases of a disorder; (2) multigenerational legacies related to illness and loss; and (3) belief systems.

### ***Psychosocial Types of Illness***

The standard disease classification used in medical settings is based on purely biological criteria that are clustered in ways to establish a medical diagnosis

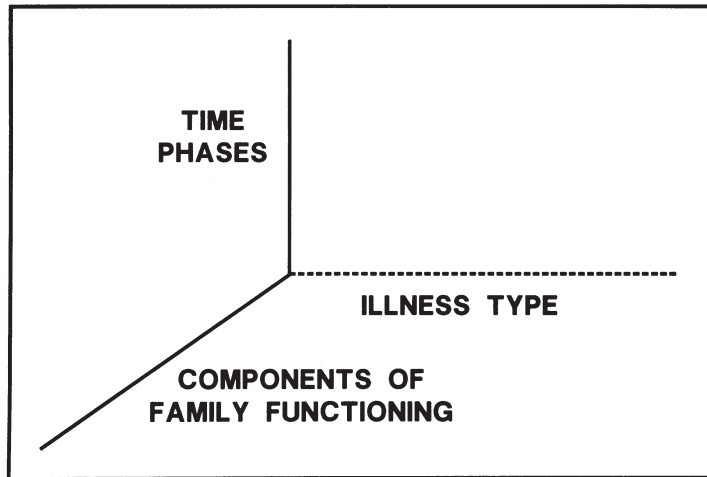


FIGURE 19.1. Three-dimensional model representing the relationship between illness type, time phases, and family functioning. From Rolland (1987a). Reprinted by permission.

and treatment plan, rather than on psychosocial demands placed on patients and their families. I have proposed a different classification scheme that provides a better link between the biological and psychosocial worlds, and thereby clarifies the relationship between chronic illness and the family (Rolland, 1984, 1994a). The goal of this typology is to define meaningful and useful categories with similar psychosocial demands for a wide array of chronic illnesses affecting individuals across the lifespan.

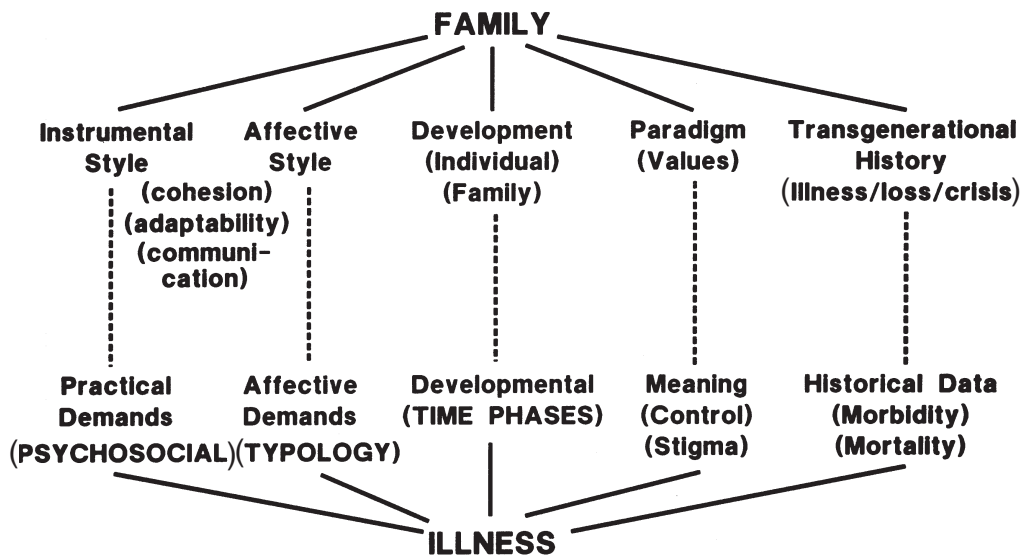


FIGURE 19.2. Interface of chronic illness and the family. From Rolland (1987b). Reprinted by permission.

### Onset

Illnesses can be divided into those that have either an acute onset, such as strokes, or gradual onset, such as Alzheimer's disease. For acute-onset illnesses, affective and practical changes are compressed into a short time, requiring more rapid family mobilization of crisis management skills. Families able to tolerate highly charged emotional situations, exchange roles flexibly, problem-solve efficiently, and utilize outside resources will have an advantage in managing acute-onset conditions. Clinicians can facilitate this process.

### Course

The course of chronic diseases can take three general forms: progressive, constant, or relapsing/episodic. Varying levels of uncertainty overlay these forms. With a *progressive* disease such as Alzheimer's disease, the family is often faced with a perpetually symptomatic family member whose disability worsens in a stepwise or gradual way. The family must live with the prospect of continual role change and adaptation to continued losses as the disease progresses. Increasing strain on family caregiving is caused by exhaustion, with few periods of relief from demands of the illness, and with more caregiving tasks over time. Diabetes is an example of a progressive disease with a much longer and unpredictable course.

With a *constant* course illness, the occurrence of an initial event, such as a one-time heart attack or spinal cord injury, is followed by a stable biological course. Typically, after an initial period of recovery, the illness is characterized by some clear-cut deficit or limitation. The family is faced with a semipermanent change that is stable and predictable over a considerable time span. The potential for family exhaustion exists without the strain of new role demands over time.

*Relapsing- or episodic-*course illnesses, such as disk problems and asthma, are distinguished by the alternation of stable low-symptom periods with periods of flare-up or exacerbation. Families are strained by both the frequency of transition between crisis and noncrisis, and the ongoing uncertainty of *when* a recurrence will occur. This requires family flexibility to alternate between two forms of family organization. The wide psychological discrepancy between low-symptom versus flare-up periods is a particularly taxing feature unique to relapsing diseases.

### Outcome

The extent to which a chronic illness leads to death or shortens one's life expectancy has profound psychosocial impact. The most crucial factor is the *initial expectation* of whether a disease is likely to cause death. On one end of the continuum are illnesses that do not typically affect the lifespan, such as disk disease or arthritis. At the other extreme are clearly progressive and fatal illnesses, such as metastatic cancer. An intermediate, more unpredictable

category includes both illnesses that shorten the lifespan, such as heart disease, and those with the possibility of sudden death, such as hemophilia. A major difference between these kinds of outcome is the degree to which the family experiences anticipatory loss and its pervasive effects on family life (Rolland, 1990).

### *Incapacitation*

Disease and disability can involve impairment of cognition (e.g., Alzheimer's disease), sensation (e.g., blindness), movement (e.g., stroke with paralysis), stamina (e.g., heart disease), disfigurement (e.g., mastectomy), and conditions associated with social stigma (e.g., AIDS) (Olkin, 1999). The extent, kind, and timing of disability imply sharp differences in the degree of family stress. For instance, the combined cognitive and motor deficits often caused by a stroke necessitate greater family role reallocation than that for a spinal cord injury in which cognitive abilities are unaffected. For some illnesses, such as stroke, disability is often worst at the beginning. For progressive diseases, such as Alzheimer's disease, disability looms as an increasing problem in later phases of the illness, allowing a family more time to prepare for anticipated changes and an opportunity for the ill member to participate in disease-related family planning while still cognitively able (Boss, 1999).

By combining the kinds of onset, course, outcome, and incapacitation into a grid format, we generate a typology that clusters illnesses according to similarities and differences in patterns that pose differing psychosocial demands (Table 19.1).

The *predictability* of an illness, and the degree of uncertainty about the specific way or rate at which it unfolds, overlays all other variables. For illnesses with highly unpredictable courses, such as multiple sclerosis, family coping and adaptation, especially future planning, are hindered by anticipatory anxiety and ambiguity about what family members will actually encounter. Families able to put long-term uncertainty into perspective are best prepared to avoid the risks of exhaustion and dysfunction.

### ***Time Phases of Illness***

Too often, discussions of "coping with cancer," "managing disability," or "dealing with life-threatening illness" approach illness as a static state and fail to appreciate the evolution of illness processes over time. The concept of *time phases* provides a way for clinicians and families to think longitudinally and to understand chronic illness as an ongoing process with normative landmarks, transitions, and changing demands. Each phase of an illness poses its own psychosocial challenges and developmental tasks that may require significantly different strengths, attitudes, or changes for family adaptation. Core psychosocial themes in the natural history of chronic disease can be described as three major phases: crisis, chronic, and terminal (Figure 19.3).

TABLE 19.1. Categorization of Chronic Disorders by Psychosocial Type

	Incapacitating		Nonincapacitating	
	Acute	Gradual	Acute	Gradual
Progressive	FATAL	Lung cancer CNS metastases Bone marrow failure Amyotrophic lateral sclerosis	Pancreatic cancer Metastatic cancer (e.g., breast, lung, liver)	
Progressive		Parkinson's disease Emphysema Alzheimer's disease Multi-infarct dementia AIDS Multiple sclerosis (late) Chronic alcoholism Huntington's disease Scleroderma		Type 1 diabetes <sup>a</sup> Malignant hypertension Insulin-dependent Type 2 diabetes
Relapsing	Angina	Early multiple sclerosis Episodic alcoholism	Sickle cell disease <sup>a</sup> Hemophilia <sup>a</sup>	Systemic lupus erythematosus
Constant	Stroke Moderate/severe myocardial infarction	PKU and other inborn errors of metabolism	Mild myocardial infarction Cardiac arrhythmia	Hemodialysis-treated renal failure Hodgkin's disease

(cont.)



TABLE 19.1. (cont.)

	Incapacitating		Nonincapacitating	
	Acute	Gradual	Acute	Gradual
Progressive		Rheumatoid arthritis Osteoarthritis		Non-insulin-dependent type 2 diabetes
Relapsing	Lumbosacral disk disease		Kidney stones Gout Migraine Seasonal allergy Asthma Epilepsy	Peptic ulcer Ulcerative colitis Chronic bronchitis Other inflammatory bowel diseases Psoriasis
Constant	Congenital malformations Spinal cord injury Acute blindness Acute deafness Survived severe trauma and burns Posthypoxic syndrome	Nonprogressive mental retardation Cerebral palsy	Benign arrhythmia Congenital heart disease (mild)	Malabsorption syndromes (controlled) Hyper/hypothyroidism Pernicious anemia Controlled hypertension Controlled glaucoma

NONFATAL

Note. Adapted from Rolland (1984). Copyright 1984 by the American Psychological Association. Adapted by permission.

<sup>a</sup>Early.

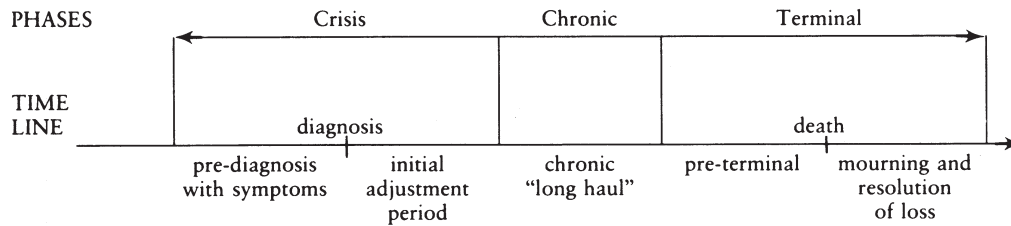


FIGURE 19.3. Timeline and phases of illness. From Rolland (1984). Copyright 1984 by the American Psychological Association. Reprinted by permission.

The *crisis* phase includes any symptomatic period before diagnosis and the initial readjustment period after a diagnosis and initial treatment planning. This phase holds a number of key tasks for the ill member and family. Moos (1984) describes certain universal, practical, illness-related tasks that include (1) learning to cope with any symptoms or disability; (2) adapting to health care settings and any treatment procedures; and (3) establishing and maintaining workable relationships with the health care team. Also, there are crucial tasks of a more general, existential nature. Families optimize well-being when they can (1) create a meaning for the illness that maximizes a sense of mastery and competency; (2) grieve for the loss of normal “life” before illness; (3) gradually accept the illness as long term, while maintaining a sense of continuity between their past and future; (4) pull together to cope with the immediate crisis; and (5) in the face of uncertainty, develop flexibility toward future goals.

During this initial crisis period, health professionals have enormous influence over a family’s sense of competence and strategies to accomplish these developmental challenges. Initial meetings and advice given at the time of diagnosis can be thought of as a “framing event.” Because family members are so vulnerable at this point, clinicians need to be extremely sensitive in their interactions with them and aware of messages conveyed by their behavior. Who is included or excluded (e.g., the patient) from a discussion can be interpreted by the family as a message of how they should plan their communication for the duration of the illness. For instance, if a clinician meets with family members separately from the patient to give them information about the illness diagnosis and prognosis, they may assume that they are being instructed implicitly to exclude the patient from any discussion of the illness. Meeting only with a spouse or primary caregiver may fuel anxiety about whether and how to share information with children or other members. Clinicians also need to be careful not to undercut a family’s attempt to sustain a sense of competence by implicitly blaming the patient or the family for an illness (e.g., delay in seeking an appointment, negligence by parents, poor health habits) or by distancing themselves from the family.

The *chronic* phase, whether long or short, is the time span after the initial diagnosis/readjustment. This era can be marked by constancy, recurrence

(e.g., heart attack), progression, or episodic flare-ups. It has been referred to as “the long haul,” or “the day-to-day living with chronic illness” phase. Often the patient and family have come to grips psychologically and organizationally with long-term changes and have devised an ongoing coping strategy. The ability to maintain the semblance of a normal life with a chronic illness and heightened uncertainty is a key family task in this phase. If the illness is fatal, this is a time of “living in limbo.” For certain highly debilitating but not clearly fatal illnesses, such as a massive stroke or dementia, the family can feel saddled with an exhausting problem “without end.” Paradoxically, a family may feel its hope to resume a so-called “normal” life can only be realized after the death of its ill member. The maintenance of maximum autonomy for all family members in the face of protracted adversity helps offset these trapped, helpless feelings. Clinicians can help families develop new priorities and see opportunities for relationship growth within a “new normal.”

For long-term disorders, customary patterns of intimacy for couples become skewed by discrepancies between the ill member and the well spouse/caregiver (Rolland, 1994b). As one young husband lamented about his wife’s cancer, “It was hard enough 2 years ago to absorb that, even if Ann was cured, her radiation treatment would make pregnancy impossible. Now, I find it unbearable that her continued slow, losing battle with cancer makes it impossible to go for our dreams like other couples our age.” Normative ambivalence and escape fantasies often remain underground and can contribute to survivor guilt. Psychoeducational family interventions that normalize such emotions related to threatened loss can help prevent destructive cycles of blame, shame, and guilt.

In the *terminal* phase of an illness, the inevitability of death becomes apparent and dominates family life. Now the family must cope with issues of separation, death, mourning, and resumption of family life beyond the loss (Walsh & McGoldrick, 2004). Family members adapt best to this phase when able to shift their view of mastery from controlling the illness to a successful process of “letting go.” Optimal coping involves emotional openness, as well as dealing with the myriad practical tasks at hand. This includes seeing this phase as an opportunity to share precious time together, to acknowledge the impending loss, to deal with unfinished business, to say good-byes, and to begin the process of family reorganization. If they have not been determined beforehand, the patient and key family members need to decide about things such as a living will; the extent of medical heroics desired; preferences about dying at home, in the hospital, or at a hospice; and wishes about a funeral or memorial service and burial or cremation.

Critical *transition periods* link the three time phases. Transitions in the illness course are times when families reevaluate the appropriateness of their previous life structure in the face of new illness-related developmental demands. Helping families resolve unfinished business from the previous phase can facilitate movement through the transitions. Families can become permanently frozen in an adaptive structure that has outlived its utility (Penn, 1983). For example, the usefulness of pulling together in the crisis phase can

become maladaptive and stifling for all family members through the chronic phase.

The interaction of the time phases and illness typology provides a framework for a normative psychosocial developmental model for chronic disease that resembles models for human development. The time phases (crisis, chronic, and terminal) can be considered broad developmental periods in the unfolding of chronic disease. Each period has certain basic tasks, independent of the type of illness. Each “type” of illness has specific supplementary tasks.

### ***The New Genetics and an Extended Illness Timeline***

With the mapping of the human genome, burgeoning scientific knowledge is rapidly increasing our understanding of the mechanisms, treatment, and prevention of disease. New genetic technologies enable physicians to test for increased risk of developing a serious and life-threatening illness before it actually occurs. This means that individuals and families now can be living with illness risk information long before they or loved ones have developed symptoms of those illnesses (Miller, McDaniel, Rolland, & Feetham, 2006). This significantly increases the amount of time and energy that families spend considering an illness, and lengthens the illness time line to include nonsymptomatic phases (Rolland & Williams, 2005). The nonsymptomatic phases include awareness, pretesting, testing/posttesting, and long-term adaptation. These phases are distinguished by questions of uncertainty. Fundamental issues include the potential amount of genetic knowledge medically available, decisions about how much of that information various family members choose to access, and living with the psychosocial impact of those choices.

For some, the nonsymptomatic crisis phase begins when predictive testing becomes available, continuing through the decision to pursue testing and initial posttesting adaptation. For others, this phase begins as individuals reach significant developmental milestones and begin to consider testing. Sometimes, plans to have children raise fears of passing on a mutation and spark an interest in testing. Some women decide to be tested for hereditary breast and ovarian cancer genes when they reach an age that coincides with the age when another blood relative—a mother, aunt, or older sister—was diagnosed. During the posttesting phases, families need to accept the permanence of the genetic information and develop meanings that preserve their sense of competency in the face of future uncertainty or loss (Rolland, 2006a; Werner-Lin, 2008).

The involvement of the health care system is very different with predictive testing than with a diagnosed illness. Despite the potentially enormous psychosocial impact of positive testing results, families usually have limited contact with health professionals after initial testing. This highlights the need for ongoing, family-centered, collaborative approaches to prevent isolation, anxiety, and depression.

We can orient families to the value of prevention-oriented consultations at key future life-cycle transitions, when the experience of genetic risk will

likely be heightened. Concerns about loss may surface that family members either postponed or thought were “worked through.” It is vital to prepare family members that their concerns about genetic risk and decisions about whether to pursue genetic testing will be more activated with upcoming transitions, such as launching young adults, marriage or partner commitments, or starting a family. Also, such feelings can be reactivated by critical events, such as genetic testing of another family member, diagnosis of a serious illness in immediate or extended families or friends, or death of a loved one. Clinicians can help family members decide when further family discussion would be helpful, who would be appropriate to include, and how to discuss genetic risk with children or adolescents.

*Genomics*, distinguished from traditional genetics, goes beyond the study of single genes to the function and interaction of all genes in the human genome, including their interactions with environmental factors. Most illnesses are thought to be affected by multiple genes and environmental factors that include life experience, social context, and interpersonal relationships. Thus, as most families learn more about their own genetic risks, members need not adopt a fatalistic, deterministic mind-set. Rather, family members will have varying degrees of control to influence the onset, course, and severity of disease expression. Recent research suggests family interaction can be an important protective factor counterbalancing genetic risk related to mental health conditions (Reiss, Neierhiser, Hetherington, & Plomin, 2000; Tienari et al., 2004; see Spotts, Chapter 22, this volume). This kind of complex interaction may operate in common physical disorders as well.

As the new genetics unfolds, families and clinicians are facing unprecedented and complex clinical and ethical challenges (Miller et al., 2006). Families will increasingly be able to choose genetically informed knowledge of their future health risks or fate. Some key research questions include the following: Which individuals and families will benefit by genetic risk screening and knowledge of their health risks or fate? How can we best help family members reach decisions about whether to pursue predictive testing? Who are the relevant family members to include in these decisions? Spouses or partners? Extended family? Our societal fixation on “the perfect healthy body” could meld seamlessly with technology and eugenics, forcing families living with disability, illness, or genetic risk to hide their suffering further, in order to demonstrate the value of their lives and avoid increased stigmatization (Roland, 1997; 1999).

### ***Clinical Utility of Framework***

This model provides a framework for clinical practice by facilitating an understanding of chronic illness and disability in psychosocial terms. Attention to features of onset, course, outcome, and incapacitation provides markers that focus clinical assessment and intervention with a family. For instance, acute-onset illnesses demand high levels of adaptability, problem solving, role

reallocation, and balanced cohesion. In such circumstances, helping families to maximize flexibility enables them to adapt more successfully.

An illness time line delineates psychosocial developmental phases of an illness, with each phase having its own salient developmental challenges. In particular, mastering initial crisis phase-related tasks provides a foundation for successful adaptation over the long haul. Attention to time allows the clinician to assess family strengths and vulnerabilities in relation to present and future phases of the illness.

The model clarifies treatment planning. Goal setting is guided by awareness of the aspects of family functioning most relevant to the particular type or phase of an illness. Sharing this information with the family and deciding on specific goals offer a better sense of control and realistic hope. This process empowers families in their journey of living with a chronic disorder. Also, it educates family members about warning signs that alert them to seek help at appropriate times for brief, goal-oriented treatment. The framework is useful for timing family psychosocial checkups to coincide with key transition points in the illness.

Preventively oriented multifamily psychoeducational or support groups and workshops for patients and their families (Gonzalez & Steinglass, 2002; Steinglass, 1998) provide cost-effective preventive services that decrease family isolation, increase networking, and can identify high-risk families. Multifamily groups can be designed to deal with different types of conditions (e.g., progressive, life-threatening, relapsing). Brief psychoeducational “modules,” timed for critical phases of particular “types” of diseases, enable families to digest manageable portions of a long-term coping process. In time-limited (e.g., four sessions) or one-day formats, couples and families can increase coping skills and discuss common disease-related relationship challenges with others in similar situations. For instance, through the Chicago Center for Family Health, we have developed programs in partnership with local medical centers to help families dealing with diabetes and cystic fibrosis and, in collaboration with the MS Society, the Resilient Partners Program, for couples living with multiple sclerosis.

## FAMILY ASSESSMENT

As chronic conditions become incorporated into the family system and all its processes, family coping is influenced by illness-oriented family processes that concern the dimension of time and belief systems.

### ***Multigenerational Legacies of Illness, Loss, and Crisis***

A family’s current behavior, and therefore its response to illness, cannot be adequately comprehended apart from its history (Bowen, 1993; Byng-Hall, 1995; McGoldrick et al., 2011; Walsh & McGoldrick, 2004). Clinicians can

use historical questioning and construct a genogram and time line (McGoldrick, Gerson, & Petry, 2008) to track key events and transitions to gain an understanding of a family's organizational shifts and coping strategies as a system in response to past stressors and, more specifically, to past illnesses. Such inquiry helps explain and predict the family's current style of coping, adaptation, and meaning making. A multigenerational assessment helps to clarify areas of strength and vulnerability. It also identifies high-risk families, burdened by past unresolved issues and dysfunctional patterns, that cannot absorb the challenges presented by a serious condition.

A chronic illness-oriented genogram focuses on how a family organized itself as an evolving system specifically around previous illnesses and unexpected crises. A central goal is to bring to light areas of consensus and "learned differences" (Penn, 1983) that are sources of cohesion, resilience, and potential conflict. Patterns of coping, replications, shifts in relationships (i.e., alliances, triangles, cutoff), and sense of competence are noted. These patterns are transmitted across generations as family pride, myths, taboos, catastrophic expectations, and belief systems. Also, it is useful to inquire about other forms of loss (e.g., divorce, migration), crisis (e.g., job loss, traumatic event), and protracted adversity (e.g., poverty, racism, war, political oppression). These experiences can provide transferable sources of resilience and effective coping skills in the face of a serious health problem (Walsh, 2006). Clinicians need to ask specifically about positive family-of-origin experiences with illness and loss that can serve as models to adapt to the current situation.

### *Illness Type and Time Phase Issues*

Whereas a family may have certain standard ways of coping with any illness, there may be critical differences in its style and success in adaptation to different "types" of diseases. It is important to track prior family illnesses for areas of perceived competence, failure, or inexperience. Inquiry about different illness types may reveal, for instance, that a family dealt successfully with non-life-threatening illnesses but reeled under the weight of metastatic cancer. Such families might be well equipped to deal with less severe conditions but be particularly vulnerable if another life-threatening illness were to occur.

Tracking a family's coping capabilities in the crisis, chronic, and terminal phases of previous chronic illnesses highlights legacies of strength as well as complication in adaptation related to different points in the illness course. One man who grew up with a partially disabled father with heart disease witnessed his parents' successful renegotiation of traditional gender-defined roles when his mother went to work, while his father assumed household responsibilities. This man, now with heart disease himself, has a positive legacy about gender roles from his family of origin that facilitated a flexible response to his own illness. Another family with a member with chronic kidney failure functioned very well in handling the practicalities of home dialysis. However,

in the terminal phase, their limitations with emotional expression left a legacy of unresolved grief. Tracking prior illness experiences in terms of time phases helps clinicians see both the strengths and vulnerabilities in a family, which counteracts the assignment of dysfunctional labels that emphasize the difficult periods.

Couples' hidden strengths, not just unresolved issues, can remain dormant and suddenly reemerge when triggered by a chronic illness. For any significant illness in either adult partner's family of origin, a clinician should try to get a picture of how those families organized to handle the range of disease-related affective and practical tasks. What role did each play in handling these tasks, and did they emerge with a strong sense of competence or failure? Such information can help to anticipate areas of conflict, consensus, and similar patterns of adaptation.

Although many families have healthy multigenerational family patterns of adaptation, any family may falter in the face of multiple disease and other major stressors that impact in a relatively short time. With progressive, disabling diseases or the concurrence of illnesses in several family members, a pragmatic approach that focuses on expanded or creative use of supports and resources outside the family is most productive.

### ***Interweaving of Illness, Individual, and Family Development***

A developmental lens provides a powerful way to construct a normative framework for serious illness. To place the unfolding of chronic disease into a developmental context, it is vital to understand the intertwining of three evolutionary threads: illness, individual, and family development.

Concepts of human and family development have evolved from models that centered on a basic, somewhat invariant sequence and unfolding of phases to ones that are more varied, fluid, and multidimensional, consistent with contemporary individual and family life course trajectories. Serious health conditions are one example of major, often unexpected, life challenges that can significantly alter the sequence and character of a family and its members' life course. For purposes of this discussion, *life structure*, a useful central concept for both family and individual development, refers to core elements (e.g., work, childrearing, caregiving) of an individual's or family's life at any phase of the life cycle. Individual and family development have in common the notion of phases (each with its own developmental priorities) and are marked by the alternation of life structure-building/maintaining (stable) and -changing (transitional) phases (Levinson, 1986). The primary goal of a building/maintaining phase is to form a life structure and enrich life within it based on the key choices an individual–family made during the preceding transition. Transition phases are somewhat more fluid, because previous individual, family, and illness life structures are reappraised in the face of new developmental challenges that may involve major changes rather than minor alterations (see Cowan & Cowan, Chapter 18, this volume).



At a macro level, the family life cycle can be viewed as oscillating between phases in which family developmental tasks require intense bonding or relatively higher cohesion, as in early childrearing, and phases such as families with adolescents, in which the external family boundary is loosened, with increasing personal identity and autonomy (Combrinck-Graham, 1985). Ethnic and racial differences influence the specific cultural expression of these phases.

These unifying concepts provide a foundation for understanding the experience of chronic disorders. The life cycle contains alternating transition and life structure-building/maintaining phases. And particular phases can be characterized as requiring relatively greater or lesser degrees of family cohesion. Illness, individual, and family development each pose priorities and challenges that move through phases of being more or less in sync with each other.

Generally, serious disorders exert an inward cohesive pull on the family system. Analogous to the addition of a new family member, illness onset sets in motion an inside-the-family focused process of socialization to illness. Symptoms, loss of function, the demands of shifting or acquiring new illness-related roles, and the fears of further disability and/or death, all push a family to focus inward.

The need for family cohesion varies enormously with different illness types and phases. The tendency for a disease to pull a family inward increases with the level of disability or risk of progression and death. Progressive diseases over time inherently require greater cohesion than constant course illnesses. The ongoing addition of new demands with illness progression keeps a family's energy focused inward, often impeding the development of other members. After an initial period of adaptation, a constant course disease (without severe disability) permits a family to get back on track developmentally. Relapsing illnesses alternate between periods of drawing a family inward and times of release from immediate demands of disease. But the on-call nature of many such illnesses keeps part of the family focus inward despite asymptomatic periods, hindering the natural flow between phases of development.

Diagnosis of a serious illness can precipitate a family transition in which one of the family's main tasks is to accommodate the anticipation of further loss and possibly untimely death. If illness onset coincides with launching or postlaunching phases in family development, it can derail a family's natural momentum. For an affected young adult, it may require a heightened dependency and return to the family of origin for disease-related caregiving. The autonomy and individuation of parents and child can be jeopardized. Separate interests and priorities may be relinquished or put on hold. Family processes, as well as disease severity, influence whether the family's reversion to a childrearing-like structure is a temporary detour or a long-term reversal.

When disease onset coincides with a phase in family development requiring higher cohesion (e.g., early childrearing), it can prolong this period. At

worst, the family can become enmeshed and developmentally stuck. Alternatively, with chronic disorders, there is a risk of the label *enmeshment* when the normative lengthening of developmental phases for child and family is disregarded. Often, families coping with a chronically ill child are tentative about giving the child more autonomy, not because of inherent family dysfunction, but because of anticipation of further loss, coupled with a lack of preventive psychoeducation from professionals.

With major health conditions, previous norms concerning family organization may need greater flexibility. Enmeshment with blurred generational boundaries is overdiagnosed as family dysfunction. Yet the very real demands on older children and adolescents to assume more adult functions, in the interest of family well-being, need to be distinguished from rigid pathological descriptions of “parentified” children. For instance, when a parent develops a serious disorder during a childrearing phase of development, a family’s ability to stay on course is most severely taxed. The impact is twofold: A new family burden is added, with some loss of parental functioning. To meet simultaneous childrearing and caregiving needs, an older child or grandparent may need to assume parental responsibilities. These forms of family adaptation are appropriate if structural realignments are flexible, shared, and sensitive to competing age-related developmental needs. Strong extended kin networks facilitate family adaptation.

When illness onset coincides with a transition in the individual or family life cycle, issues related to existing and anticipated loss tend to be magnified. Transition periods are often characterized by upheaval, rethinking of prior commitments, and openness to change. Such times often hold a greater risk for the illness to become either embedded or ignored in planning for the next life phase. During a transition period, the process of thinking through future commitments can bring to the forefront family norms regarding loyalty through sacrifice and caregiving. The following example highlights this point.

In one Latino family, the father, a factory worker and primary financial provider, had a mild heart attack. He also suffered from emphysema. At first his impairment was mild and stabilized, allowing him to continue his work. The family, including the oldest son, age 15, seemed relatively unaffected. Two years later, the father experienced a second, more life-threatening heart attack and became totally disabled. His son, now 17, had dreams of going away to college. The specter of financial hardship and the perceived need for a “man in the family” created a serious dilemma for the son and the family. Moreover, the parents had worked hard to move out of the housing projects and to ensure that their children could get a good education for a better future. There was a clash among simultaneous transition periods: (1) the illness transition to a more incapacitating progressive course; (2) the son’s individual transition to early adulthood with individuation, leaving home, and educational pursuits; and (3) the family developmental transition in the family life cycle, with

dreams for the future. It also illustrates the significance of the type of illness: One that was less incapacitating and life-threatening might have interfered less with individual and family developmental priorities.

It is essential to situate these developmental issues in the context of cultural values, socioeconomic considerations, availability of family or community resources, and access to health care. In many cultures, as in this Latino family, a strong emphasis on loyalty to family needs would normatively take priority over individual goals, especially with a major illness or disability. Also, a lack of community and health care resources can severely constrain family adaptation options.

Illness onset that coincides with a life structure-building/maintaining developmental phase presents a different challenge. These phases are characterized by living out choices made during the preceding transition. Relative to transition phases, family members try to protect their own and the family unit's current life structure. Milder conditions may require some revision but not a radical restructuring. A severe condition (e.g., traumatic brain injury) can force families into a more complete transition at a time when individual-family inertia is to preserve the momentum of a stable phase. To navigate this kind of crisis successfully, family adaptability often requires the ability to transform the entire life structure to a prolonged transitional state.

Systemically, at the time of diagnosis, it is important to know the life-cycle phases of the family and each member, not just the ill one. Chronic disease in one family member can profoundly affect developmental goals of another member. For instance, an infant disability can be a serious roadblock to parents' preconceived ideas about competent childrearing, or a life-threatening illness in a young, married adult can interfere with the well spouse's readiness to become a parent. Also, family members frequently adapt in varied ways. Each member's ability to adapt, and the rate at which he or she does so, is related to his or her own developmental phase and role in the family. When family members are in tune with each other's developmental processes, while promoting flexibility and alternative means to satisfy developmental needs, successful long-term adaptation is maximized.

The timing of chronic illness in the life cycle can be normative (e.g., expectable in relation to chronological and social time) or non-normative (e.g., "off-time"). Chronic illness is considered a normally anticipated challenge in later adulthood, whereas its occurrence earlier is "out of phase" and developmentally more disruptive (Neugarten, 1976). For instance, chronic diseases that occur in the childrearing phase can be more challenging because of their potential impact on family childrearing responsibilities. The actual impact depends on the "type" of illness and preillness family roles. Families with flexible gender-influenced rules about financial provision and childrearing tend to adjust better.

The concept of "out of phase" illnesses can be refined to highlight patterns of strain over time. Because diseases have an inward pull on most families,

they can be more disruptive to families in a launching children phase of development. If the particular illness is progressive, relapsing, increasingly incapacitating, and/or life-threatening, then the unfolding phases of the disease will be punctuated by numerous transitions. Under these conditions, a family will need to alter its life structure more frequently to accommodate shifting and increasing demands of the disease. This level of demand and uncertainty keeps the illness in the forefront of a family's consciousness, constantly impinging on its attempts to get back "in phase" developmentally.

Finally, the transition from the crisis to the chronic phase is the key juncture at which the intensity of the family's socialization to living with chronic disease is lessened. In this sense, it offers a window of opportunity for the family to reestablish or sometimes chart a "new normal" developmental course.

An overarching goal is to deal with the developmental demands of the illness without family members sacrificing their own or the family's development as a system over time. It is important to determine whose life plans have been or might be cancelled, postponed, or altered, and when plans put on hold and future developmental issues will be addressed. In this way, clinicians can anticipate developmental nodal points related to "autonomy within" versus "subjugation to" the condition. Family members can be helped to strike a healthier balance, with life plans that resolve feelings of guilt, overresponsibility, and hopelessness, and find family and external resources to enhance freedom both to pursue personal goals and to provide needed care for the ill member.

## HEALTH/ILLNESS BELIEF SYSTEM

When illness strikes, a primary developmental challenge for a family is to create a meaning for the illness experience that promotes a sense of mastery and competency. Because serious illness is often experienced as a betrayal of our fundamental trust in our bodies and belief in our invulnerability (Kleinman, 1988), creating an empowering narrative can be a formidable task. Family health beliefs help us grapple with the existential dilemmas of our fear of death, our tendency to want to sustain our denial of death, and our attempts to reassert control when suffering and loss occur. They serve as a cognitive and interpersonal road map guiding decisions and action; they provide a way to approach new and ambiguous situations for coherence in family life, facilitating continuity of past, present, and future (Antonovsky & Sourani, 1988; Reiss, 1981). Our appreciative inquiry to understand family beliefs is perhaps the most powerful foundation stone of collaboration between families and health professionals (Wright & Bell, 2009).

In the initial crisis phase, it is valuable for clinicians to inquire about key beliefs that shape the family's illness narrative and coping strategies. This includes tracking beliefs about (1) normality; (2) mind-body relationship,

control, and mastery; (3) meanings attached by a family, ethnic group, religion, or the wider culture to symptoms (e.g., chronic pain; Griffith & Griffith, 1994), types of illnesses (e.g., life-threatening), or specific diseases (e.g., HIV/AIDS); (4) assumptions about what caused an illness and what will influence its course and outcome; (5) multigenerational factors that have shaped a family's health beliefs; and (6) anticipated nodal points in illness, individual, and family development when health beliefs will likely be strained or need to shift. Clinicians should also assess the fit of health beliefs among family members, as well as between the family and health care system, and the wider culture.

### ***Beliefs about Normality***

Family beliefs about what is normal or abnormal, and the importance members place on conformity and excellence in relation to the average family, have far-reaching implications for adaptation to chronic disorders. When family values allow having a "problem" without self-denigration, it enables members to seek outside help yet maintain a positive identity. When families define help seeking as weak and shameful it undercuts this kind of resilience. Essentially, with chronic disorders in which problems are to be expected, and the use of professionals and outside resources is necessary, a belief that pathologizes this normative process adds insult to injury.

Two useful questions elicit these beliefs: "How do you think other *average* families would deal with a similar situation to yours?" and "How would families *ideally* cope with your situation?" Families with strong beliefs in high achievement and perfectionism are prone to apply standards that are impossible to achieve in a situation of illness. Particularly with untimely conditions that occur early in the life cycle, there are additional pressures to keep up with socially expectable developmental milestones of age peers. The fact that life goals may take longer or need revision requires a flexible belief about what is normal and healthy. To sustain hope, particularly with long-term adversity, effectively, families need to embrace a flexible definition of normality.

### ***The Family's Sense of Mastery in Facing Illness***

It is vital to determine how a family defines *mastery* or *control* in general, and in situations of illness. Mastery is similar to the concept of *health locus of control* (Lefcourt, 1982), which can be defined as the belief about influence over the course/outcome of an illness. It is useful to distinguish whether a family's beliefs are based on the premise of internal control, external control by chance, or external control by powerful others.

An internal locus-of-control orientation means that individuals or families believe they can affect the outcome of a situation. Such families believe they are directly responsible for their health and have the power to recover from illness (Wallston, 2004). An external orientation entails a belief that outcomes are not contingent on the individual's or the family's behavior. Families

that view illness in terms of chance believe that when illness occurs, it is a matter of luck, and that fate determines recovery. Those who see health control as being in the hands of powerful others view health professionals, God, or sometimes “powerful” family members as exerting control over their bodies and the illness course.

A family may adhere to a different belief about control when dealing with biological as distinct from typical, day-to-day issues. Therefore, it is important to inquire about a family’s (1) core values, (2) beliefs about control of serious illness, and (3) the specific disease. For instance, regardless of the actual severity or prognosis in a particular case, cancer may be equated with “death” or “no control” because of medical statistics, cultural myth, or prior family history. Alternatively, families may have enabling stories about a relative or friend, who, in spite of cancer and a shortened lifespan, lived a “full” life centered on effectively prioritizing the quality of relationships and goals. Clinicians can highlight these positive narratives as a means to help families counteract cultural beliefs that focus exclusively on control of biology as defining success.

A family’s beliefs about mastery strongly affect its relationship to an illness and to the health care system. Beliefs about control can affect treatment adherence and a family’s preferences about participation in the ill member’s treatment and healing process. When families view disease course/outcome as a matter of chance, they tend to establish marginal relationships with health professionals and may not adhere to treatment recommendations, largely because their belief system minimizes the importance of their own or the professional’s impact on a disease process. Also, poor minority families too often receive inadequate care or lack access, leading to a fatalistic attitude and lack of engagement with health care providers, who may not be trusted to help. Because any therapeutic relationship depends on a shared belief system about what is therapeutic, a workable accommodation among the patient, family, and health care team in terms of these fundamental beliefs is essential. Families that feel misunderstood by health care professionals are often reacting to a lack of engagement at this basic value level.

The goodness of fit in family beliefs about mastery can vary depending on the illness phase. For some disorders, the crisis phase involves protracted care outside the family’s direct control. This may be stressful for a family that prefers to tackle its own problems without outside control and “interference.” The patient’s return home may increase the workload but allow members to reassert more fully their competence and leadership. In contrast, a family guided more by a preference for external control by experts can expect greater difficulty when their family member returns home. Recognition of such normative differences in belief about control can guide an effective psychosocial treatment plan tailored to each family’s needs and affirming rather than disrespecting core values.

In the terminal phase, a family may feel least in control of the biological course of disease and the decision making with regard to the overall care

of the dying member. Families with a strong belief about being involved in a member's health care may need to assert themselves more vigorously with health providers. Effective decision making about the extent of heroic medical efforts requires a family-provider relationship that respects the family's basic beliefs (Lynn, Schuster, Wilkinson, & Simon, 2007).

Clinicians must be cautious about judging the relative usefulness of minimization versus direct confrontation with and acceptance of painful realities. Often both are needed. The healthy use of minimization or selective focus on the positive and timely uses of humor should be distinguished from the concept of denial, regarded as pathological (Walsh, 2006). As distinct from denial, Taylor's research underscores that with "positive illusions," information about a stressful situation, such as major illness, has been understood and its implications incorporated (Taylor, Kemeny, Reed, Bowers, & Gruenwald, 2000). The skilled clinician can support both the usefulness of hope and the need for treatment to control the illness or a new complication. Families can be helped to confront denial and illness severity when there is hope that preventive action or medical treatment can affect the outcome, or when an illness is entering a terminal phase. Yet to cope with an arduous, uncertain course, families often simultaneously need to acknowledge the condition and to minimize treatment risks or the likelihood of a poor outcome.

### ***Family Beliefs about the Cause of an Illness***

When a significant health problem arises, many wonder, "Why me (or us)?" and "Why now?" (Roesch & Weiner, 2001). We attempt to construct an explanation or story that helps us organize our experience. With the limits of current medical knowledge, tremendous uncertainties persist about the relative importance of myriad factors, leaving individuals and families to make idiosyncratic attributions about what caused an illness. A family's causal beliefs need to be assessed separately from its beliefs about what can influence the outcome. It is important to ask each family member for his or her explanation. Responses generally reflect a combination of medical information and family mythology. Beliefs about cause might include punishment for prior misdeeds (e.g., an affair), blame of a particular family member ("Your drinking made me sick!"), a sense of injustice ("Why am I being punished? I have been a good person"), genetics (e.g., cancer runs on one side of the family), negligence of the patient (e.g., careless driving) or of parents (e.g., sudden infant death syndrome), religious beliefs (punishment for sin), or simply bad luck.

Optimal family narratives respect the limits of scientific knowledge, affirm basic competency, and promote the flexible use of multiple biological, psychosocial, and spiritual healing approaches. In contrast, causal attributions that invoke blame, shame, or guilt are particularly important to uncover, as they can derail family coping and adaptation. With a life-threatening illness, a blamed family member may be held accountable if the patient dies. A mother who is blamed by her husband for their son's leukemia may be less

able to stop a low-probability experimental treatment for their dying child. A husband who believes his drinking caused his wife's coronary and subsequent death may increase self-destructive drinking in his profound guilt.

### ***Belief System Adaptability***

Because illnesses vary enormously in their responsiveness to psychosocial factors, *both families and providers* need to distinguish between beliefs about their overall participation in a long-term disease process, beliefs about their ability to control the biological progression of an illness, and flexibility in applying these beliefs. Families' experience of competence or mastery depends on their grasp of these distinctions. Optimal family and provider narratives respect the limits of scientific knowledge, affirm basic competency, and promote the flexible use of multiple biological and psychosocial healing strategies.

A family's belief in its participation in the total illness process can be thought of as independent of whether a disease is stable, improving, or in a terminal phase. Sometimes, mastery and the attempt to control biological process coincide, such as when a family tailors its behavior to help maintain the health of a member with cancer in remission. This might include changes in family roles, communication, diet, exercise, and balance between work and recreation. Optimally, when an ill family member loses remission, and the family enters the terminal phase of the illness, participation as an expression of mastery is transformed to a successful process of letting go that eases suffering and allows palliative care to be provided. Families can play an important role in easing suffering by both providing comfort through pleasurable visits and outings, and openness to healing and repairing old grievances and relationship wounds.

Families with flexible belief systems are more likely to experience death with a sense of equanimity rather than profound failure. The death of a patient whose long, debilitating illness has heavily burdened others can bring relief, as well as sadness, to family members. Relief over death, even when it ends patient suffering, and family caregiving and financial burdens, can trigger massive guilt reactions that may be expressed through symptoms such as depression and family conflict. Clinicians need to help family members accept mixed feelings they may have about the death being natural, as well as often an end to the suffering of a loved one.

Thus, flexibility both within the family and the health care team is a key variable in optimal family functioning. Rather than linking mastery in a rigid way with biological outcome (survival or recovery) as the sole determinant of success, families can define control in a more "holistic" sense, with involvement and participation in the overall process as the main criteria defining success. This is analogous to the distinction between curing "the disease" and "healing the system." Psychosocial-spiritual healing may influence the course and outcome, but a positive disease outcome is not necessary for a family



to feel successful. This flexible view of mastery permits the quality of relations within the family, or between the family and health care professional, to become more central to criteria of success. The health care provider's competence becomes valued from both a technical and caregiving perspective not solely linked to the biological course.

### ***Ethnic, Spiritual, and Cultural Beliefs***

Ethnic, racial, and spiritual beliefs and dominant cultural norms can strongly influence family values concerning health and illness (McGoldrick, Giordano, & Garcia-Preto, 2005; Rolland, 2006b; Walsh, 2009). Significant ethnic differences regarding health beliefs often emerge at the time of a major health crisis. Although American families are a continuum that frequently represents a blend of different ethnic, racial, and spiritual beliefs, health professionals need to be mindful of the diversity of belief systems of various subpopulations in their community, particularly as these are expressed in different behavioral patterns. Cultural norms vary in areas such as the definition of the appropriate "sick role" for the patient; the kind and degree of open communication about the disease; who should be included in the illness caregiving system (e.g., extended family, friends, professionals); who is the primary caretaker (most often wife/mother/daughter/daughter-in-law); and the kind of rituals viewed as normative at different illness phases (e.g., hospital bedside vigils, healing, and funeral rituals). This is especially true for racial minority groups (e.g., African American, Asian, Hispanic) that experience discrimination or marginalization from the prevailing European American culture. Illness provides an opportunity to encourage role flexibility and shift from defining one female member as the caregiver to a collaborative caregiving team that includes male and female siblings/adult children.

Clinicians need to be mindful of these cultural differences in themselves, the patient, and the family to forge a workable alliance that can endure a long-term illness (Seaburn, Gunn, Mauksch, Gawinski, & Lorenz, 1996). Effective collaboration occurs when professionals explore and understand families' cultural and spiritual beliefs about illness and healing. Disregarding these issues can lead families to wall themselves off from health care providers and available community resources—a major source of adherence issues and treatment failure. Sometimes professionals may need the flexibility to suspend their need to be "in charge," especially in relation to family/cultural beliefs that proscribe certain standard forms of medical care (e.g., blood products for Jehovah's Witness). This requires an acceptance that patients, not physicians, retain final responsibility for decisions about their bodies.

### ***Fit among Clinicians, Health Systems, and Families***

It is a common, but unfortunate, error to regard "the family" as a monolithic unit that feels, thinks, believes, and behaves as an undifferentiated whole.

Clinicians should inquire both about the level of agreement and tolerance for differences among family members' beliefs, and between the family and the health care system.

Family beliefs that balance the need for consensus with diversity and innovation are optimal and maximize permissible options. If consensus is the rule, then individual differentiation implies disloyalty and deviance. If the guiding principle is "We can hold different viewpoints," then diversity is allowed. This is adaptive, because it facilitates bringing to the family novel and creative forms of problem solving that may be needed in a situation of protracted adversity, such as serious illness. Families also need open communication and effective conflict resolution when members differ on major health care/treatment decisions.

The same questions concerning beliefs asked of families are relevant to the health care team:

1. What are health professionals' attitudes about their own and the family's ability to influence the course/outcome of the disease?
2. How do they see the balance between their own and the family's participation in the treatment process?
3. If basic differences in beliefs about control exist, how can these differences be bridged?

Because of the tendency of most health facilities to disempower individuals and thereby foster dependence or alienation, utmost sensitivity to family values is needed to forge a therapeutic alliance. Many breakdowns in relationships between "noncompliant" or marginal patients and their providers can be traced to natural disagreements at this basic level that were not addressed.

Normative differences among family members' health beliefs may emerge into destructive conflicts during a health crisis, as in the following case:

When Stavros, a first-generation Greek American, became ill with heart disease, his mother kept a 24-hour bedside vigil in his hospital room, so she could tend to her son at any hour. His wife Dana, from a Scandinavian family, greatly resented the "intrusive behavior" of her mother-in-law, who in turn criticized Dana's emotional "coldness" and relative lack of concern. Stavros felt caught between his warring mother and wife, and complained of increased symptoms.

In such situations, clinicians need to sort out normative cultural differences from pathological enmeshment. In this case, all concerned behaved according to their own cultural norms. In Greek culture, it is normal to maintain close ties to one's family of origin after marriage and expected that a mother would tend to her son in a health crisis. A son would be disloyal not to allow his mother that role. This sharply differs from the wife's northern European traditions. Each side pathologized the other, creating a conflictual

triangle, with the patient caught in the middle. In such situations, the clinician who affirms multicultural differences promotes a transformation of process from blaming or demonizing to accommodating varied cultures respectfully.

It is common for differences in beliefs or attitude to erupt at any major life-cycle or illness transition. For instance, in situations of severe disability or terminal illness, one member may want the patient to return home, whereas another may prefer long-term hospitalization or transfer to an extended care facility. Because the primary caregiver role is typically assigned to the wife/mother, she is apt to bear most burdens in this regard. Anticipating the collision of gender-based beliefs about caregiving with the potential overwhelming demands of home-based care for a dying family member can help families flexibly modify their rules and avert the risk of family caretaker overload, resentment, and deteriorating family relationships.

The murky boundary between the chronic and the terminal phase highlights the potential for professionals' beliefs to collide with those of family members. Physicians can feel bound to a technological imperative that requires them to exhaust all possibilities at their disposal, regardless of the odds of success. Family members may not know how to interpret continued lifesaving efforts, and may assume real hope where virtually none exists. Health care providers and institutions can collude in a pervasive societal tendency to deny death as a natural process truly beyond technological control (Becker, 1973). Endless treatment can represent medical team members' inability to separate a general value placed on controlling diseases from their beliefs about participation (separate from cure) in a patient's total care, which includes biopsychosocial-spiritual well-being.

## CONCLUSIONS

Facing the risks and burdens of a serious illness, the "healthiest" families are able to harness that experience to improve the quality of life. Families can achieve a healthy balance between accepting limits and promoting autonomy and connectedness. For illnesses with long-range risks, including genomic disorders, families can maintain mastery in the face of uncertainty by enhancing the following capacities: acknowledge the possibility of loss; sustain hope of medical advances; and build flexibility into family life-cycle planning that conserves and adjusts major goals, and helps circumvent the forces of uncertainty. The systemic model described here, which integrates the psychosocial demands of disorders over time with individual and family development and belief systems, provides a foundation for such a normative perspective.

A serious illness or brush with death provides an opportunity to confront catastrophic fears about loss. This can lead family members to develop a better appreciation and perspective on life that results in clearer priorities and closer relationships (Walsh, 2006). Seizing opportunities can replace procrastination

for the “right moment” or passive waiting for the dreaded moment. Serious illness, by emphasizing life’s fragility and preciousness, provides families with an opportunity to heal unresolved issues and develop more immediate, caring relationships. For illnesses in a more advanced stage, clinicians should help families emphasize quality of life by defining goals that are attainable more immediately and that enrich their everyday lives.

Imber-Black, Roberts, and Whiting (2003) have underscored the importance of rituals for many families dealing with chronic and life-threatening disorders and loss (see Imber-Black, Chapter 20, this volume). Heightened uncertainty and loss increase awareness that each family gathering may be the last together. Clinicians can help families dealing with serious illness by promoting the timely creation and use of rituals of celebration, transition, and inclusion. A family reunion can invigorate members and serve to coalesce healing energies to support the ill member and key caregivers. With a serious illness, holidays and family traditions offer an opportunity to affirm, strengthen, and repair all family relationships.

Finally, clinicians need to consider their own experiences and feelings about illness and loss (McDaniel, Hepworth, & Doherty, 1997). Awareness and ease with our own multigenerational and family history with illness and loss, our health beliefs, and our current life-cycle passage will enhance our ability to work effectively with families facing serious illness.

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To reveal positive impacts of family strengths on the course of illness and quality of life for all family members. Who developed the illness model? Rolland. What are the 3 dimensions of the illness model? Psychosocial types of illnesses Time phases in their course Core family system variables. What is a deficit approach? Tends to focus on past family damage and individual disturbed behaviour. What is a resource based approach? Orientation aims to identify and encourage strengths clients possessed. What are the 3 formats of family intervention and psychoeducational approaches?? Chapter 9: Challenges and Resilience Over Family Life Cycle. 5 terms. sam\_newland. Chapter 8: Applying a Family Resilience Framework in Community-Based Services. 10 terms. Chapter 17 - Mastering Family Challenges in Serious Illness and Disability 460. Part V - Healthy Couple and Family Processes: Mapping the Complexity 491. Chapter 18 - Interactional Patterns in Marital Success or Failure 493. Chapter 19 - Circumplex Model of Marital and Family Systems 514. Chapter 20 - Measuring Family Competence 549. References 574. Chapter 21 - The McMaster Model 581. Coping with Chronic Illness and Disability: Theoretical, Empirical, and Clinical Aspects. © The Uninvited Guest. Disability permeates the wrinkles of our lives and can blossom into new growth, as we shed the shame and pain that usher in its arrival. Erin Martz. Contents. 18. Coping with Traumatic Brain Injury: Existential Challenges and Managing Hope . . . 389 Joseph H. Hinkebein and Renee C. Stucky. Appendix of Commonly Used Coping Instruments . . .