CHAPTER 1

A Family Psychosocial Map with Chronic Conditions

Miriam, a young married woman with two small children, received the most up-to-date medical treatment and expert surgical interventions during her 4-year bout with cancer. Eight months after her physician pronounced her cured, Miriam and her husband, Dave, separated. Behind the scenes and unknown to the health care team, serious family difficulties had developed over this stressful period. A previously stable marriage had become increasingly conflictual and distant. Dave had developed a serious drinking problem and became verbally abusive toward his wife. A prolonged emotional and financially draining divorce and custody battle followed. Both children developed behavioral problems that required crisis intervention, bringing this struggling family to therapy for the first time.

In a twist on the popular aphorism "the treatment was successful, but the patient died," conventional treatments of serious illness may save the patient, but the family may suffer irreparable harm from the accumulation of psychosocial strains. Chronic or life-threatening conditions confront families with profound challenges. The diagnosis, or recurrence, of cancer or the ongoing challenges of a serious disability reverberate throughout the family system leaving no one untouched. For some families the quality of life deteriorates, whereas others forge ahead with resilience and thrive.

Illness and disability strike all families. The questions are when in our lives they will occur, under what conditions, how serious they will be, and how long they will last. Perhaps most important is how the experience will affect couple and family bonds and shared hopes and dreams. With major advances in medical technology and with improved standards of living for many segments of society, people with access to health care are living much longer and better with conditions such as cancer, heart disease, diabetes, and HIV/AIDS. Many children with chronic illnesses that previously were fatal or necessitated institutional care are surviving into adulthood, often needing extensive family support to integrate into mainstream life.

Longer life spans have heightened strains on sons and daughters and their families, who are increasingly geographically dispersed and contending with the competing demands of elder care, child rearing, and job responsibilities. Ever-growing numbers of families are living with chronic disorders over an increasingly long time period and are coping with multiple challenges simultaneously.

In acute health crises that are resolved within weeks or months, a focus on good biomedical care takes priority. Psychosocial demands on families may be intense, but they are time limited. Like sleep-deprived parents with an infant, a predictable time frame helps families endure the inevitable hardships and maintain a positive outlook. With chronic conditions, however, uncertainties and ambiguities can extend into the distant future, frequently with the expectation that the illness will worsen and eventually result in death. Over time, cumulative strains on the family unit are unavoidable.

THE SOCIAL CONTEXT OF ILLNESS AND DISABILITIES

Families' experiences of illness and disability are enormously influenced by the dominant culture and the health systems embedded in it. In the United States, a major illness often means financial ruin, with almost two-thirds of bankruptcies linked to illness and medical bills (Himmelstein, Thorne, Warren, & Woolhandler, 2009). Millions with disabilities cannot obtain the assistance that would enable independent living. Tens of thousands die each year needlessly because they lack health care coverage for necessary treatments and medications (Wilper et al., 2009).

A lack of access to adequate basic health care has serious ramifications in terms of the incidence of illness, disease course, survival, quality of life, and varied forms of suffering caused by discrimination. For racial and ethnic minority and low-income groups, chronic diseases are more prevalent, tend to occur earlier in the life cycle, and have a worse course and prognosis because of inadequate medical care and limited access to resources. They are disproportionately represented among the approximately 33 million uninsured (U.S. Census Bureau, 2015) and the tens of millions underinsured (Collins, Rasmussen, Beutel, & Doty, 2015). Recent data, showing that black male life expectancy is almost 5 years less than that of white males, give a glaring example of these larger societal issues (Kochanek, Arias, & Anderson, 2013).

As populations age worldwide, the number of people with chronic conditions will vastly increase over coming decades. Over half of the U.S. adult population lives with at least one chronic condition (U.S. Census Bureau, 2015), a number that is climbing rapidly. With advances in technology and extended survival with chronic illnesses, the strain on families to provide adequate caregiving is unprecedented. For example, in the United States in 1970, there were 21 potential family caregivers for each elderly person. By 2010, there were only 7 potential caregivers, and this caregiver support ratio is projected to decline further to 4 to 1 by 2030 and to 3 to 1 by 2050 (Redfoot, Feinberg, & Houser, 2013). Many factors are involved, including decreasing birthrates, family networks that are becoming smaller and more top-heavy, with more older than younger family members, and geographic distance among members. Most women are in the workforce, juggling job and child-rearing demands, and are unable to fill traditional female role expectations to serve as unpaid family caregivers.

AIMS OF THIS BOOK

This book describes the Family Systems Illness (FSI) model for psychoeducation, consultation, assessment, and intervention with couples and families challenged by chronic and life-threatening conditions. It extends my earlier framework (Rolland, 1984, 1987a, 1990, 1994a, 2012, 2013) to include in-depth coverage of a wide range of practice applications. The FSI model offers a comprehensive way of organizing our thinking about the multiple interactions involving a patient, his or her family, and health care professionals during the course of dealing with a chronic condition. It considers the complexities and diversity of contemporary family life in a social context and in relation to health care systems. It can be used to address the breadth of clinical issues faced by couples and families, where one or more members suffer a serious illness or disability. This model is distinctive in addressing the changing interactions among these parts of the system over the course of the illness and the evolving phases of the life cycle.

FSI is a family-focused, resilience-based, and prevention-oriented clinical model that fosters healthy psychosocial adaptation. Intended for a broad range of health and mental health care practitioners across disciplines in varied health care and counseling settings, this book provides core knowledge and skills to work effectively with families facing illness and disability. It offers both families and clinicians a useful approach that promotes a sense of mastery and empowerment over a complex and uncertain long-term process.

The Need for an Integrated Family Systems Illness Model

Over the past 30 years, family-centered, collaborative, and biopsychosocial models of health care have grown and evolved (Doherty & Baird, 1983; Engel, 1977; Kissane & Parnes, 2014; McDaniel, Doherty, & Hepworth, 2014; Miller, McDaniel, Rolland, & Feetham, 2006; Peek, 2015; Rolland, 1994a; Seaburn, Gunn, Mauksch, Gawinski, & Lorenz, 1996; Talen & Burke Valeras, 2013; Wood et al., 2008, Wright & Bell, 2009). There is substantial evidence for the mutual influence of family functioning, health, and physical illness (Carr & Springer, 2010; D'Onofrio & Lahey, 2010; Proulx & Snyder, 2009; Weihs, Fisher, & Baird, 2002) and for the usefulness of family-centered interventions with chronic health conditions (Campbell, 2003; Hartmann, Bazner, Wild, Eisler, & Herzog, 2010; Kazak, 2006; Law & Crane, 2007; Martire, Lustig, Schultz, Miller, & Helgeson, 2004; Martire, Schulz, Helgeson, Small, & Saghafi, 2010; Shields, Finley, Chawla, & Meadors, 2012). Highly regarded texts describe applications in various health care settings and across different disciplines (Gelhert & Browne, 2018; Heru, 2013; Hodgson, Lamson, Mendenhall, & Crane, 2014). The multidisciplinary journal *Families, Systems, and Health* has been a crucial voice advocating theoretical and clinical research and provider training in family-oriented collaborative health care. The many advances in specific areas will be interwoven throughout the book.

The vast majority of research and clinical publications address a particular illness or disability (Shields et al., 2012). For instance, family therapy interventions with diabetes are the most intensively researched and have included Multisystemic Therapy (MST) (Ellis et al., 2008) and Behavioral Family Systems Therapy (BFST-D) (Wysocki et al., 2007) models. Other investigators have included a combination of cognitive and behavioral interventions with childhood cancer (Kazak, 2005, 2006) and the bio-behavioral family model with pediatric asthma (Wood et al., 2008). While this research provides valuable insights about a specific disorder using specific interventions, the interventions may be applied either too narrowly or too broadly to conditions with markedly different psychosocial demands. The application of a particular psychosocial intervention can become overgeneralized, with insufficient stock taken of the complexities of different conditions over time. The Family Systems Illness model described in this book addresses this issue, providing a conceptual framework that can be applied to a full range of adult- and child-onset illnesses and disabilities, including neurocognitive and genomic disorders.

Promoting Family Resilience

Nearly two-thirds of patients and families referred to me and my colleagues at the Chicago Center for Family Health over the past three decades have never before seen a mental health professional. This has profound clinical implications: Any comprehensive model needs to be useful for typical families coping with common illness-related strains, not just for those with serious dysfunction more often seen in mental health settings.

Our thinking has advanced past stereotypical definitions of "the family." Research has amply documented that a broad range of diverse, multicultural family forms and styles of functioning are compatible with normal, healthy individual and family development (Walsh, 2012). Countering the myth of normal family life as "problem-free," we know that all families are challenged by adversity. When serious illness strikes, we need to reject an outdated, rigid, or romanticized ideal of coping. This family-centered model views a broad range of family forms and processes as normative. Supported by a growing body of research on resilience, it describes how families can adapt successfully to illness and disability along many varied pathways (Walsh, 2016b).

Families with problematic relational patterns may well have more difficulty handling the stresses of a chronic illness. Yet, clinicians need to be careful not to reflexively append the label "pathological" or "dysfunctional" to families beset by serious conditions. In fact, components of family functioning, such as cohesion, exist on a continuum, and cultural norms vary widely. Different types or phases of illness may need varying levels of family cohesion for optimal coping and adaptation. High versus low family cohesion is not viewed as inherently healthy or unhealthy. Rather, the organizing principle becomes relative: What degree of family cohesion tends to work optimally with this illness at this time, and how might that change in future phases of the condition? Very high levels of cohesion should not be presumed to be dysfunctional. Studies have found high cohesion in positive close, caregiving bonds to be adaptive with a major health condition (Green & Werner, 1996). And, I have seen families with enmeshment function very well when faced with a rapidly progressive, fatal illness, such as metastatic cancer, where high cohesion is needed.

Family Systems-Oriented Unit of Care

The FSI model broadens the unit of care from the medical model's narrow focus on the ill individual to the family or caregiving system ("health-related family unit") (McDaniel et al., 2014), including all members and relationships affected by the illness-related challenges and those who could be helpful allies in care. The model considers the impact for siblings of an ill child or for the couple bond of a spouse who is providing elder care. Systemically, an effective biopsychosocial model attends to the impact of the illness on the family network of relationships, 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 cornerstone of the caregiving system, as suggested by the Institute of Medicine report (Weihs et al., 2002), the model describes successful coping and adaptation based on supporting family system strengths and addressing its vulnerabilities.

This model is a sharp contrast to the narrow focus on the patient by most current models of intervention in behavioral medicine, consultation-liaison psychiatry, and psychotherapy. At worst, families are relegated to the background; it is recognized that they affect the patient's psychosocial adjustment, but they are not considered to need help with their own stressful challenges. Early intervention acknowledges the importance and concerns of all family members, prevents them from being marginalized, and draws on their potential as vital partners and resources in the treatment process. Further, I view collaboration as a mindful way of resisting pressures to dehumanize the experience of illness and reduce the ill person and a living family system to a diseased patient or disorder.

From Psychosomatic to Holistic and Interactive

The literature describing the impact of chronic disorders on individuals and families is extensive. However, the influence of individual and family processes on disease has historically been defined in terms of psychosomatic processes and almost invariably in pathological terms. The designation 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. This designation tends to overpathologize families and to label them pejoratively as "psychosomatic families." Further, a skewed focus on dysfunction distorts our understanding of typical or optimal family coping and adaptation to illness. More recent investigators have shifted attention toward the influences of social support and key family processes that promote adaptation. A growing literature examines the positive impact of individual and family functioning on health and well-being and, in the context of illness, the quality of life for all family members as well as the disease course and outcome (Carr & Springer, 2010; D'Onofrio & Lahey, 2010; Weihs et al., 2002).

The FSI model 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. Even with regard to highly virulent diseases such as HIV/AIDS, there is compelling evidence that family and community support affects the patient's quality of life and the course of the illness. 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 biopsychosocial interaction as an opportunity to make a positive difference. This mindset increases their sense of control and overall quality of life.

Rigid, gender-based standards for couples and families define a narrow range of roles and expectations 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. The FSI model expands views of role functioning for men and women and views the family network as a caregiving team.

To summarize, the FSI model gives clinicians a useful way of describing the complex mutual interactions among the illness, the ill family member, and the family system within a normative framework attuned to the diversity in contemporary families. It provides a framework for addressing the challenges families confront and for expanding their possibilities for adaptation and growth. Throughout this book, we will see how illness challenges and strains family functioning, affecting all members and their relationships; and how, in turn, family processes can influence the well-being of all members, their relationships, and the management and course of the condition. A serious health crisis can shake the foundation of the family, and it can awaken family members to opportunities for more satisfying, fulfilling bonds and life pursuits. This useful clinical model addresses these challenges and emphasizes the possibilities for patient and family positive adaptation and growth.

THE CORE CONCEPTS AND COMPONENTS OF THE FAMILY SYSTEMS ILLNESS MODEL

Family Systems Theory

The Family Systems Illness (FSI) model is grounded in systems theory. Family systems theory emphasizes interaction and context; individual behavior is viewed within the context in which it occurs. From this perspective, function and dysfunction are defined by the fit between the individual and the family and their social context, the psychosocial demands of the health condition, and other stressors in family life.

A family systems orientation is distinguished by its view of the family as a transactional system. The ongoing interactive patterns within the family and between a family and other systems (for example, health institutions) are considered central in influencing individual behavior. Stressful events and the problems of an individual member, such as a major health crisis, affect the whole family as a functional unit and have ripple effects for all members and their relationships. In turn, the family response to problems and major life challenges, such as serious illness, contributes significantly to positive adaptation or to individual and relational dysfunction. Family members are interrelated such that each individual affects all the others and the group as a whole, in turn, affecting the first member in an ongoing chain of mutual influence. Thus, individual challenges, such as a serious health condition, need to be assessed and treated in the context of the family system and its social and developmental location. Overall, *the family is regarded as an essential resource and partner in treatment, with the potential of fostering optimal adaptation.*

In a systemic model of human development, individual and family development are seen to coevolve over the life course and across the generations. Therefore, a broad multigenerational and multicultural conception of the family evolving over the life cycle is essential (McGoldrick, Garcia Preto, & Carter, 2016). Relationships grow and change, boundaries shift, roles are redefined, and adaptation is needed when a new child is born or a member dies.

Each developmental phase presents salient challenges; distress often occurs around major transitions, such as the birth of the first child or later-life caregiving needs.

For clinicians and researchers alike, transactional patterns are at the heart of all systems-oriented biopsychosocial inquiry. In physical illness, particularly chronic and life-endangering disorders, the primary focus is systemic—which means a condition, individual and family processes, and other biopsychosocial systems mutually influence one another (Engel, 1977). The FSI model views the family as its central unit because in clinical assessment and intervention it may provide the best system through which to understand these multilevel systems. This choice is made with the recognition of biological influences and ongoing family transactions with larger environmental factors. The impact of chronic disorders is affected by economic resources, extended kin and social support, and the health care system, particularly through access, availability, and the quality of services.

The FSI model is based on the concept of systemic interaction between an illness and family that evolves over time. The FSI model has three dimensions: (1) a psychosocial typology of illness, (2) major time phases in an illness's evolution, and (3) key family systems components.

A Psychosocial Typology of Chronic Conditions

The landscape of chronic conditions is diverse and complex, presenting a vast range of symptoms and trajectories, accompanied by a variety of psychosocial demands over the evolution of the disorders. Although there are elegant and detailed descriptions of the physical demands of particular conditions, these accounts do not consider the pattern of psychosocial demands of the illness over time or the systemic ramifications in the relational network. This book presents a psychosocial typology of illness that organizes the diversity and the commonalities of chronic disorders in a way that can be useful to both clinicians and families and serves as a bridge between the biomedical and the psychosocial worlds. As shown in Figure 1.1, illnesses can be typed by their pattern of onset, course, outcome, degree of disability, and level of uncertainty.

Illness Time Phases

A longitudinal perspective is essential with chronic conditions. We need a multigenerational developmental model that coherently integrates legacies and themes related to the illness with three interwoven threads—the illness, individual family members, and family development—in a manner useful for assessment and intervention.

By their nature, chronic conditions evolve over many years. The model presented here is useful in combining illness and disability in a schema that

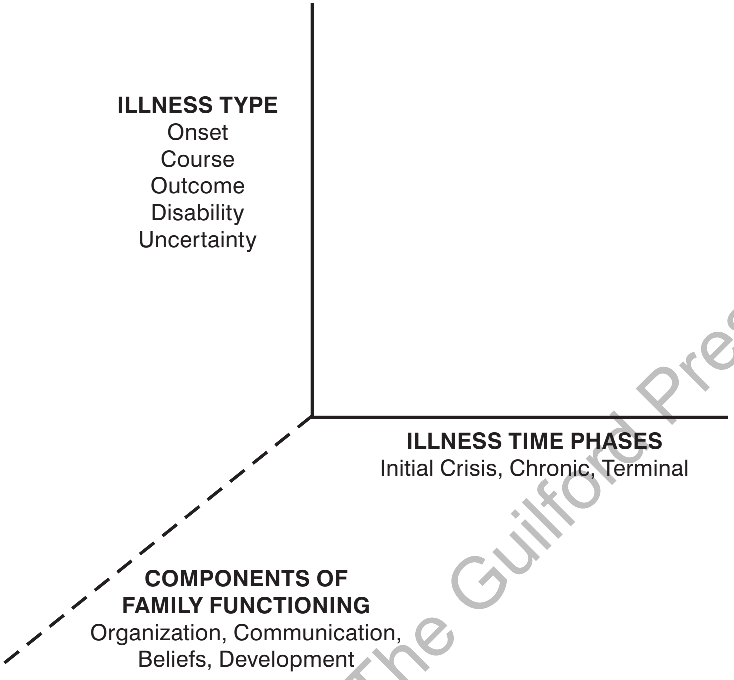

FIGURE 1.1. FSI model: Three dimensions.

links the past, present, and future. The literature has generally focused on a specific phase of what I refer to as the "illness life course" (e.g., disease onset, terminal phase, or bereavement). There are three illness time phases in the FSI model: the initial crisis phase, including the initial diagnosis and adjustment; the chronic phase; and the terminal phase. It is crucial to consider the evolution of illness-related developmental challenges over the entire course of a disorder.

Components of Family Functioning

The framework of family assessment in the FSI model is based on an evaluation of four basic domains of family functioning, drawing from Walsh's family resilience framework and advances in research on normal family processes (Walsh, 2012, 2016b).

- Organizational/structural patterns
- Communication processes
- Belief systems
- Development: multigenerational patterns and family life course

At its core, the FSI model attends to the expected psychosocial demands of a disorder through its various time phases in relation to these domains of family functioning. The model emphasizes family and individual life-course development, multigenerational patterns, and belief systems. It includes the influences of culture, ethnicity, race, spirituality, gender, and socioeconomic level, along with related forms of discrimination. Figure 1.2 represents one way to conceptualize the relationship between these different levels of influence.

Interaction with Individual and Family Development

It is vital to attend to illness-associated developmental issues of other key family members and the family as a functional unit. Too often, if developmental issues are addressed, they tend to be restricted to a particular person, usually the patient. The impact of chronic conditions differs for the patient, for a child in cases of parental or sibling illness, and for key caregivers, and depends on when an illness strikes in family development and in each member's individual life course. Because the course of different conditions varies greatly over time, developmental implications for the family unit and all members need to be highlighted. Developmental skews among family members become inevitable during the course of an illness or disability. Thus, the FSI model coherently integrates individual and family life-cycle passage in relation to the evolving disorder over time.

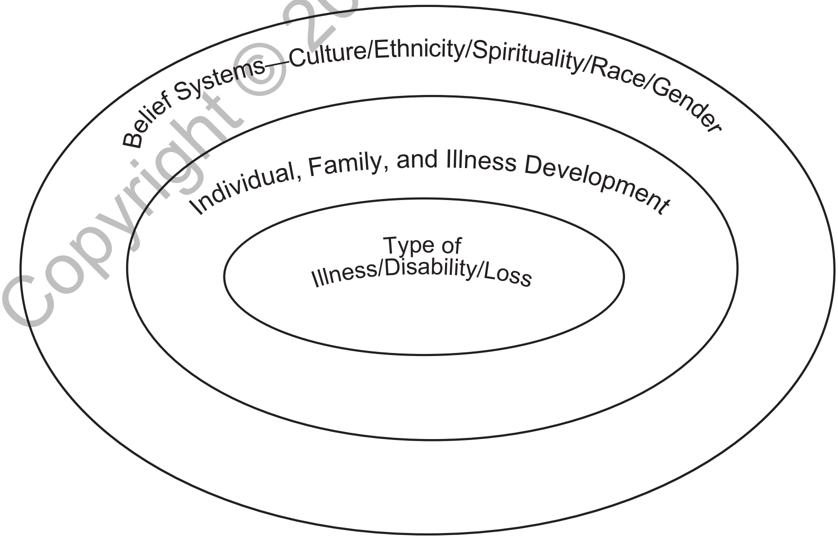

FIGURE 1.2. FSI model: Levels of influence.

Multigenerational Influences

Systems thinkers have stressed that a family's present behavior cannot be adequately understood apart from its history (e.g., Bowen, 2004; Byng-Hall, 2004; McGoldrick et al., 2016). Multigenerational legacies and patterns of adaptation shape beliefs and expectations that strongly influence how families perceive a current health crisis and guide its modes of dealing with adversity. Attention to these legacies is part of the FSI model.

Family Belief Systems

Belief systems play a central role in family coping and adaptation with chronic disorders. Vivid descriptions from medical anthropology highlight the kinds of explanations and meanings people attach to health problems (Groleau, Young, & Kirmayer, 2006; Kirmayer, Guzder, & Rousseau, 2014; Kleinman, 1988, 2009). In the area of cognitive psychology, attribution theory and social construction theory have examined the ways in which people develop narratives and meanings about how things happen, especially significant personal events (e.g., Beck & Haigh, 2014; Niemeyer, 2001). Meaning-making occurs through the narratives individuals and families develop to make sense of their experiences, their social context, and their place in it (Freedman & Combs, 1996). With a serious health condition, efforts in meaning-making come to the fore as individuals and families strive to integrate its significance into their life passage.

There have been important contributions to our understanding of family-shared meaning systems and the evolution and significance of family belief systems (Antonovsky, 1998; Hansson & Cederblad, 2004; Reiss, 1981; Walsh, 2009, 2016b). This includes understanding the ongoing systemic processes in families relative to meaning systems with illness and loss (Nadeau, 2008; Wright & Bell, 2009).

In situations of chronic disorders, a basic task for families is to make meaning for a health condition that promotes the family's sense of active agency and mastery. At the extremes, competing ideologies can leave families divided between a biological explanation of an illness and one that holds the individual family member responsible (e.g., illness as retribution for wrongdoing). Also, families desperately need guidance and reassurance that they are handling illnesses as best they can (and that bad things do happen to good people). Thus, belief systems are included in the FSI.

The FSI model emphasizes the *quality of fit* between the psychosocial demands of the chronic condition over time and the family style of functioning and resources. This is a prime determinant of successful versus dysfunctional coping and adaptation. The systemic interaction between an illness and the family is shown schematically in the diagram in Figure 1.3. From this perspective, no single family pattern is regarded as inherently healthy or

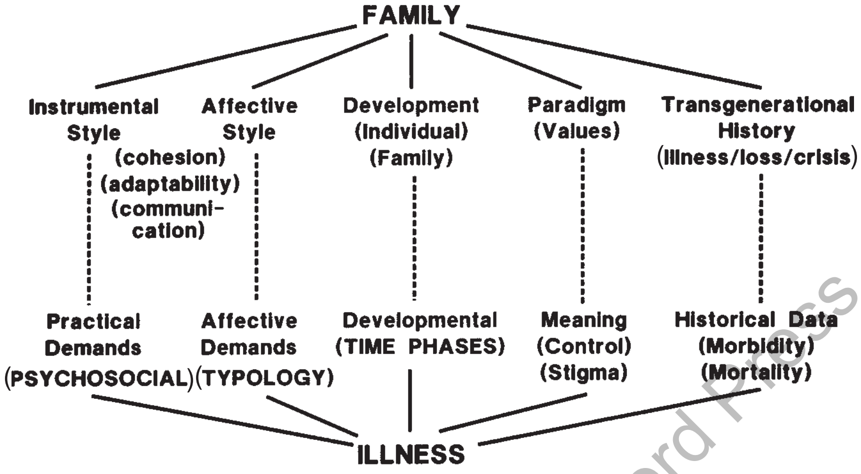

FIGURE 1.3. Interface of chronic illness and the family. From Rolland (1987b). Reprinted by permission.

unhealthy. Rather, the organizing principle becomes relative: What degree of family cohesion or kind of communication is optimal for adaptation in diverse families, with different kinds of conditions, and in different phases of chronic disorders?

A Psychosocial Map for the Experience of Illness and Disability

Families encounter the world of illness and disability without a psychosocial map. Often they desperately need a psychosocial guide that can provide information, support, and reassurance that they are handling an illness well. Many families, particularly those with untimely disorders, find themselves in unfamiliar territory without a map. A preventive, psychoeducational approach helps families anticipate normative illness-related developmental tasks in a fashion that maximizes their sense of active agency, mastery, and acceptance in dealing with the condition. To create a normative context for their illness experience, families need to understand the following:

1. *Understand themselves as a systemic functional unit.*
2. *Have a psychosocial understanding of the condition in systems terms.* This means learning the expected pattern of practical and affective demands of a disorder and its treatment over the course of the condition. This includes a time frame for disease-related developmental tasks associated with different phases of an unfolding condition.

3. *Appreciate individual and family life-cycle patterns and transitions.* This facilitates incorporation of changing developmental priorities for the family unit and individual members in relation to evolving challenges of a chronic disorder.
4. *Understand the cultural, ethnic, spiritual, and gender-based beliefs that inform the type of caregiving system they construct.* This includes guiding principles that delineate roles, rules of communication, meaning-making, definitions of success or mastery, and the fit with the beliefs of the health care providers.

Family understanding in these areas facilitates a more holistic integration of their illness experience and the family as a functional family-health/illness system evolving over time.

Application to Diverse Health Care Disciplines and Settings

The FSI model provides a conceptual base for approaching clinical practice and research regarding illness and disability from a family systems perspective. The emphasis is on the initial consultation and assessment process and the common issues and challenges faced by families as they experience a condition. This model and practice guidelines are useful for clinicians who may use varied intervention approaches. The model can be applied across disciplines by both health and mental health care providers. It has been designed with an awareness that the level of psychosocial intervention will vary considerably depending on the context and the professional training and role of the clinician. Throughout this book, using the FSI model, I will underscore different levels of psychosocial involvement with families, beginning with minimal provision of biomedical information and psychoeducation, consultation and a systemic assessment, brief interventions, periodic "family checkups," and more intensive family-oriented therapy (Doherty, McDaniel, & Baird, 1996; McDaniel, Campbell, Hepworth, & Lorenz, 2005). (See Chapter 18.) The FSI model should be helpful at every level of intervention.

Each chapter provides enough detail to be useful for more comprehensive assessments or intensive interventions. I will discuss a range of important issues and dilemmas and offer sample questions, so that clinicians can get a feel for how I might elicit information about various areas of family life. Naturally, I never cover all questions or all issues in detail with any one family. Those clinicians who function under enormous time pressures and have limited opportunities with families can adapt this approach to make best use of their time. For instance, instead of doing a detailed multigenerational history, asking a few well-chosen questions can serve as a "screening scan." If a critical issue is identified, clinicians can decide whether to pursue it further or refer the family to an appropriate colleague.

THE ORGANIZATION OF THIS BOOK

This volume is organized into four parts. The rest of Part I (Chapters 2 and 3) focuses on the illness aspects of the FSI model by describing the psychosocial typology and illness time phases.

Part II (Chapters 4–8) describe the family aspect of the model, providing case vignettes and clinical guidelines to work with families. Chapter 4 describes basic principles of effective systemic interventions for practitioners, and I provide guidelines for family-oriented consultations for both an initial session and timely follow-up sessions. Flexible use of individual, couple, family, and multifamily discussion group interventions and psychoeducation are described. Chapter 5 discusses family organizational and communication processes in chronic disorders. Chapter 6 describes the importance of multigenerational themes related to illness and loss, and offers case examples. It covers family legacies, including toxic issues, catastrophic expectations, strengths, and learned differences between family members. Using concepts from contemporary individual and family life-course models, Chapter 7 discusses the mutual interactions between the course of an illness and the development of the family and its individual members. Timing of onset and future nodal transition points are highlighted.

Chapter 8 describes the role of belief systems in chronic disorders. The discussion includes key elements of families' health belief systems and the influences that shape them over the course of a condition. Special consideration is given to beliefs about normative illness experiences; biopsychosocial–spiritual influences in health and illness; mastery, control, and acceptance; cultural and ethnic meanings attached to symptoms and illnesses; gender issues; assumptions about influences in the cause, course, or outcome of a disorder; the fit of beliefs among family members; and the role of integrative medicine. The chapter examines beliefs that induce blame, shame, and guilt and the interventions that foster more adaptive beliefs and promote competency and mastery.

Part III (Chapters 9–16) discusses applications of the FSI model and offers practice guidelines for phase-related and specific populations. Chapter 9 addresses anticipatory loss issues for families over the entire course of a chronic or life-threatening condition. Beyond the concept of anticipatory grief, in the terminal phase of an illness, the concept of anticipatory loss recognizes that families often live for years with painful ambiguities and the uncertainties of threatened loss. This includes living with genetic risk information. Considered here are specific issues such as distinguishing among anticipation of disability, cognitive impairment, suffering, and death and the different strains for families dealing with possible versus probable or inevitable loss. The chapter highlights ways to help families think about anticipated loss in relation to future nodal points in their personal and family life course.

Facing our own mortality or the death of a loved one is profoundly challenging. The way we approach life's end and painful losses can yield unexpected personal relational growth and transformation. Chapter 10 provides guidelines that address key clinical and ethical challenges in the terminal phase such as meaning-making; handling dilemmas related to end-of-life decisions; opening blocked communication; secrecy and denial; facilitating reconciliation and healing of intergenerational conflicts and estrangement; integrating medical treatment with palliative care and hospice; dignity and control in the dying process; and conflicts in values of health care professionals, patients, and families.

Chapter 11 addresses assessment and treatment issues for chronic conditions in childhood and adolescence. Guidelines are provided for such issues as communication, control, determining reasonable medical management goals that support normative development, transition to adulthood, and meeting the challenges for siblings. Chapter 12 explores family challenges with parental illness and disability, and with later life conditions. It includes caregiving issues related to gender, negotiating shared responsibilities among family members, balancing caregiving of parents/elders with child rearing, inclusion of professional caregivers, and skilled facility placement planning.

Chronic disorders often wreak havoc on a couple's relationship. Chapters 13 and 14 address the challenges in maintaining a viable mutual relationship, coping with uncertainties, and achieving developmental goals in the face of threatened loss. The FSI model provides a basis for discussing common challenges regarding intimacy, sexuality, communication issues, patient–caregiver and other relationship imbalances, gender roles, coparenting, and the use of individual and conjoint consultations.

Chapter 15 addresses the impact of advances in genomics, which pose unprecedented clinical and ethical challenges for families and health care professionals. Expanding on my Family Systems Genetic Illness (FSGI) model (Rolland & Williams, 2005), this chapter examines core clinical issues and sociocultural influences in decision making about genetic testing, communication with partners and family members, and living with risk information across the life cycle. The areas discussed include belief conflicts, ethical issues and decisions (e.g., privacy vs. right to know by others at risk, fetal information), couples and childbearing, multigenerational patterns, and behavioral genetics.

Chapter 16 employs the FSI model to address some key family challenges with mild and advanced dementia and traumatic brain injury. Conditions involving neurocognitive impairment are among the most difficult for couples and families. Although there are a number of approaches to help individual caregivers, a broad family systems approach, now underutilized, can be effective.

Part IV (Chapters 17 and 18) focuses on the clinician's experience and collaborative practice. Chapter 17 addresses the vital importance for clinicians to understand how our own belief systems, personal experiences, and multigenerational and life-cycle issues related to illness and loss affect our professional engagement with patients and their families and our practice effectiveness. The chapter examines health care professional challenges related to facing loss and personal limits in the context of work demands, while striving to maintain a satisfying personal and family life. I describe an in-depth case example involving a personal illness story and its relational ramifications for a couple coping with cancer.

The concluding Chapter 18 uses the FSI model to look at larger systems and the ways in which families can be connected to systems of care. The chapter provides an overview of integrated family-oriented care and describes innovative examples of family-based programs of collaborative care in specialty care services and with consumer-based organizations. In this context, I prefer the word *consumer* because it connotes a more balanced, less hierarchical relationship to health care professionals than *patient* or *patient's family*. As is common in health care settings, I will use the word "patient" throughout the book, yet with the respect due to the "consumer of care." The chapter discusses clinical challenges (e.g., belief systems) at the interface between the patient and family, health care providers, and systems of care, over the illness course. Finally, key principles and policies for advancing family-oriented health care are provided.

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