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Chapter 1 A family psychosocial map with chronic conditions

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.

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Each developmental phase presents salient challenges; distress often occurs around major transitions, such as the birth of the first child or later-life care-giving 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 ill-ness's evolution, and (3) key family systems components.

Chapter 4: An Integrated Practice Approach with Couples and Families

BASIC PRINCIPLES OF INTERVENTION

The FSI model is used most effectively in a preventive, normative manner. Ideally all families facing illness and disability should have from the beginning a psychosocial component of care that includes the key members of the family system and engages them as valued partners and resources. When all health care team members adopt this approach (at whatever level is appropriate for professionals in their role), then biomedical and mental health care providers, the patient, and the family are powerfully enjoined and avoid unhelpful mind–body divisions. This posture ensures a psychosocial aspect of care from the start and simplifies a referral for more intensive mental health care, if needed, at some future point in the illness course. Every time a psychosocial consultation is included in the initial crisis phase or a provider suggests a "psychosocial checkup" at predictable transitions, it models (1) that it is normative for a chronic condition to affect the family system and its emotional health and (2) that it is possible to be proactive about expected condition-related challenges.

Initial Family-Oriented Consultation

Optimally, all families facing chronic illness or disability would routinely have a family consultation in the initial crisis phase, near the time of onset. As a preventive measure, this accomplishes three vital therapeutic tasks.

1. It includes a systems-oriented behavioral health care consultant as a member of the health care team.
2. It engages the family as a key resource and partner of care.
3. It normalizes the expectation of common psychosocial strains for the entire family in a positive, nonpejorative manner that enables them to utilize psychosocial support effectively, minimizing stigma and shame.

It also reduces feelings of helplessness that can lead to family withdrawal and isolation. Inviting a family early into this kind of collaborative process pro-motes open and flexible communication among all professionals and family members involved in the caregiving system.

The following assessment and intervention goals should be incorporated into a basic family-centered consultation.

Engaging the Family System

When an initial family-oriented biopsychosocial collaboration occurs, families are less likely to experience feelings of shame or blame when referrals for psychosocial treatment occur later in the chronic or terminal phase. Professionals need to be careful not to unwittingly contribute to these feelings, commonly by making a referral when biomedical treatment has reached its natural limit, treatments have failed, or a condition has progressed.

Chapter 8: Tapping the Power of Family Belief Systems

OVERVIEW

Our beliefs are represented and continually revised in the narratives we construct together to help make meaning of our world and our place in it

(Freedman & Combs, 1996; Hoffman, 1990; White & Epston, 1990). Core beliefs predominate when major life challenges, such as serious health conditions, arise. Collaborative health care emphasizes the cocreation of narratives about health conditions that incorporate the belief systems of patients, families, and health care providers.

THE EXPERIENCE OF ILLNESS: LEVELS OF MEANING AND INFLUENCE

Arthur Kleinman (1988) conceived three health levels of meaning—disease, illness, and sickness. I've expanded these levels to an ecosystemic, family-oriented perspective that includes the biomedical level, the human experience level, and macrosystem level of meaning. A biopsychosocial understanding requires an appreciation of the ongoing mutual influences among these levels of meaning over the illness course.

The biomedical level refers to a purely biological description or under-standing of a patient's condition. Health professionals function mostly at this level, consistent with how they have been traditionally trained. From this perspective, when they ask, "Tell me about your pain," they want to know where it is, when it occurs, how intense it is, what treatment has already been tried, and what other physical symptoms are associated with it. These questions are intended to discover a physical explanation for the pain.

Patients and their families live primarily in the realm of the human experience of illness, at the level of symptoms and suffering. This refers to "how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability" (Kleinman, 1988, p. 3). The experience of illness involves the synthesis of biological phenomena with personal, family, and cultural meanings.

At a third macrosystemic (larger system) level, health meanings are derived from larger cultural, macrosocial, economic, political, or institutional forces that are often beyond a patient's

and family's control. For example, some health conditions are strongly influenced by poverty, racism, and technological oppression (e.g., flawed environmental policies), or are viewed pejoratively as due to an "immoral" lifestyle. The policies and ideology of our health care delivery system, which limits universal quality care for everyone, actually causes health care disparities. Diseases, such as lead poisoning, cancer, asthma, and HIV, which are more common in inner cities, need to be viewed through this larger societal lens. Affected patients and their families internalize the messages about their conditions that they receive from the dominant cultural milieu. This process can profoundly influence their illness experience.

In the traditional biomedical model, the health care provider decodes and reduces descriptions of the human experience of illness to biological disease

ASSESSMENT OF HEALTH BELIEFS

• Normative illness experience

• Ethnic, cultural, and spiritual influences

• Gender-related expected roles and behavior

• Mastery, control, and acceptance

• The cause(s) of an illness

• Factors that can influence the course and outcome

• Sense of hope or optimism, or pessimism

• Particular symptoms (e.g., chronic pain), types of illnesses (e.g., life-threatening), or specific diseases (e.g., HIV/AIDS) by a family, ethnic group, religion, or the wider culture

• Family rituals

• Fit of health beliefs among family members as well as between the family and the health care system and the wider culture (also see Chapter 18)

• Integrative healing practices

Ethnocultural and Spiritual Influences in Illness and Health

Practitioners need to be mindful of the diversity of belief systems of ethnic and religious groups in their community and of how they are expressed in different behavioral patterns. Simultaneously, we need to avoid cultural stereotyping and recognize and respect the unique perspectives of each patient and family. Cultural norms and religious expectations vary …

Beliefs about Agency and an Illness's Future Course

Belief-System Flexibility

Because illnesses vary enormously in their responsiveness to psychosocial fac-tors, both families and providers need to distinguish between beliefs about their overall participation, or active agency, in long-term disease management and beliefs about their ability to control the biological progression and out-come. Clinicians can encourage a family's flexible participation in the over-all illness and treatment process, independent of whether a disease is stable, improving, or terminal. Proactive attempts to influence a biological course can make a difference, such as when parents stop serving sweet desserts so as not to tempt an adolescent with diabetes. Or, family life might be adjusted to help maintain the health of a member with cancer in remission by adjusting members' roles, communication patterns, diets, type of exercise, and the balance between work and recreation.

Flexibility on the part of the family and the health care team is a key variable in optimal functioning. Rather than linking mastery in a rigid way with survival or recovery, families can define mastery in a more "holistic" sense. Involvement and participation in the overall process can be the main criteria defining success. Psychosocial–spiritual healing may influence the course or 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 medical providers to become a

Illness Narratives

A central clinical goal is to draw out family members' narratives so they can share them with one another. In this process, different perspectives can be explored and clarified, leading to an acceptance of varied positions or consensus building. Empowering life themes can be gleaned from accounts of courage, overcoming adversity, or repairing injustice. Clinicians can affirm each member's meaning-making efforts to facilitate the joining process needed in a collaborative therapeutic process. This ought to be done in an empathic, respectful manner, without blame, and with an emphasis on family strengths and aspirations.

Diagnosis and Labeling

The labeling language used to communicate a diagnosis conveys a revealing message about the locus and extensiveness of pathology. Do family members and professionals refer to diabetes in a family as "Joe has diabetes," "Joe is a diabetic," or even "Joe's diabetic family"? The way all the parties involved communicate about a condition strongly influences the meanings and beliefs that shape enduring narratives. These narratives, in turn, shape the identity of the affected person and of the family system. "Joe is a diabetic" implies that a physical disorder has become the whole person. This is more common in conditions, such as diabetes, that affect the whole body physiologically or in others that are highly visible ("an amputee"). Conditions that have a high level of uncertainty about their cause, control, or cure or have associated stigma lend themselves to more extensive labels (Sontag, 1978).

When families refer to the ill member or themselves in all-encompassing terms (for example, "our alcoholic family"), the entire family is pathologized. Clinicians need to be mindful of their own way of speaking about an illness or disability and encourage families to refer to a chronic condition in more circumscribed terms in order to facilitate healthy adaptation.

Some conditions are associated with embarrassment and shame, particularly those with visible characteristics and public reactions. Examples include psoriasis, Tourette's syndrome (which includes uncontrolled tics, guttural sounds, and cursing), musculoskeletal disorders (e.g., MS, Parkinson's disease, or muscular dystrophy), seizure disorders, and physical deformities. Other conditions can foster shame because of the stigma attached to cognitive impairment. These include intellectual disabilities; TBI; and major mental disorders

such as schizophrenia, Alzheimer's disease and other forms of dementia, and substance-abuse-related organic brain syndromes. Some conditions, such as inflammatory bowel diseases, can have hidden shame-laden features (e.g., a colostomy) or entail risk of public embarrassment. Mastectomy for breast cancer can be particularly problematic because of the cultural association of breasts with a woman's beauty and desirability, as well as with the maternal qualities associated with breast-feeding. Conditions that disfigure the face or produce facial signs of emotional and physical pain become outward, public signs of suffering and the changed identity of the afflicted person. The follow-ing case is illustrative.

CHAPTER 9: Helping Families with Anticipatory Loss and Suffering

The anticipation of loss in physical illness can be as challenging and painful for families as the actual death of a family member. It touches the existential knowledge of their own mortality that they may want to deny (Becker, 1973).

Scant attention has been given to the process of families' anticipation of future loss and suffering and how that experience evolves with illness, individual, and family development. Most literature on loss has focused on anticipatory grief in terminal illness, when loss is imminent (Rando, 2000). It has not addressed the "if" aspect of threatened loss and has narrowed the "when" to the last phase. When diagnosed, most illnesses are uncertain (Mishel, 2014). The issues are the degree of uncertainty and when loss might become salient. What is overlooked are the enormous challenges to families living with uncertainty, while needing to sustain hope. I term this experience anticipatory loss.

The FSI model clarifies how the meaning of potential loss evolves with the life-cycle passage (Rolland, 1987a, 1990, 2004, 2006a, 2016). The salience of anticipatory loss varies, depending on members' multigenerational experience with actual and threatened loss. It also differs with the kind of illness, its psychosocial demands over time, and the degree of uncertainty about prognosis.

TABLE 9.1. Anticipatory Loss in Context

1. Kind of Illness (including genetic risk):

> • Possible vs. Probable vs. Inevitable Loss
> • Threat of Death, Disability, and/or Suffering
> • Physical and/or Cognitive Disability

2. Phase of Illness or Genetic Risk

3. Phase of Family and Individual Development

4. Multigenerational Experience with Illness and Loss

5. Belief Systems

Chronic Phase: Ambivalence, Shameful Thoughts, and Feelings

The chronic phase presents different dilemmas for families. Exhaustion and ambivalence are common, as financial and emotional resources may become depleted. The emotional tide of anticipation can be fraught with enormous guilt and shame as families sometimes replace a fear of death with a wish for it.

During a period of increased suffering, the patient may express the wish to die and end the ordeal. One woman with unremitting severe pain shouted at her husband, "If I have to feel like this every day, then I wish I would die. I wish you could feel what this pain is like for 5 minutes!" At a moment of exhaustion and exasperation, a caregiver may think or exclaim, "Yes, I wish you would die so I could be free to move on with my life." The patient, who is physically and psychosocially shackled, is implicitly sanctioned for having such thoughts. It goes with the rights and privileges of being a patient. Family caregivers may feel as psychosocially burdened as the patient but be ashamed of having such ambivalent thoughts or openly expressing them. Often, these thoughts are expressed in ways that under other circumstances would be labeled pathologically cruel. Most of us can reveal such thoughts only within our closest relationships. Here, heightened emotions and reactivity are some-times inevitable. Family members need to understand and forgive themselves and each other for hurtful comments made in the heat of the moment. They can be helped to become aware that this situation occurs when the patient expresses anger at his or her plight, anger that may be communicated to other family members as "You are fortunate to have your health, and I am jealous"

Shameful thoughts and feelings are a major impediment to openness. Explaining in advance that having intense and seemingly "irrational" feelings of anger, ambivalence, death wishes, or escape fantasies is typical can help counteract feelings of secrecy, shame, and guilt on the part of well family members.

The fundamental issue here is that the caregiving burden is underappreciated because being physically burdened with disability and possible death cannot be readily compared with

anything else. One solution is to suggest that the patient and caregivers live in somewhat separate and distinct worlds, each with its own burdens. The caregiving burden might then be considered to have equally valid currency. This helps address the imbalance that fuels survivor guilt.

The Expected Illness Course

Progressive diseases, such as Alzheimer's, involve numerous losses. Illnesses vary in terms of the balance between expected physical and cognitive disability. With Alzheimer's, the timing of these losses is variable, but the inevitable deterioration is not. Neurocognitive impairment involves a range of deficits that interfere with participation in family life. Family members may anticipate and grieve each milestone, such as loss of memory of shared experiences or even recognition of loved ones (see Chapter 16).

CHAPTER 10: Helping Families in the Terminal Phase

Supporting the terminally ill member. This task includes helping the sur-vivors and dying member to live as fully as possible in whatever time remains. Also, clinicians can help families transition from hoping that the ill member won't die toward hoping for loved ones to be nearby and spend precious time together. For the dying member, the most important needs are controlling pain and suffering, preserving dignity and self-worth, and receiving love and affection from family and friends (Gawande, 2014).

Meaning-Making: Existential and Spiritual

The narratives that families develop over time during the illness experience have major implications for meaning-making in the terminal phase (see Chapter 8).

The family's coconstruction of a narrative about the dying member and his or her illness is key to positive adaptation, independent of the individual narratives they create. Clinicians need to facilitate the family's own process, rather than offer their own interpretations. Possibly troublesome explanations, such as blaming others for the impending death, deserve sensitive clinical attention and exploration (see Chapter 8).

For most of us, whether we are religious or not, dying raises existential questions about the meaning and significance of life, not just for the dying member, but his or her loved ones as well.

Children, in particular, adjust better when they can do something—draw a picture, make a card, or pick flowers for a loved one—rather than feeling helpless on the sidelines.

CHAPTER 11: Chronic Conditions in Childhood and Adolescence

When a child develops an illness or disability, the family faces several basic challenges, including the following.

 • The need for parents to keep the child safe often conflicts with the affected child's need for increased autonomy. It can be challenging to achieve a balance between protecting the child and promoting exploration and "acceptable risk."

• The child needs to be integrated into his or her own peer group and be allowed to play in ways that are age appropriate and consistent with reasonable safety.

• Ill and disabled children need to be reassured about their intrinsic value and guided to develop life-cycle goals that promote self-esteem, hopefulness, and a positive sense about future possibilities.

• Over time, affected children need to be encouraged to take an increasingly major role in their own care. Because parents often develop a sense of pride and self-worth through caring for an ill child, as the child becomes more competent, the parents may experience some sense of loss. Parents often need permission from professionals to tend to their own adult needs and relationships.

• When parents have significant strains or conflicts in their relationship before a child's health problem becomes known, attention to those issues may be displaced by focusing on the affected child, which often increases family dysfunction.

• Families, out of necessity, must learn how to interact and assert them-selves effectively with many other systems within the broader social ecology that may be discriminatory or inadequately structured to deal with the special needs of ill or disabled children, their siblings, and parents. Important examples include the educational and legal systems and the workplace environment.

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The child's illness can become a source of resentment, guilt, blame, and hope-lessness. When these feelings occur, parents may dutifully provide care, but give up on the child psychologically on a deeper level. This fosters feelings of rejection, inadequacy, and being a burden in the affected child.

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An important question is whether, when, and how to include children and adolescents in deliberations about balancing medical management and psychosocial development. Although parents make decisions about various trade-offs, children, at any age, deserve an explanation about their decisions. Actual participation in the decision-making process is more complex, particularly with adolescents. A chronic disorder can seriously impede the natural movement toward central developmental tasks of autonomy and independence. Generally, when children have been overprotected, they respond in adolescence either by remaining fearfully dependent or by vigorously defy-ing parental control. When parents establish early on a pattern of including

chronically ill children in disease-related discussions, then in adolescence a more natural, less reactive, gradual transfer of decision-making authority can occur.

CHALLENGES FOR SIBLINGS

Particularly with life-threatening and disabling disorders, siblings can easily become forgotten family members. Resentment about not receiving as much attention as an ill sibling, guilt-ridden fantasies about how they might have wished for or even caused their brother's or sister's condition, fears about the death of the affected sibling, and concerns about their own or their parents' vulnerability are just a few of the typical experiences of healthy siblings that require therapeutic attention (Barlow & Ellard, 2006).

CHAPTER 18: Collaborative Health Care

The complementary value of professional knowledge and skills in tandem with those of consumers and their communities have the extraordinary potential of advancing better health care.

I believe that health and mental health professionals have the ethical responsibility, when possible, to challenge and change the systems we work in, particularly hierarchical power relationships that marginalize and subordinate the family. Challenging underlying assumptions and biases would help promote valuable strategic alliances that are so essential in achieving the next developmental phase of family-oriented, integrated health care.

PRINCIPLES FOR FAMILY-ORIENTED PROGRAMS AND POLICIES

Any family that has lived with illness and disability understands at some basic level that clinical care, effective coping, and adaptation can best occur within a healing environment that is family-oriented, contextual, and, above all, collaborative. I strongly believe that the future of our profession lies in our ability to envision and translate systemic thinking and issues related to social justice into the larger society. Systemic thinking that transcends the boundaries of the patient and family can best guide our involvement with families and pro-mote healing and health. To this end, we need family-oriented health policies and programmatic initiatives. The following principles are essential in sup-porting families coping with illness and disability.

• Health care reform should provide universal care that includes reimbursable, prevention-oriented family and relational-centered mental health services. Psychosocial care needs to be reimbursed on the same basis as physical health care.

• The definition of family should be broad enough to encompass the diversity of family forms and kin networks in contemporary society.

• Cost-effective family-oriented integrated care models need to be further developed and researched. They should include the entire range of biomedical and mental health care providers. Collaborative care models that include health care institutions, families, and communities can significantly reduce direct and indirect costs and enhance overall family well-being.

• Professional education and service delivery models need to better address the psychosocial needs of families facing major health conditions. Basic knowledge about family systems and the normative psychosocial demands of various health disorders throughout illness phases should be included in the education of all health and mental health care professionals.

• More resources must be directed toward preventing the psychosocial difficulties associated with chronic disorders. The efficacy of routinely offering a family behavioral health consultation at the time of diagnosis or early in the initial crisis phase of a serious health condition needs further research documentation.

• Policies that advocate comprehensive home and community-based care should be advanced, thereby reducing the need for institution-based health care. They include expanded provisions for rehabilitation and long-term care that supports family caregiving roles, while protecting families' job and eco-nomic security.

• Policies concerning continuing life support and end-of-life decisions, including physician-assisted dying to support patients' rights, dignity, and control in the dying process, need further advancement. These complex decisions need to be addressed, not just from technological and ethical perspectives, but also in terms of the profound impact on patient and family well-being and resources.

• Innovative programs should be implemented to address workplace and family caregiving needs. These should include more flexible work arrangements that accommodate the immediate and long-term demands of illness and dis-ability, while maintaining the continuity of home and work life equitably for both men and women. This includes adequate insurance coverage for home health care.

• Programs should be sensitive and flexible so that families of many different cultural orientations and at various life-cycle phases can be accommodated.

Above all, we must advocate for a humane, responsive system of health care that provides this vision of care not as a privilege, but as a basic right for all patients and their families.