Family Illness Paradigms:
Evolution and Significance

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This article attempts to clarify some of the important variables of family-illness paradigms. Four key variables that shape the evolution of the paradigm are described. They are the family's: health locus of control, multigenerational evolutionary process with illness and loss, ethnic and cultural background, and assumptions about disease etiology. The interplay between family health belief systems, the family life cycle, the "psychosocial type" and time phases of illness, as well as the fit between the beliefs of the family and health-care team is discussed. The article concludes by offering a modest proposal for an optimum belief system based on a flexible family approach that is process- rather than cure-focused. Understanding the family-illness paradigm can enhance our predictions about the patient's compliance with medical treatment, disease course, and the family's adaptation to an illness.

The purpose of this article is to describe how beliefs shape the way families adapt to chronic and life-threatening illness. Reiss (23) has argued that families develop paradigms or models for how the world operates. The *paradigms* dictate how families interpret events and behaviors in their environment. This article addresses one component of a family's overall construction of reality, their set of health beliefs, which comprise a family-illness paradigm. Key elements of this family-illness paradigm will be discussed in relation to a model I have described elsewhere (26, 27, 28, 29, 30) that integrates a psychosocial typology and time phases of illness with the family life cycle.

The following discussion will consider value orientations that are essential

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components of the family-illness paradigm, in particular those value orientations related to competency, mastery, control, and participation. I will address the following questions: In what ways and by what processes does a family's illness paradigm remain synchronous or diverge from its overall paradigm? How can a family's beliefs vary according to the "psychosocial type" or phases in the course of disease? What cultural and transgenerational family experiences with illness, loss, and crisis are most influential in the evolution of illness beliefs? What key transitions in the interplay of illness, individual, and family life cycles are conducive to paradigm shifts of a discontinuous nature? The issue of fit or discrepancy in health beliefs will also be examined, specifically the fit among family members, and between the patient, family, and health-care system. Finally, I will consider the question: Is there an "ideal" family-illness paradigm?

PSYCHOSOCIAL TYPOLOGY OF ILLNESS

The psychosocial typology (26, 27) distinguishes on two separate dimensions "psychosocial types" of illnesses and key phases in their natural history. The typology of illness conceptualizes broad distinctions of disease onset (acute v. gradual), course (progressive v. constant v. relapsing), outcome (fatal v. shortened life span or possible sudden death v. no effect on longevity), and incapacitation (none v. mild v. moderate v. severe). To capture the core psychosocial themes in the natural history of chronic disease, three major phases were described: initial crisis, chronic, and terminal. Critical transition points link each phase. By combining the typology and time phases, a matrix is created that allows psychosocial description of a particular "type" of illness at a particular phase of its natural history. Finally, the inclusion
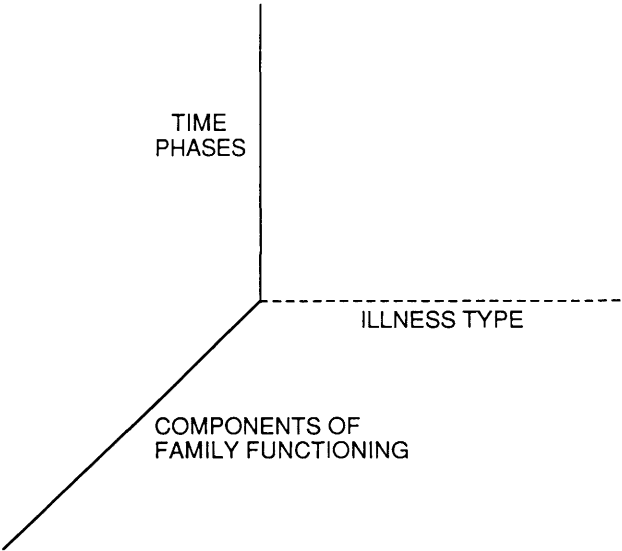

Figure 1. Three-Dimensional Model: Illness Type, Time Phase, Family Functioning

of a family-systems model as a third dimension facilitates the generation of hypotheses about the importance of various components of family life (e.g., family belief systems) in relation to specific types of illness at a specific phase in the "illness life cycle" (Figure 1).

ILLNESS VALUE SYSTEM

Each of us as an individual and as part of a larger system adopts a value orientation, belief system, or philosophy that shapes our patterns of behavior toward the common problems of daily life. Beliefs lend coherence to cognitive and affective dimensions of family life and temporal continuity to past, present, and future. Values provide a mode of approaching new and ambiguous situations. Depending on which system we are speaking of, this phenomenon can be labeled as values, culture, religion, belief system, world view, or family paradigm.

Kluckhohn, the anthropologist, has described five universal problems for which all societies must find some solution. She hypothesizes a limited range of solutions or possible value orientations toward each problem (10). Within this finite set of value orientations, each society assigns priorities to its own preferred world view. Finally, Kluckhohn maintains that all variations of solutions to these problems are present in varying degrees in all societies at all times.

The five universal problems and possible value orientations include

1) The question of innate human nature. Human nature can be perceived as good, evil, or neutral/mixed. Each of these orientations can be perceived as fixed or changed (good people are corruptible, evil people can be saved).
2) The temporal orientation of a culture. Does the society give priority to past, present, or future?
3) The preferred pattern of human activity. The three possible value orientations are being, being in becoming, and doing. The first two stress the expression of what the human already is, while the third focuses on striving to accomplish something else. American culture would be described as a doing culture.
4) The relationship between humans and nature. The three orientations are subjugation to nature, harmony with nature, and mastery over nature.
5) The preferred pattern of relationship between humans. The value orientations are lineal (hierarchical/cross-generational), collective, and individualistic. The first two view group life as primary over individual autonomy, with the lineal pattern also emphasizing the continuity of the group through time with a specified succession of hierarchy. The third group gives priority to individual autonomy over the commitment to group life.

In this article, I will highlight the last two of Kluckhohn's five orientations:

the relationship between humans and nature, and the relational orientation between people. Relationship orientation addresses the notion of fit and congruence between an ill individual, family, and health-care providers. Both of these orientation issues are important determinants of a family's coping style and adaptation to chronic illness.

There are four key elements of the family illness belief system that will be described:

1) The family's sense of mastery and control over the illness.
2) The family's multigenerational evolutionary process with illness, loss, and crisis.
3) The family's ethnic, cultural, and religious beliefs.
4) The family's assumptions about the etiology of illness.

The Family's Sense of Mastery over an Illness

Kluckhohn's continuum from subjugation to mastery over nature closely corresponds to the concept of a health locus of control, which can be defined as the belief that an individual or family has about their influence over the course/outcome of an illness. An internal locus-of-control orientation means that there is a belief that an individual can affect the outcome of a situation (mastery over nature). An external orientation entails a belief that outcomes are noncontingent upon the individual's or family's behavior (subjugation to nature) (6, 11).

Levenson (12, 13, 14) further refined locus of control by suggesting that there are three orientations: internal, external by powerful others, and external by chance. Based upon Levenson's contribution, Wallston and colleagues developed the Multidimensional Health Locus of Control Scales (31, 32).

Whether a family views control of physical processes as being either in the hands of powerful others, or a matter of luck or chance, is an important distinction with far-reaching clinical implications. Families that view illness in terms of chance will endorse statements such as, "Luck plays a big part in determining how soon my family member will recover from an illness," or "When I become ill, it's a matter of fate." Individuals who see health control as in the hands of powerful others will see health professionals, not themselves, as exerting control over their bodies. They will endorse statements such as, "Regarding my health, I can only do what my doctor tells me to do," or "My family has a lot to do with my becoming sick or staying healthy."

Long-standing Western cultural beliefs concerning an inherent split between a person's mind and body (not to mention the interactional split between the family as a system and a family member's biological processes) suggest that there will frequently be discrepancies between a general value orientation about mastery and the particular orientation pertaining to "the

body." A family may adhere to a different set of values concerning control when dealing with a *biological* process as opposed to other day-to-day types of problems. It is important, therefore, to assess a family's basic value system first. Then, with increasing specificity, the clinician can assess a family's notions about control for illnesses in general, chronic and life-threatening illness, and finally, for the specific disease facing the family. It is crucial to note that a family normally guided by an internal locus of control may switch to an external viewpoint when a member develops a chronic illness or life-threatening disease. Such a change might occur in a family with a strong need to remain in accord with society's values, a particular ethnic background, or a specific cross-generational experience with life-threatening diseases. One can inquire whether a family has any particular beliefs surrounding specific types of illnesses. Regardless of the actual severity in a particular instance, cancer may be equated with "death" or "no control" because of medical statistics, cultural myth, or prior family history. For many, certain types of heart disease with a similar life expectancy as certain forms of cancer could be seen as more manageable because of prevailing cultural beliefs.

It is critical to distinguish whether a family's belief system is based on the premise of internal control, external via "chance," or external via "powerful others." A family's value orientation about mastery constitutes the fundamental substrate of the family's health paradigm and strongly affects the nature of its relationship to an illness and to the health-care system. A family's beliefs about control are a predictor of certain health behaviors, particularly treatment compliance, and suggest the family's preferences about participation in their family member's treatment and healing. In my experience, families that view disease course/outcome as a matter of chance tend to establish marginal relationships with health professionals largely because their belief system minimizes the importance of their own or a health professional's relationship to a disease process. Just as any psychotherapeutic relationship depends upon a shared mythology or belief system, a fit between the patient, his/her family, and the health-care team in terms of these fundamental values is essential. Families that express feelings of being misunderstood by health professionals are often referring directly or indirectly to a lack of joining at the basic value level. Early in a family assessment, clinicians should ascertain the family's overall belief system, then determine if it is congruent with the family's beliefs about illness in general, the specific disease in question, and with the anticipated practical/affective demands of the specific illness over time. This means teasing apart the degree to which their illness paradigms are influenced by more general cultural, religious, racial or ethnic beliefs and the family's transgenerational experiences with illness, loss, and crisis.

Two brief clinical vignettes illustrate the importance of a family's health locus of control.

Case 1. Charles, 19, was the oldest of three children in an intact

Chinese-American family. He developed intense pain in his upper arm, which was treated with herbal compresses by the Chinese community healer. When the pain did not remit, Charles's family reluctantly brought him to a teaching hospital, where bone cancer was diagnosed.

The family's overall belief was that their behavior markedly affected outcome. Their emphasis on education and self-discipline yielded three outstanding students in their children and continued economic mobility. Their health locus of control, however, was that illness is in the hands of fate. Western medical approaches were tried out of desperation, with no faith that the teaching-hospital staff could really accomplish a cure. After a few aversive chemotherapy administrations, Charles withdrew from treatment, with full family support, to pursue continued traditional Chinese medical approaches. The hospital staff was bewildered and angry and failed to recognize the clash in their health beliefs.

Case 2. Rebecca, six, was recently diagnosed with juvenile diabetes. Her family had a strong belief in their ability to control their environment and accomplish positive outcomes. The parents, college-educated professionals, had sought a simple lifestyle in rural New England. They built their own house, grew much of their food, tended farm animals, and had strong opinions about nutrition and lifestyle. Their health locus of control concerning Rebecca's diabetes was decidedly internal. They believed they could regulate their daughter's illness and prevent periods of exacerbated symptoms. However, they did not readily "buy" the hospital team's proposed management approach. They differed particularly on nutritional issues, a key concern in effective diabetic management. The physician's and family therapist's ability to acknowledge the family/health-care team differences allowed for a viable partnership to emerge. This case suggests that even when families do have a sense of control over illness, the partnership with health providers requires sensitivity and finely tuned interventions.

The Evolution of Family Illness Beliefs

The specific contribution of a family's past history to its current paradigm can best be clarified by a family genogram (17). This method tracks 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. A genogram oriented to illness involves the same basic tracking process as a standard genogram, but focuses on how a family has organized itself specifically around previous illnesses and unexpected crises in the current and previous generations (28, 29). A central goal is to bring to light the adults' "learned differences" about illness (22). At a paradigm level, these learned differences typically get expressed as family myths, taboos, rituals, and catastrophic expectations (19).

For any significant chronic illness in the family of origin, a clinician should learn how the family organized itself to handle a range of disease-related practical and affective tasks. A clinician should find out what role each family member played in handling the emotional and practical tasks. Were the parents (as children) given too much responsibility (parentified) or shielded from involvement? Did they emerge with a strong sense of competence or failure? These transgenerational learned differences concerning illness episodes are predictive of how the current nuclear family will preferentially organize itself around an array of disease-related practical and affective tasks. This might include the family's mode of communication, structural and role shifts, and style of problem-solving.

At the level of the family paradigm, these cross-generational experiences may be incorporated into and alter the family's basic belief system. For some families, nodal illness experiences may become incorporated in an encapsulated way into the family's illness paradigms, only being expressed during periods of illness. For other families, prior illness experiences can become elaborated and generalized as part of the overall family paradigm. This latter process coincides with Reiss's ideas about the elaboration of family paradigms (23). Reiss posits that new paradigms or discontinuous changes of old ones first make their appearance during periods of severe family stress, which generate a level of family disorganization in which the family sees the potential for its own dissolution. At the same time, the family acknowledges the failure of their original paradigm to handle the specific stressor. The family's subsequent innovative shift leads to a successful resolution of the crisis that "stands out as an extraordinary achievement to all members of the family." The success in a period of grave crisis represents the beginning of a paradigm shift that the family then attempts to generalize over time to the problems of everyday life.

Negative illness experiences in the family of origin can affect illness paradigm in different ways. In one particular case, involving a family with three generations of hemophilia, the father had been shielded from the knowledge that his older brother, who died in adolescence, had had a terminal form of kidney disease. This man had, in addition, not been allowed to attend his brother's funeral. From that trauma he made a strong commitment to openness about disease-related issues with his two sons with hemophilia and his daughters who were genetic carriers. As a direct result of an experience of helplessness, this man shifted his beliefs about mastery in a direction of greater personal participation, and he carried out this increased mastery with a relational style that emphasized shared knowledge rather than a shielded, protective attitude.

A similar experience that is defined by the family as "a failure" but does not lead to the family's dissolution can cause a powerful shift in the family paradigm regarding their views about mastery in an opposite direction. At its most general level, the family can come to view change as dangerous rather than as a challenge or even an opportunity. One way that this shift

to a negative, external locus-of-control value orientation can be expressed is in the elaboration of a rigid, enmeshed, consensus-sensitive family style. Imagine a family traditionally guided by a strong sense of personal control. If the paternal grandfather, the staunch patriarch of the family, dies because of a rapidly progressive and painful form of cancer, the family may undergo a paradigm shift in terms of their beliefs about control. This change in their views about control toward a more external or pessimistic position may remain encapsulated to cancer or encompass progressively larger parts of their world view. It may become generalized to include all life-threatening illnesses, all physical illnesses, or all major illness and general stressors to the family. In addition, if the family had had faith or an expectation that health providers were going to control/cure grandfather, then this kind of episode might provide the basis for a shift in their beliefs about what health providers or resources outside the family can accomplish. This could translate into a shift in the family's positive beliefs about "powerful others" toward a more fateful value orientation.

It is beyond the scope of this discussion to decipher why some people shift their paradigms in a healthier direction while others going through similar experiences will rigidify or extend dysfunctional paradigms from their families of origin.

The relative need for and kind of paradigmatic shifts will depend on the interaction between the psychosocial type of illness and the family. For example, some types of diseases exert enormous strain on the family by a pileup of psychosocial demands over a short period of time. Illnesses that begin with an acute onset, are progressive, moderate to severely incapacitating, and life-threatening are most extreme in this regard. This kind of illness that requires the greatest level of crisis reorganization presents an immediate and forceful test of a family's illness paradigm. On the other hand, illnesses that are nonfatal, constant, relapsing or slowly progressive in course, or increasingly incapacitating are more likely to result in family exhaustion. For these kinds of illness, the paradigm shifts may occur in either a gradual, insidious way, or at the point of exhaustion when a full-blown crisis happens.

Using the psychosocial typology and time phases of illness as a framework for historical questioning can help clinicians distinguish between shifts in a family's belief system that have generalized, remained specific to their illness paradigm, or become encapsulated around a specific type of disease or time phase of the illness.

Although a family may have certain standard ways of coping with any illness, there may be critical differences in their style and success in adaptation to different types of diseases. For instance, a family may have consistently organized itself successfully around nonlife-threatening illnesses but reeled under the impact of the paternal grandmother's metastatic cancer. This family may develop a circumscribed belief of family incompetence and lack of possible mastery that would only reemerge in the context of another life-

threatening disease. A different family may have had experience only with nonlife-threatening illnesses and be ignorant of how to cope with the un-certainties particular to chronic life-threatening diseases. This second family may have coped effectively with sudden loss, but lacks the experience of living with chronic illness where the potential for loss looms as a possible disease outcome. Such a family's belief system may have a blind spot that will interfere with coping with illnesses such as heart disease or cancer.

Genetically transmitted diseases that recur on a regulr basis over many generations offer a unique opportunity to see how the repetition of a par-ticular kind of illness interacting repeatedly with the individual and family life cycles can profoundly affect the overall family paradigm. Consider hem-ophilia as one example. The life-threatening nature of bleeding episodes that can be caused by trauma, intense affect, or prolonged periods of stress necessitate modifications in terms of how affected individuals are socialized. A buffer zone is created between a child and his environment. Certain forms of play are severely restricted or prohibited. Some children are actually clothed with protective padding. Children are taught to a greater or lesser degree to avoid situations of conflict that may lead to physical interaction. If they can learn to notice the early stages of strong affects, like anger, children can learn to diffuse it or even disguise the feeling from self-recog-nition. This kind of socialization can lead to a finely tuned form of mastery over one's body juxtaposed with a distrustful, fearful view of the outside world, where affect in social interaction is carefully monitored in the interest of self-preservation. Unaffected family members adapt their own social in-teractions to fit the survival of affected members. Family beliefs about con-trol, mastery, and the rules for social interaction may change to become congruent with an illness that has become a permanent part of their trans-generational system.

The degree to which a family's overall or illness beliefs about mastery and control are affected by a prior experience with disease can be uncovered by tracking changes in the expression of this value through time. A particular illness can have effects that range from reinforcing the family's original paradigm, to altering its illness beliefs selectively, to shifting the entire family unit's overall paradigm in a fundamentally new direction.

The Family's Ethnic, Cultural, and Religious Beliefs

Ethnicity, race, and religion are major determinants of a family's beliefs concerning health and illness (18, 33). There also tend to be cultural dif-ferences in definitions of what constitutes a family, what the family's re-sponsibility is for the care of ill members, who in the family is chiefly responsible for this care, the role of the extended family in patient care, and so on. These overlapping factors warrant extensive discussion that goes well beyond the scope of ths article. Health professionals need to familiarize themselves with belief systems of various ethnic, racial, and religious groups

in their community; particularly as these translate into different behavioral patterns in regard to illness. Clinicians need to be mindful of the cultural differences between themselves, the patient, and the family. Deference to these distinctions is a necessary step to forging a workable provider-patient-family alliance that can endure a long-term illness. Disregarding these issues can lead families to wall themselves off from health providers and available community resources—a major cause of noncompliance and treatment failure. For instance, it is customary for Italians and Jews to describe physical symptoms freely and in detail. Individuals and families from Irish or white Anglo-Saxon descent tend to deny or conceal ailments. One can surmise the potential for misunderstanding and tension that could develop between Italian or Jewish health providers and Irish or white Anglo-Saxon patients and their families. A mutually frustrating cycle of health providers pursuing a distancing family could develop. At minimum, dissatisfaction would be the end result. At worst, a family might leave treatment and use their negative experience as a rationale to rigidify its alienation and isolation from adequate care.

Once again, a few clinical vignettes may further elucidate the import of ethnicity in shaping family health beliefs.

> *Case 1.* Stavros H, a successful professional in his early thirties, had recently married Dana. Stavros was a first-generation Greek American, while Dana was from an Anglo-Saxon family. When Stavros became ill with a manageable cardiac illness, his mother moved into the newlyweds' home to "help" care for her son. She slept on the floor next to the bed so she could tend to her son at any hour of the night. Dana greatly resented her mother-in-law's intrusive behavior and was uncomfortable with her mother-in-law's constant crying and lamentation over Stavros's health. Mrs. H was disappointed in Dana's "coldness" and apparent lack of concern over Stavros's illness. Stavros felt caught between his warring mother and wife and complained of new cardiac symptoms. The cardiologist asked the family therapist's assistance in sorting out what was a cultural lack of congruence, what was family enmeshment, and what might lead to an exacerbation or reduction in symptoms.

> *Case 2.* Leon was a successful businessman with a wife and two adult sons. He had recently sustained a myocardial infarction and was recovering in the cardiac stepdown unit. His family was Jewish and quite assertive in making certain that their husband and father was being well cared for. They did not hesitate to ask questions, make special requests, and attempt to bend visiting rules to allow the large extended family access to Leon. The primarily young and Irish Catholic nursing staff found the family's assertiveness uncomfortable and developed a resentment toward them. The quality of Leon's care declined tempo-

rarily in the face of the family's style. The liaison consultant on the floor was able to recognize the culture clash and work with the staff to recognize and alter their preconceptions of the family.

The Family's Beliefs about the Etiology of Illness

The context within which an illness event occurs is a very powerful organizer and mirror of a family's belief system. The limits of current medical knowledge mean that tremendous uncertainties persist about the relative importance of a myriad of biopsychosocial factors in disease onset. This fact allows individuals and families to make highly idiosyncratic attributions about what caused their family member's illness. Therefore, a family's beliefs about the etiology of an illness need to be assessed separately from its beliefs about control once an illness is present. One way to gather this information is to ask each family member for his or her explanation of the existence of the disease. Responses will reflect a combination of the current level of medical knowledge about the particular disease in concert with family mythology. This mythology might include punishment for prior misdeeds (e.g., an affair), blame of a particular family member or dyad ("Your drinking made me sick"), a sense of injustice ("Why am I being punished, I have been a good person"), genetics/blame (e.g., cancer runs on one side of the family), negligence by the patient or parents, or bad luck. Asking this question can function as an effective family Rorschach, bringing to light unresolved family conflicts. Further, families guided by a strong sense of potential control of disease course frequently see disease onset as more of a chance event. In my clinical experience, families with the strongest, at times extreme, beliefs about personal responsibility, and those with the most severely dysfunctional patterns will be those most likely to attribute the cause of illness to a psychosocial factor. For high internal locus-of-control families, an ethos of personal responsibility guides all facets of life, including the etiology of an illness. For these families, a relative lack of acknowledgment of "outrageous fortune" as a factor in illness events can create for these families a nidus for blame, guilt, and shame. For highly dysfunctional families, characterized by unresolved conflicts and intense blaming, attributions of what or who is responsible for an illness often become ammunition in long-term family power struggles.

To the extent family members maintain very different beliefs about etiology, decisions about treatment can become confounded and filled with tension. A mother who feels blamed by her husband for her son's leukemia may be less able to accept stopping a low-probability experimental "curative" treatment than the angry, blaming husband. A husband who believes his drinking caused his wife's coronary and subsequent death may have a pathological grief reaction and may increase his drinking to mask his profound guilt.

Having examined several key components in the evolution of family-illness

paradigms, I will next explore how this paradigm interacts with the family life cycle and time phases of illness. Then, the clinical implications of within-the-family and family/health-provider congruence or incongruence of health beliefs will be considered. I will conclude with a discussion of a hypothetical "ideal" family-health paradigm.

LIFE-CYCLE CONSIDERATIONS

Family Life Cycle

A developmental perspective that views the unfolding of chronic disease within the context of the individual and family life cycles can help clarify questions about the degree and timing of an illness's impact on family belief systems. The concept of nodal periods in the individual and family life cycles has been well described in the individual and family life-cycle literatures (4, 15, 16). Typically, these are periods where processes of termination and initiaton are central to transition between phases of the life cycle. During these transition periods all system levels are in greater flux. In this sense, transition periods are potentially the most vulnerable because previous individual, family, and illness life structures are reappraised in the face of new developmental tasks that may require discontinuous change rather than minor alterations (8).

Chronic and life-threatening illnesses can create or intensify nodal points in several ways. First, chronic and life-threatening illness precipitates the loss of the pre-illness identity of the family. It forces the family into a transition in which one of the family's main tasks is to accommodate the anticipation of further loss and possibly untimely death. When the onset of a chronic illness coincides with a transition in the individual or family life cycle, the clinician might expect that issues related to previous, current, or anticipated loss will be magnified. Because transition periods are often characterized by upheaval, rethinking, and change, there exists at those times a greater risk for the illness to become unnecessarily embedded or inappropriately ignored when planning for the next developmental period. This can be a major precursor of family dysfunction in the context of chronic disease. This very process can set the stage for a crisis that shifts a family's belief system. An adolescent who is diagnosed with Hodgkin's disease may find his emancipation from the family delayed or even "frozen." The parents, who had been allowing for greater independence, may now move toward intensified caretaking and a stifling of moves toward the adolescent's autonomy from the family.

Chronic illnesses are more likely to create nodal points of stress if they occur more "out of phase" with the individual and family life cycles. Clinicians and researchers generally agree that there exists a normative and nonnormative timing of chronic illness in the life cycle. Coping with chronic illness and death are considered normally anticipated tasks in late adulthood.

On the other hand, illnesses and losses that occur earlier are "out of phase" and tend to be developmentally more disruptive (7, 21). Therefore, diseases that historically occur out of phase will create a context for discontinuous change as a forerunner to permanent belief-system shifts.

Levinson (15, 16), in describing individual adult male development, has characterized individual development as alternating between life-structure transition periods and life-structure building/maintaining periods. In the building/maintaining period, the individual is concerned with enriching his life based on the key choices he made during the preceding transition period. The family is oriented toward protecting this current life structure. The onset of a major illness tends to create a period of transition. An illness of sufficient severity that occurs during this structure-building and -maintaining period may induce the return to a prolonged transitional state and disrupt the natural unfolding of development.

The concepts of centripetal and centrifugal phases in the family life cycle are particularly useful to thinking about out-of-phase nodal points that create an environment conducive to paradigm shifts (1, 2, 5). Combrick-Graham (5) describes a family life spiral model where she envisions the entire three-generational family system oscillating through time between periods of family closeness/normal cohesion (centripetal) and periods of separateness or low cohesiveness (centrifugal). Using these constructs, one can consider chronic diseases as exerting a centripetal pull on the family system. Occurrence of chronic illness in a family resembles the addition of a new member, which sets in motion for the family a centripetal process of socialization to illness. Symptoms; loss of function; the demands of shifting or new illness-related, practical, and affective roles; and the fear of loss through death all serve to refocus a family inwardly.

If the onset of an illness coincides with a centrifugal period for the family, then it is out of phase with the family's natural momentum. For example, if a young adult becomes ill, he or she may need to return to his or her family of origin for disease-related caretaking. Each family member's autonomy and individuation is at risk. The young adult's initial life structure away from home is threatened either temporarily or permanently. Both parents may have to relinquish budding interests outside the family. A family can come through this crisis with a new or strengthened sense of mastery and competence or a profound sense of failure and helplessness that will manifest itself as a permanent involutional shift of the family unit. Either outcome will probably leave its mark on the family's belief system.

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

mentally. For these kinds of illnesses family burnout, a vehicle for shifting the family's belief system, can be seen in another way. It is more than the duration of the illness that fosters paradigm shifts, but the fact that certain types of illness and the pattern of their unfolding over time make it extremely difficult for a family to get back on track developmentally. In this sort of predicament, families with an internal locus-of-control orientation are pressed to rethink and revise their belief system to maintain their sense of mastery and competence. A family's success or failure with this challenge will determine whether their value orientation moves toward a greater sense of internal competence or a perception of life as out of their control.

Clinicians should track this historical unfolding for individual family members as well as for the family as a unit. Both the intensity of the psychosocial demands of the illness and the length of time a family is exposed to such a stressor play a major role in determining the need for and timing of paradigm shifts. In the same way, individual family members undertake differential amounts of the illness-related role demands and for differing lengths of time. As a result, individuals may shift their beliefs in discrepant ways.

Time Phases of Illness

Variations in a family's beliefs about mastery can depend not only on the family life cycle, but also on the time phase of the illness. For some illnesses, the crisis phase demands much involvement outside the family. For instance, the crisis phase after a stroke may begin with an intensive-care unit and months of extended care at a rehabilitation facility. This kind of extensive and protracted care that occurs largely outside the family's direct control may be particularly taxing for a family that prefers to tackle its own problems with a minimum of outside involvement. The patient's return home may increase the workload in this family, but will allow members to reestablish their values concerning control. A family guided more by a preference for external control by experts will have greater difficulty when their family member returns home. For this family, leaving the rehabilitation hospital means the loss of their locus of competency—the professionals. Health providers' cognizance about this basic difference in belief about control can tailor a psychosocial treatment plan to each family's needs.

The terminal phase of an illness is a time when a family may feel least in control of the biological course of the disease and the decisions regarding the overall care of their ill member. Family members with a strong need to sustain their centrality may need to assert themselves more vigorously with health providers. To make effective decisions about the extent to which medical efforts should go, or whether a patient will die at home, an institution or hospice requires an effective family/health-care team relationship that respects the family's basic beliefs.

FAMILY AND FAMILY-PROVIDER CONGRUENCE

Once a family has articulated their illness belief system, a clinician should explore the degree of family congruence or consensus among family members concerning a particular value, such as health locus of control. This is vitally important because 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. Congruence needs to be considered in light of Kluckhohn's fifth orientation of how the family weighs individual versus group process.

Before assessing the family's actual level of agreement, one should inquire as to the family's metarule concerning congruence. Is the family rule "We must agree on all/some values," or are diversity and different viewpoints acceptable? This metarule corresponds in many ways to Reiss's dimension of family coordination, which refers to family members' ability and commitment to developing a "group" solution to a problem (23, 24). Further, clinicians should determine if the family metarule about consensus is adhered to across its external boundary in relation to prevailing cultural or societal beliefs. Can the family hold values that differ from the wider culture? The family's metarule has multiple determinants, which include cultural norms, historical context (era of "family consensus" v. each member "doing his/her own thing"), and the value systems of the adults' families of origin, including the role the kin network plays in family life. A family's metarule about consensus can have profound implications on permissible options when a family faces chronic illness. If consensus is the rule, then individual differentiation implies deviance. If the metarule is "We can hold different viewpoints," then diversity is allowed. When working with illness-related values in a family where consensus is the rule, attention to each family member is mandatory. One goal of treatment can be for clinicians to help families negotiate their differences and support the separate identity, needs, and goals of each member. In a family where diversity is permitted, there may be greater latitude to work on certain disease-related psychosocial issues with the ill member alone or with particular members of the family without mobilizing family resistance.

Having established the family's metarule concerning consensus, it is important to look into the *actual* degree of congruence with regard to illness values both within the family and between the family and medical system.

How congruent are the family's basic beliefs about control with their illness value system? A family that is uniformly external will generally adapt best if psychosocial interventions are tailored to that fact. On the other hand, a family that generally adheres to an internal locus of control but feels the opposite with a particular disease may, through exploration of underlying issues, be able to change its beliefs about illness. It is critical to keep in mind that beliefs about control refers to a family's beliefs about the importance

of their participation in the total illness process rather than just their beliefs about a disease's curability.

It is important to analyze differences among family members in terms of illness values. Disparities in dyadic and triadic relationships involving the ill member are particularly significant. Consider a common situation in which there is a longstanding loyalty conflict for a man caught between his spouse and his mother. Both women vie for his devotion, while he is unable to define boundaries between his family of origin and nuclear family. This dysfunctional triangle may have smoldered for years in a precarious balance. Suppose the man develops a slowly progressive and debilitating illness such as multiple sclerosis. If the man and his mother share a strong sense of internal control while his spouse grew up in a family that saw chronic illness as a matter of fate, an unbalancing of this triangle is likely to occur. The mother-son coalition now reemerges in full force fueled by shared basic beliefs concerning mastery, while the marital system is driven apart.

As the earlier example of Stavros and Dana highlighted, the different ethnic backgrounds of the adults in a family may be a primary reason for the kind of discrepancies about illness beliefs that emerge at the time of a major illness. Differences may occur in such areas 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 caretaking system (e.g., extended family, friends, professionals), and the kind of rituals that are seen as normative at different stages of an illness (e.g., hospital bedside vigils, healing and funeral rituals). In families of mixed ethnic heritage, clinicians should thoroughly assess these areas for congruence and discrepancies.

It is common for differences in beliefs or attitudes between family members to erupt at transition points in the treatment or disease course. For instance, in situations of severe disability or terminal illness, one member may want the patient to return home while another prefers that the patient remain hospitalized or be transferred to an extended-care facility.

It is essential to assess the fit between the belief systems of the family and the health-care team. The same questions asked of the family are relevant to the medical team. What is the attitude of the health-care team about their and the family's ability to influence the course/outcome of the disease? How does the health team see the balance between their versus the family's participation in the treatment and control of the disease? If basic differences in beliefs about health locus of control exist, it is critical to assess how to reconcile these differences. Because of the tendency of most health facilities to disempower individuals, thereby fostering dependence, utmost sensitivity to family values is needed to create a true therapeutic system. A significant number of the breakdowns in relationships between "noncompliant" or marginal patients and their health-care providers may be related to lack of agreement at this basic level.

The relative need for congruence between patient, family, and health pro-

viders will vary according to the phase of the illness. One point where this congruence of values is usually needed is the acute phase of the initial crisis period when health providers are heavily involved (25). This often involves much high-technology medicine and is characterized by rapid decision-making and exchange of information, especially if life-threatening circumstances prevail. Teamwork is particularly important. Illnesses characterized by recurrent crises will have nodal points of stress where this kind of congruence will again become important. As discussed earlier, major transitions in the illness, as between the chronic and terminal phases, are key junctures where problems in family-health provider congruence may emerge.

The attitudes and behaviors of the medical team (many derived from the medical model) can have a major influence in either facilitating or hindering this process for a family. A medical team that maintains heroic efforts to control the terminal phase of an illness can convey confusing messages. It can be extremely difficult for families to know how to interpret continued lifesaving efforts by the health-care team. Is there still real hope, which should be read by families as a message to redouble their faith in and support of medical improvement? Do the physicians feel bound to a technological imperative that requires them to exhaust *all* possibilities at their disposal, regardless of the odds of success? Often physicians feel committed to this course for ethical reasons, a "leave no stone unturned" philosophy, or because of fears concerning legal liability. Is the medical team having its own difficulties letting go emotionally? This situation can be caused by the team members' own emotional attachments to a patient or their own history with similar experiences.

Strong relationships with certain patients can be fueled by identifications with losses, often unresolved, in health-care providers' own lives. Health-care professionals and institutions can collude in a pervasive societal wish to deny death as a natural process truly beyond technological control (3). Endless treatment can represent the medical team's inability to separate a general value placed on controlling diseases from their beliefs about participation (separate from cure) in a patient's total care. Professionals need to closely examine their own motives for treatments geared toward cure rather than palliation, particularly when a patient may be entering a terminal phase. Professionals' self-examination needs to be done in concert with a careful understanding of the family's belief system. In the management of end-stage disease, community resources such as hospice programs, visiting nurses, and home health aides may be very useful. The family's willingness, however, to use outside resources may be limited by ethnic/cultural values, certain family dynamics, and their own illness paradigms.

For example, rigidly enmeshed families tend to view the world as dangerous and threatening to their fragile sense of autonomy. Individual autonomy is sacrificed to keep the family system intact. Their beliefs about control will need to be defined within a framework of family exclusiveness that minimizes the role of outsiders. The occurrence of a chronic illness

presents a powerful dilemma for these families. The illness may necessitate frequent excursions beyond the family borders or require the inclusion of outside professionals in disease management. Any hope of establishing a viable family/health-care team relationship depends upon exquisite sensitivity to this interplay of dysfunctional family dynamics and belief system.

For any family coping with long-term illness, health-care providers need to be mindful of the myriad issues that determine whether an effective alliance can be forged across the boundaries between the family and larger community systems. Attention to family beliefs and rules that govern transactions across its boundary needs to be assessed within the context of access and availability of community resources.

Finally, the clinician must assess how family health beliefs will influence the family's overall behavior in the community (9, 20). Whether the family avails itself of rehabilitation, respite, visiting nurses, hospice care, financial entitlements, self-help groups, religious group supports, or other programs will depend on several factors. The family's knowledge of these services, their beliefs about accepting "outside" help, and their past experiences (affirming versus alienating) with community agencies will all mediate their willingness to pursue or accept such services.

IS THERE AN "IDEAL" FAMILY-HEALTH PARADIGM?

It is difficult to characterize an "ideal" family-illness paradigm. On the one hand, a major thesis of family systems medicine is that there is always an interplay between disease and other system levels. On the other hand, illnesses and phases in the course of disease may vary considerably in responsiveness to psychosocial factors and their inherent nature. Distinctions need to be made between a family's beliefs about their overall participation in a long-term disease process, their beliefs about their ability to actually control the biological unfolding of an illness, and the flexibility with which a family can apply these beliefs. An optimal expression of family competence or mastery depends on their grasp of these distinctions.

A family's belief in their participation in the total illness process can be thought of as independent from whether a disease is stable, improving, or in a terminal phase. Sometimes mastery and the attempt to control biological processes coincide. A family coping with a member who has cancer in remission may tailor its behavior to help her/him maintain health. This might include changes in family roles, communication, diet, exercise, and balance between work and recreation. Suppose the ill family member loses his/her remission and vigorous efforts to reestablish a remission fail. As the family enters the terminal phase of the illness, participation as an expression of mastery must now be transposed to mean a successful process of letting go. The difference between a family experiencing a loss with a sense of competency versus profound failure is intimately connected to this kind of flexible use of their belief system.

TABLE 1
Patient/Family Reaction to Disease Outcome Based on Beliefs about Mastery/Control

BELIEFS ABOUT MASTERY/LOCUS OF CONTROL

DISEASE OUTCOME	INTERNAL		EXTERNAL BY POWERFUL OTHERS		EXTERNAL BY CHANCE
	Rigid Biological	*Flexible Participation*	*Rigid Biological*	*Flexible Participation*	
+	Successful Control	Successful Participation	Successful Control	Successful Participation	Good Luck
−	Self-blame Guilt	Sadness without Blame	Blame Health Providers Family God	Sadness without Blame	Fatalism

Thus, flexibility within the family and the health-provider system is the key variable in optimal family functioning. With this in mind, a revision in the locus-of-control schema should be made. Families that have an internal locus-of-control value orientation can either hold this value in a rigid, circumscribed way that views biological outcome as the sole determinant of success or failure, or families can define control in a more "holistic" sense where involvement and participation in the overall process is the main criteria defining success. This is analogous to the distinction between healing "the system" and curing "the disease." Healing the system is envisioned as a major influence on improving or curing a disease, but disease outcome is not necessary to a family feeling successful. This kind of definition of mastery permits the quality of relations within the family or between the family and health providers to become more central to criteria of success.

This same flexible notion of participation can be applied to situations where the family views mastery as mainly in the hands of "powerful others." If successful control by the physician is viewed in strictly biological terms, then blame and anger toward health providers are likely if a disease progresses or has a fatal outcome. A more flexible view of a success permits the health provider's competence to be viewed from both a technical and a caregiving perspective (25) that is not linked only to the biological course of the illness. Of course, for this patient/family/health-provider system to function optimally is dependent equally on the fit between the family's illness value system and the providers themselves.

This revised and expanded version of mastery/locus of control and how each value orientation might be interpreted by the family dependent on disease outcome can be diagrammed as follows (Table 1).

CONCLUSION

This article has attempted to clarify some of the important variables that contribute to the concept of family illness paradigms. Beginning from an anthropological base, this discussion focused on beliefs related to mastery/control and the implications of fit or congruence of health beliefs at the level of the individual, family, and health provider. A psychosocial typology and time phases of illness model integrated with a transgenerational and life-cycle perspective was used to discuss the evolution and significance of family illness paradigms. Finally, a closer approximation to an "ideal" paradigm was suggested that is based upon a flexible, participatory model of competency that operates at the level of the patient-family-provider system.

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