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Chronic Illness and the Life Cycle:A Conceptual Framework

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This article provides a conceptual framework for thinking about the system created at the interface of chronic illness with the family life cycle. First, a psychosocial typology and time phases of illness schema is described as a necessary, preliminary step to create a common language that bridges the worlds of illness, individual, and family development. This schema organizes similarities and differences between diseases in a manner useful to psychosocial-developmental rather than biomedical inquiry. Then, drawing on several major life-cycle theories in the literature, key concepts (periods of transition, life-structure building and maintaining, centripetality, and centrifugality) are used in a complementary fashion to link these three lines of development. Equipped with these psychosocial languages, consideration is given to transgenerational aspects of illness, loss, and crisis, and the interwoven threads of illness, family, and individual development. Clinical vignettes are provided to highlight this conceptual framework.

INTRODUCTION

In the arena of physical illness, particularly chronic disease, the focus of concern is the system created by the interaction of a disease with an individual, family, or other biopsychosocial system (11, 12). From the family point of view, family systems theory must include the illness system. Further, to place the unfolding of chronic disease into a developmental context, it is crucial to understand the intertwining of three evolutionary threads: the illness, individual, and family life cycles.

In order to think in an interactive or systemic manner about the interface of these three developmental lines, one first needs a common language and set of concepts that can be applied to each and permits a trialogue. This article describes a conceptual framework that addresses this need. Two preliminary steps are needed to lay the foundation for such a model. First, one needs a language that permits diseases to be characterized in psychosocial and longitudinal terms, analogous to descriptions of family types and development. Second, individual and family life-cycle, theoretical models need to be linked by culling from each its key, overarching concepts. At present, the developmental relationship between these different system levels remains mostly unexplored.

A schema to conceptualize chronic diseases is required that remains relevant to the interactions of the psychosocial and biological worlds and provides a common metalanguage that transforms or reclassifies the usual biological language. Chronic illnesses need to be conceptualized in a manner that organizes their similarities and differences over the disease course so that the type and degree of demands relevant to psychosocial research and clinical practice are highlighted in a more useful way.

The first section of this article briefly reviews a psychosocial typology of chronic or life-threatening illness (30, 31). The problems of illness variability and time phases are addressed on two separate dimensions. First, chronic illnesses are grouped according to key biological similarities and differences that dictate significantly distinct, psychosocial demands for the ill individual and his or her family. Second, the prime developmental time phases in the natural evolution of chronic disease are identified. In the second section of the article, once one is equipped with a psychosocial language to describe chronic diseases, transgenerational aspects of illness, loss, and crisis will be considered. In the last section, which integrates key concepts from family and individual developmental theory, the interface of disease with the family life cycle will be described.

PSYCHOSOCIAL TYPOLOGY OF ILLNESS

A disease classification that is based on purely biological criteria clusters illnesses in ways to meet the needs of medicine. This nosology is most useful to establish a medical diagnosis and formulate a medical treatment plan. However, a different classification schema may provide a better link between the biological and psychosocial worlds, and thereby clarify the relationship between chronic illness and the family life cycle. The goal of this typology is to facilitate the creation of categories with similar psychosocial demands for a wide array of chronic illnesses. This typology is not intended for traditional medical purposes but, rather, to examine the relationship between family dynamics and chronic disease.

The typology conceptualizes broad distinctions of onset, course, outcome, and degree of incapacitation of illness. For a broad range of diseases, these categories are hypothesized to be the most psychosocially significant at the interface of the illness and the family. Whereas each variable is in actuality a continuum, each will be described in a categorical manner by the selection of key anchor points along the continuum.

Onset

Illnesses can be divided into those that have either an acute onset, such as strokes, or gradual onset, such as Parkinson's disease. Although the total amount of family adaptation might be the same for both types of illness, for acute-onset illnesses these affective and instrumental changes are compressed into a short time. This will require of the family more rapid mobilization of crisis-management skills. Families that are able to tolerate highly charged affective states, exchange clearly defined roles flexibly, problem solve efficiently, and use outside resources, will have an advantage in managing acute-onset illnesses. The rate of family change required to cope with gradual-onset diseases allows for a more protracted period of adjustment.

Course

The course of chronic diseases can take essentially three general forms: progressive, constant, or relapsing/episodic. A *progressive* disease (for example, Alzheimer's disease or emphysema) is one that is continually or generally symptomatic and progresses in severity. The individual and family are faced with the effects of a perpetually symptomatic family member whose disability increases in a stepwise or progressive fashion. Periods of relief from the demands of the illness tend to be minimal. Continual adaptation and role change are implicit. Increasing strain on family caretakers is caused by both the risks of exhaustion and the continual addition of new caretaking tasks over time.

A *constant-course* illness is one where, typically, an initial event occurs, after which the biological course stabilizes. A single-episode myocardial infarction or spinal cord injury are two examples. Typically, after an initial period of recovery, the chronic phase is characterized by some clearcut deficit or residual, functional limitation. Recurrences can occur, but the individual or family is faced with a semipermanent change that is stable and predictable over a considerable time span. The potential for family exhaustion exists without the strain of new role demands over time.

The third kind of course is characterized as *relapsing* or *episodic.* Illnesses like ulcerative colitis and asthma are typical. The distinguishing feature of this disease course is the alternation of stable periods of varying length, characterized by a low level or absence of symptoms, and with periods of flare-up or exacerbation. Strain on the family system is caused by both the frequency of transitions between crisis and noncrisis and the ongoing uncertainty of *when* a recurrence will occur. This requires a family flexibility that permits movement back and forth between two forms of family organization. Also, the wide psychological discrepancy between periods of normalcy versus illness is a particularly taxing feature unique to relapsing diseases.

Outcome

The extent to which a chronic illness will be a likely cause of death and the degree to which it can shorten one's life span is a critical, distinguishing feature with profound psychosocial impact. The most crucial factor is the *initial expectation* of whether a disease will be a likely cause of death. On one end of the continuum are illnesses that do not typically affect the life span, such as lumbosacral disc disease or arthritis. At the other extreme are illnesses that are clearly progressive and usually fatal, such as metastatic cancer or AIDS. There is also an intermediate, more unpredictable category. This includes both illnesses that shorten the life span, such as cardiovascular disease, and those with the possibility of sudden death, such as hemophilia. Perhaps the major difference between these kinds of outcome is the degree to which the family experiences anticipatory grief and its pervasive effects on family life (8, 9, 32, 33, 35).

When loss is less imminent or certain an outcome, illnesses that may shorten life or cause sudden death provide a fertile ground for idiosyncratic family interpretations. The "It could happen" nature of these illnesses creates a nidus for both overprotection by the family and powerful secondary gains for the ill member. This is particularly relevant to childhood illnesses such as hemophilia, juvenile-onset diabetes, and asthma (1, 15, 23, 24).

Incapacitation

Incapacitation can result from impairment of cognition (Alzheimer's disease), sensation (blindness), movement (stroke with paralysis, multiple sclerosis), energy production (cardiovascular disease), disfigurement (severe burns, leprosy), or medical causes of social stigma (AIDS).

The extent, kind, and timing of incapacitation imply sharp differences in the degree of stress facing a family. For instance, the combined cognitive and motor deficits of a person with a stroke necessitate greater family role reallocation than a spinal-cord-injured person who retains his or her cognitive faculties. Some chronic diseases, like hypertension, cause either none, mild, or only intermittent incapacitation. For some illnesses, like stroke, incapacitation is often worst at the time of onset and would magnify family coping issues related to onset, expected course, and outcome. For progressive diseases, like Alzheimer's disease, disability looms as an increasing problem in later phases of the illness, allowing a family more time to prepare for anticipated changes, and it provides an opportunity for the ill member to participate in

disease-related family planning.

By combining the kinds of onset, course, outcome, and incapacitation into a grid format, we generate a typology with 32 potential psychosocial types of illness. Certain types of disease are so rare that for practical purposes they can be eliminated. This grid is shown in Figure 1.[1] The degree of uncertainty about the specific way or rate at which a disease unfolds can be seen as a metacharacteristic that overlays and colors the other attributes: onset, course, outcome, and incapacitation.

		INCAPACITATING		NONINCAPACITATING	
		ACUTE	GRADUAL	ACUTE	GRADUAL
PROGRESSIVE	FATAL		Lung cancer with CNS metastases A.I.D.S. Bone marrow failure Amyotrophic lateral sclerosis	Acute leukemia Pancreatic cancer Metastatic breast cancer Malignant melanoma Lung cancer Liver cancer, etc.	Cystic fibrosis *
RELAPSING	FATAL			Cancers in remission	
PROGRESSIVE	POSSIBLY FATAL / SHORTENED LIFE SPAN		Emphysema Alzheimer's disease Multi-infarct dementia Multiple sclerosis (late) Chronic alcoholism Huntington's chorea * Scleroderma		Juvenile diabetes * Malignant hypertension Insulin dependent adult onset diabetes
RELAPSING	POSSIBLY FATAL / SHORTENED LIFE SPAN	Angina	Early multiple sclerosis Episodic alcoholism	Sickle cell disease * Hemophelia *	Systemic lupus erythematosis *
CONSTANT	POSSIBLY FATAL / SHORTENED LIFE SPAN	Stroke Mod/severe myocardial infarction	P.K.U. and other inborn errors of metabolism	Mild myocardial infarction Cardiac Arrhythmia	Hemodialysis treated renal failure Hodgkins disease
PROGRESSIVE	NONFATAL		Parkinson's disease Rheumatoid arthritis Osteo-arthritis		Non-insulin dependent adult onset diabetes
RELAPSING	NONFATAL	Lumbosacral disc disease		Kidney stones Gout Migraine Seasonal allergy Asthma Epilepsy	Peptic ulcer Ulcerative colitis Chronic bronchitis Other inflam. bowel diseases Psoriasis
CONSTANT	NONFATAL	Congenital malformations Spinal cord injury Acute blindness Acute deafness Survived severe trauma & burns Post-hypoxic syndrome	Non-progressive mental retardation Cerebral palsy	Benign Arrhythmia Congenital heart disease	Malabsorption syndromes Hyper/Hypothroidism Pernicious anemia Controlled hypertension Controlled glaucoma

* early

Figure 1.
Categorization of chronic illnesses by psychosocial type.

TIME PHASES OF ILLNESS

To create a psychosocial schema of chronic diseases, the developmental time phases of an illness can be considered as a second dimension. An understanding of the evolution of chronic diseases is hindered because clinicians rarely follow the family through the complete life history of an illness. The concept of time phases provides a way for the clinician to think longitudinally and to reach a fuller understanding of chronic illness as an ongoing process with landmarks, transitions, and changing demands. Each phase has its own unique psychosocial developmental tasks that require significantly different strengths, attitudes, or changes from a family. To capture the core psychosocial themes in the natural history of chronic disease, three major phases can be described: crisis, chronic, and terminal. The relationship between a more detailed chronic disease time-line and one grouped into broad time phases can be diagrammed as follows (see Figure 2).

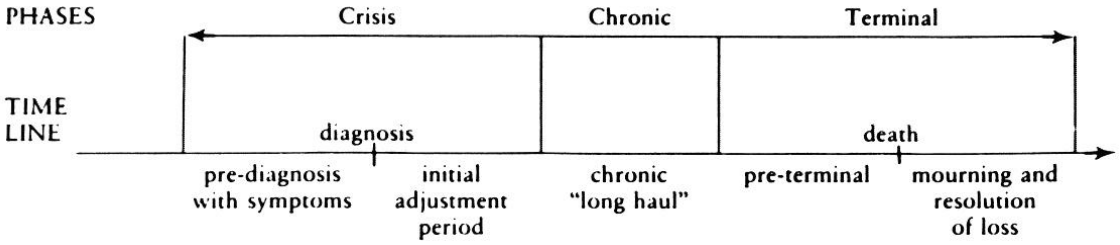

Figure 2.
Time line and phases of illness.

The *crisis* phase includes any symptomatic period before actual diagnosis and the initial period of readjustment and coping after the problem has been clarified through a diagnosis and initial treatment plan. During this period, there are a number of key tasks for the ill member and his or her family. Moos (25) describes certain universal, practical illness-related tasks. These include: learning to deal with pain, incapacitation, or other illness-related symptoms; learning to deal with the hospital environment and any disease-related treatment procedures; and establishing and maintaining workable relationships with the health care team. In addition, there are critical tasks of a more general, sometimes existential nature. The family needs to: create a meaning for the illness event that maximizes a preservation of a sense of mastery and competency; grieve for the loss of the pre-illness family identity; move toward a position of acceptance of permanent change while maintaining a sense of continuity between its past and future; pull together to undergo short-term crisis reorganization; and, in the face of uncertainty, develop a system flexibility toward future goals.

The *chronic* phase, whether long or short, is the time span between the initial diagnosis and readjustment period and the third phase when issues of death and terminal illness predominate. It is an era that can be marked by constancy, progression, or episodic change. In this sense, its meaning cannot be grasped by simply knowing the biological behavior of an illness. Rather, it is more a psychosocial construct that has been referred to as "the long haul," or a phase of "day-to-day living with chronic illness." Often the individual and family have come to grips psychologically and/or organizationally with the permanent changes presented by a chronic illness and have devised an ongoing modus operandi. The ability of the family to maintain the semblance of a normal life under the "abnormal" presence of a chronic illness and heightened uncertainty is a key task of this period. If the illness is potentially fatal, this is a time of "living in limbo." For certain highly debilitating but not clearly fatal illnesses, such as a massive stroke or dementia, the family can become saddled with an exhausting problem "without end." Paradoxically, a family's hope to resume a "normal" life cycle might be realized only after the death of their ill member. This highlights another crucial task of this phase: the maintenance of maximal autonomy for *all* family members in the face of a pull toward mutual dependency and care-taking.

The last or *terminal* phase includes the pre-terminal stage of an illness wherein the inevitability of death becomes apparent and dominates family life. This phase is distinguished by issues surrounding separation, death, grief, resolution of mourning, and resumption of "normal" family life beyond the loss.

Critical transition periods link the three time phases. Carter and McGoldrick (6) and Levenson (19, 20) have clarified the importance of transition periods in the family and adult life-cycle literature. The transition periods in the illness life cycle are times when families reevaluate the appropriateness of their previous life structure in the face of new illness-related, developmental demands. Unfinished business from the previous phase can complicate or block movement through the transitions. As Penn (28) has pointed out, families can become permanently frozen in an adaptive structure that has outlived its utility. For example, the usefulness of pulling together in the crisis period can become a maladaptive and stifling prison for all family members in the chronic phase. Enmeshed families, because of their fused nature, would have difficulty negotiating this delicate transition.

The interaction of the time phases and typology of illness provides a framework for a chronic-disease, psychosocial-developmental model. The time phases (crisis, chronic, and terminal) can be considered broad developmental periods in the natural history of chronic disease. Each period has certain basic tasks independent of the type of illness. In addition to the phase-specific developmental tasks common to all psychosocial types of disease, each type of illness has specific, supplementary tasks. This is analogous to the relationship between a particular individual's development and certain universal life tasks. The basic tasks of the three illness time phases and transitions recapitulate in many respects the unfolding of human development. For example, the crisis phase is similar in certain fundamental ways to the era of childhood and adolescence. Piaget's (29) research demonstrated that child development involves a prolonged period during which the child learns to assimilate from and accommodate to the fundamentals of life. Parents often temper other developmental plans (for example, career) in order to accommodate raising children. In an analogous way, the crisis phase is a period of socialization to the basics of living with chronic disease. During this phase, other life plans are frequently put

on hold by the family in order to accommodate its socialization to illness. Themes of separation and individuation are central in the transition from adolescence to adulthood. Erikson (13) pointed out that adolescents are granted a moratorium or postponement period during which the identity of childhood gradually merges with that of adulthood. Eventually, the adolescent must relinquish this moratorium and assume adult responsibilities. In a similar way, the transition to the chronic phase of illness emphasizes autonomy and the creation of a viable, ongoing life structure adapted to the realities of the illness (life). In the transition to the chronic phase, the "hold" or moratorium on other developmental tasks that served to protect the initial period of socialization/adaptation to a life with chronic disease is reevaluated. The separate developmental tasks of "living with chronic illness" and "living out the other parts of one's life" must be brought together and forged into one coherent life structure. We will return to this concept of illness development later.

At this point, we can combine the typology and phases of illness to construct a two-dimensional matrix (see Figure 3) that permits the grouping and differentiation of illnesses according to important similarities and differences. It subdivides types of chronic illness into three time phases.

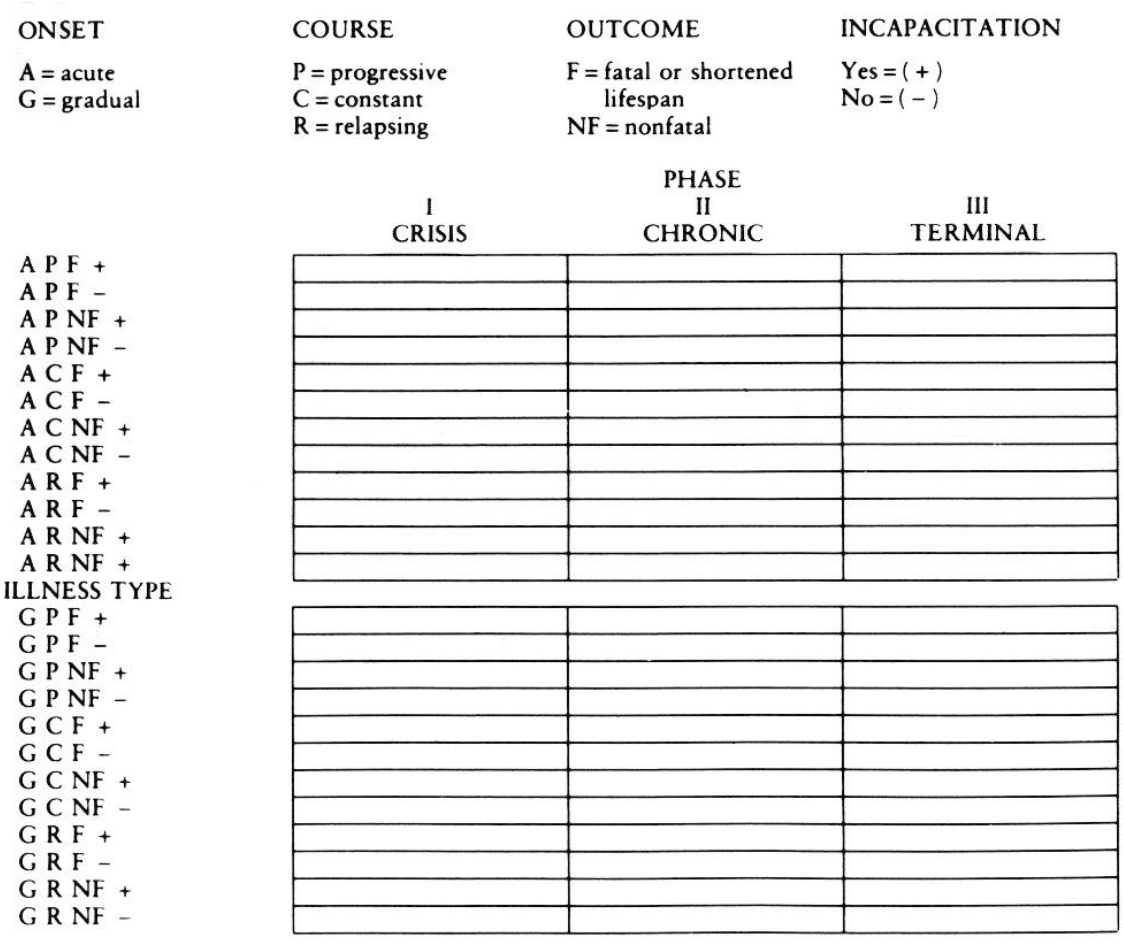

Figure 3.
Matrix of illness types and time phases.

By the addition of a family-systems model to this matrix, we can create a three dimensional representation of the broader illness/family system (see Figure 4). Psychosocial illness types, time phases of illness, and components of family functioning constitute the three dimensions. This model offers a vehicle for flexible dialogue between the illness aspect and family aspect of the illness/family system. In essence, this model allows speculation about the importance of strengths and weaknesses in various components of family functioning in relation to different types of disease at different phases over the illness life course. As one specific application of this model, this discussion will focus on the dimension of time. Using the typology and time phases of illness as a starting point, we will look at: the family's transgenerational history of adaptation to illness, loss, and crisis; and the interface of disease with family and individual development.

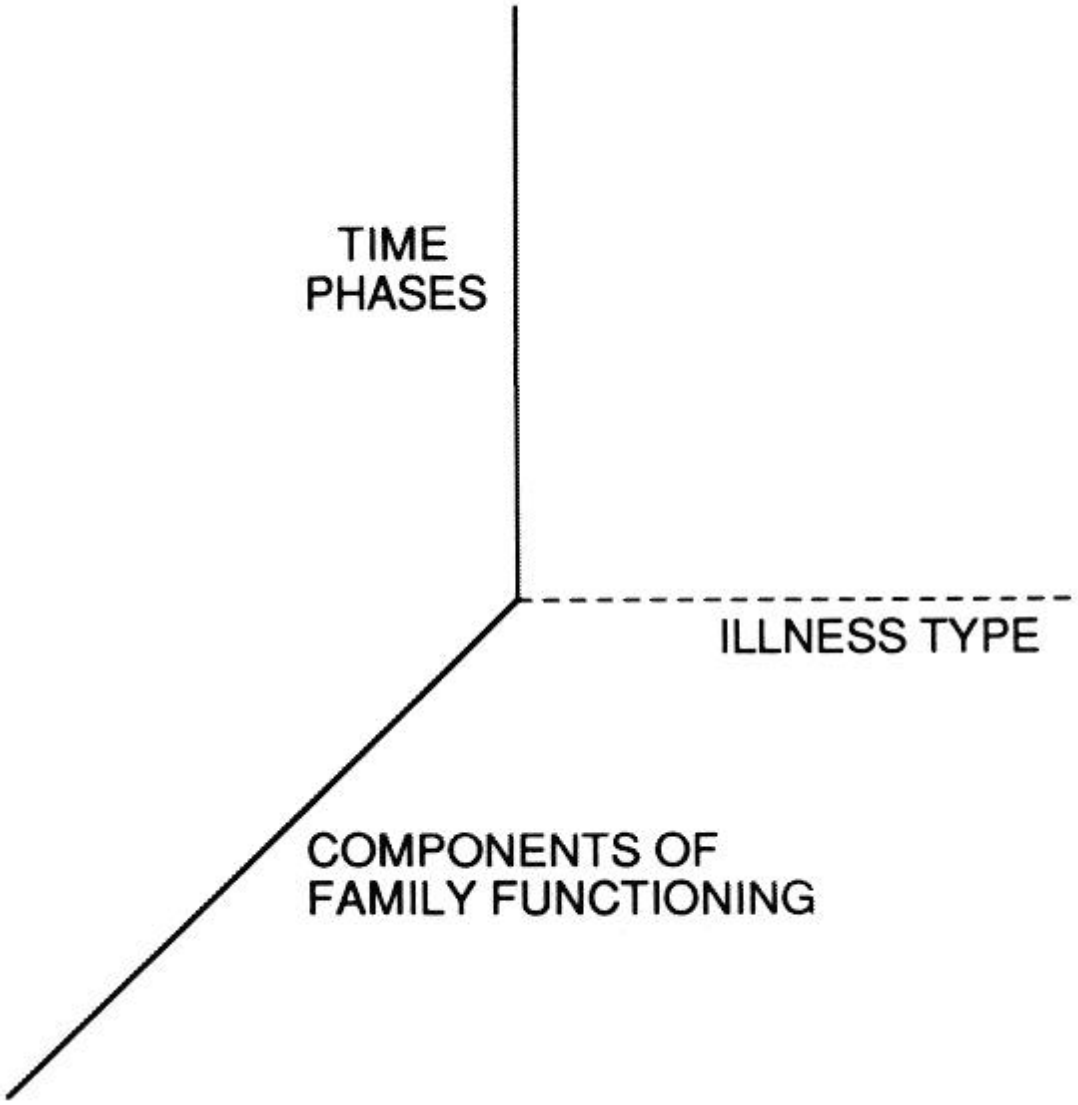

Figure 4.
Three dimensional model: illness type, time phase, and family functioning.

TRANSGENERATIONAL HISTORY OF ILLNESS, LOSS AND CRISIS

Systemically oriented theoreticians have emphasized that a family's present behavior cannot be adequately comprehended apart from its history (4-5, 14, 22, 27). They see historical questioning as a way to track key events and transitions in order to gain an understanding of a family's organizational shifts and coping strategies as a *system* in response to past stressors. A historical, systemic perspective involves more than simply deciphering how a family organized itself around past stressors; it also requires tracking the evolution of family adaptation over time. In this respect, patterns of adaptation, replications, discontinuities, shifts in relationships (alliances, triangles, cutoffs), and sense of competence are important considerations. McGoldrick and Walsh (22) describe how these patterns are transmitted across generations as family myths, taboos, catastrophic expectations, and belief systems. By gathering this information, a clinician creates a basic family genogram (21).

A genogram oriented to chronic illness involves the same basic tracking process, but focuses on how a family organized itself as an evolving system specifically around previous illnesses and unexpected crises in the current and previous generations. A central goal is to bring to light the adults' "learned differences around illness" (28, p. 20).

The typology of illness and time phases are useful concepts in this part of the family evaluation. 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. A family may disregard the differences in demands related to different kinds of

illnesses and thus may show a disparity in their level of coping with one disease versus another. If the clinician inquires separately about the same or similar types of illnesses versus different types (relapsing versus progressive, life-threatening versus nonlife-threatening), he or she will make better use of historical data. 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 be particularly vulnerable if another life-threatening illness were to occur. A different family may have had experience only with nonlife-threatening illnesses and be ignorant of how to cope with the uncertainties particular to life-threatening diseases. Cognizance of these facts will draw attention to areas of strength and vulnerability for a family coping with an illness like cancer. A recent family consultation highlights the importance of tracking prior family illnesses.

Case Example

Joe, his wife Ann, and their three teenage children presented for a family evaluation 10 months after Joe's diagnosis with moderate-severe asthma. Joe, age 44, had been successfully employed for many years as a spray painter. Apparently, exposure to a new chemical in the paint triggered the onset of asthmatic attacks that necessitated hospitalization and disability in terms of his profession. Although somewhat improved, he continued to have persistent and moderate respiratory symptoms. Initially, his physicians had said that there would be some improvement, but remained noncommittal as to the level of chronicity. His continued breathing difficulties contributed to increased symptoms of depression, uncharacteristic temperamental outbursts, alcohol abuse, and family discord.

As part of the initial assessment, I inquired about their prior experience in coping with chronic disease. This was the nuclear family's first encounter with chronic illness. In terms of their families of origin, they had limited experience. Ann's father had died seven years earlier of a sudden and unexpected heart attack. Joe's brother had died in a verified accidental drowning. Neither had had experience with disease as an ongoing process. Joe had assumed that improvement meant "cure." Illness for both had meant either death or recovery. The physician/family system was not attuned to the hidden risks for this family that was going through the transition from the crisis to chronic phase of his asthma—the juncture where the permanency of the disease needed to be addressed.

Tracking a family's coping abilities in the crisis, chronic, and terminal phases of previous chronic illnesses will highlight complications in adaptation related to different points in the illness life cycle. A family may have adapted well in the crisis phase of living with the paternal grandfather's spinal cord injury, but failed to navigate the transition to a family organization consistent with long-haul adaptation. An enmeshed family, with its tendency toward rigid overcloseness, may have become frozen in a crisis structure and been unable to deal appropriately with issues of maximizing individual and collective autonomy in the chronic phase. Another family with a member with chronic kidney failure may have functioned well in handling the practicalities of home dialysis. However, in the terminal phase, their limitations around affective expression may have left a legacy of unresolved grief. A history of time-phase-specific difficulties can alert a clinician to potential vulnerable periods for a family over the course of the current chronic illness. The following example of a family coping with a current illness illustrates the interplay of problems that are fueled by unresolved issues related to disease experience in one's family of origin.

Case Example

Mary, her husband Bill, and their son, Jim, presented for treatment 4 months after Mary had been involved in a life-threatening, head-on auto collision in which she had sustained a serious concussion. The driver of the other vehicle was at fault. For several months, there was some concern by the medical team that she might have suffered a cerebral hemorrhage. Ultimately, it was clarified that this had not occurred. Mary had become increasingly depressed and, despite strong reassurance, continued to believe she had a life-threatening condition and would die from a brain hemorrhage.

During the evaluation, she revealed that she was experiencing vivid dreams of meeting her deceased father. Apparently her father, with whom she had been extremely close, had died from a cerebral hemorrhage after a four-year history of a progressive, debilitating brain tumor. His illness had been marked by progressive and uncontrolled epileptic seizures. Mary was fourteen at the time and was the "baby" in the family. The family shielded her from his illness and decided not to have her attend either the wake or the funeral. This event galvanized her position as the "child in need of protection"—a dynamic that carried over into her marriage. Despite her hurt, anger, and lack of acceptance of the death, she had avoided discussing her feelings with her mother for over 20 years. Other family history revealed that her mother's brother had died from a sudden stroke and a cousin had died after being struck on the head by a streetlamp.

Her own life-threatening head injury had triggered a catastrophic reaction and dramatic resurfacing of previous losses involving similar types of illness and injury. Therapy focused on a series of tasks and rituals that involved her initiating conversations with her mother and visiting her father's gravesite.

The family's history of coping with crises in general, especially unanticipated ones, should be explored. Illnesses with

acute onset (heart attack), moderate-severe sudden incapacitation (stroke), or rapid relapse (ulcerative colitis, diabetic insulin reaction, disc disease), demand in various ways rapid crisis-mobilization skills. In these situations, the family needs to reorganize quickly and efficiently, shifting from its usual organization to a crisis structure. Other illnesses can create a crisis because of the continual demand for family stamina (spinal cord injury, rheumatoid arthritis, emphysema). The family history of coping with moderate-severe, ongoing stressors is a good predictor of adjustment to these types of illness.

For any significant chronic illness in either adult's family of origin, a clinician should try to get a picture of how those families organized themselves to handle the range of disease-related affective and practical tasks. Also, it is important for a clinician to find out what role each played in handling these emotional or practical tasks. Whether the parents (as children) were given too much responsibility (parentified) or shielded from involvement is of particular importance. What did they learn from those experiences that influences how they think about the current illness? Whether they emerge with a strong sense of competence or failure is essential information. In one particular case, involving a family with three generations of hemophilia transmitted through the mother's side, the father had been shielded from the knowledge that his older brother who died in adolescence had had a terminal form of kidney disease. Also, this man had 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.

By collecting the above information about each adult's family of origin, one can anticipate areas of conflict and consensus. Penn (28) and Walker (34) have described how unresolved issues related to illness and loss can remain dormant in a marriage and suddenly reemerge when triggered by a chronic illness in the current nuclear family. Penn describes how particular coalitions that emerge in the context of a chronic illness are isomorphs of those that existed in each adult's family of origin.

> [I]f a mother has been the long-time rescuer of her mother from a tyrannical husband, and then in her own family bears a son with hemophilia, she will become his rescuer, often against his father. In this manner, she continues to rescue her mother but, oddly enough, now from her husband rather than from her own father... In this family with a hemophiliac son, the father's father had been ill for a long period and had received all the mother's attention. In his present family, this father, though outwardly objecting to the coalition between his wife and son, honored that relationship, as if he hoped it would make up for the one he had once forfeited with his own mother. The coalition in the nuclear family looks open and adaptational (mother and son), but is fueled by coalitions in the past (mother with her mother, and father with his mother) ... [p. 18]

The reenactment of previous system configurations around illness can occur largely as an unconscious, automatic process. Further, the dysfunctional complementarity one sees in these families can emerge *de novo* specifically within the context of a chronic disease. On detailed inquiry, couples will frequently reveal that a tacit, unspoken understanding existed that if an illness occurred they would reorganize to reenact "unfinished business" from their families' of origin. Typically, the role chosen represents a repetition of or an opposite role played by themselves or the same-sex parent in their family of origin. This process resembles the unfolding of a genetic template that gets switched on only under particular biological conditions. It highlights the need for a clinician to maintain some distinction between functional family process with and without chronic disease. For families that present in this manner, placing a primary therapeutic emphasis upon the resolution of family-of-origin issues may be the best approach to prevent or rectify an unhealthy triangle.

Families with encapsulated illness "time bombs" need to be distinguished from families that show more pervasive and longstanding dysfunctional patterns. For the latter, illnesses will tend to become embedded within a web of existing, fused family transactions. Just as parents can enact a detouring triangle through an ill child in order to avert unresolved marital conflict (23, 24), so too the therapist can collude with a family's resistance by overfocusing on the disease itself. Distinctions between the family's illness versus nonillness patterns are, to a large degree, semantic when the illness serves to rigidify preexisting family dysfunction. In the traditional sense of "psychosomatic," a severely dysfunctional family displays a greater level of baseline reactivity such that when an illness enters their system, this reactivity gets expressed somatically through a poor medical course and/or treatment noncompliance. Because these families lack the foundation of a functional nonillness system to tackle family-of-origin patterns around disease, the initial focus of therapeutic intervention may need to be targeted more on the nuclear family. The prognosis for severely dysfunctional families is more guarded.

A third group of symptomatic families facing chronic disease are those without significant intra- or intergenerational family dysfunctional patterns. Any family may falter in the face of multiple, superimposed disease and nondisease stressors that impact in a relatively short time. Progressive, incapacitating diseases or the occurrence of illnesses in several family members are typical scenarios. A pragmatic approach that focuses on expanded or creative use of supports and resources outside the family is most productive.

INTERFACE OF THE ILLNESS, INDIVIDUAL, AND FAMILY LIFE CYCLES

To understand the unfolding of the illness, individual, and family life cycles as three interwoven threads is a highly

complex process that remains largely unexplored. This discussion will emphasize the intersection of the illness and family life cycles, but draw upon concepts applicable to individual development.

Because an illness is part of an individual, it is essential to think simultaneously about the interaction of individual and family development. To create a context for dialogue, a language is needed that bridges these developmental threads. A central concept for each is that of a life cycle (6, 10, 19, 20). The notion of cycle suggests an underlying order of the life course whereby individual, family, or illness uniqueness occurs within a context of a basic sequence or unfolding. A second key concept is that of the human life structure. Although Levinson's (19) original description of the life structure was within the context of his study of individual, male-adult development, the generic notion of life structure can also be applied to the family as a unit. By life structure, he means the underlying pattern or design of a person's/family's life at any given point in the life cycle. Its primary components are a person's/family's reciprocal relationships with various "others" in the broader ecosystem (person, group, institution, culture, object, or place). The life structure forms a boundary between the individual/family and the environment. It both governs and mediates the transactions between them.

Levinson's model elucidated four broad eras in the human life cycle. He noted that these eras are characterized by the alternation of life structure-building/maintaining and life structure-changing (transitional) periods linking developmental eras. These constructs can be applied to family and illness development. The primary goal of a structure-building/maintaining period is to form a life structure and enrich life within it based on the key choices an individual/family made during the preceding transition period. As mentioned earlier, 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 (17).

The concepts of centripetal versus centrifugal family styles and phases in the family life cycle are particularly useful to the task of integrating family, individual, and illness development (2, 3). Recent work of Combrinck-Graham (7) elaborates the application of centripetal/centrifugal phases to the family life cycle. She describes a family life-spiral model in which she envisions the entire three-generational family system oscillating through time between periods of family closeness (centripetal) and periods of family disengagement (centrifugal). In life-cycle terms, centripetal/centrifugal connote a fit between developmental tasks and the relative need for internally directed, personal and family-group cohesive energy to accomplish those tasks. During a centripetal period (for example, early childrearing) both the individual member's and family unit's life structure emphasize internal family life. External boundaries around the family are tightened while personal boundaries between members are somewhat diffused to enhance family teamwork. In the transition to a centrifugal period, the family life structure shifts to accommodate goals that emphasize the individual family member's exchange with the extrafamilial environment. The external family boundary is loosened while nonpathological distance between some family members increases.

Several key concepts culled from these major models of the individual and family life cycles provide a foundation for discussion of chronic disease. We can consider the life cycle to contain alternating transition and life structure-building/maintaining periods. Further, particular transition or life structure-building/maintaining periods can be characterized as either centripetal or centrifugal in nature. This set of relationships is diagrammed in Figure 5. The following discussion will use these overarching concepts rather than particular age- or event-specific periods as its central reference point.

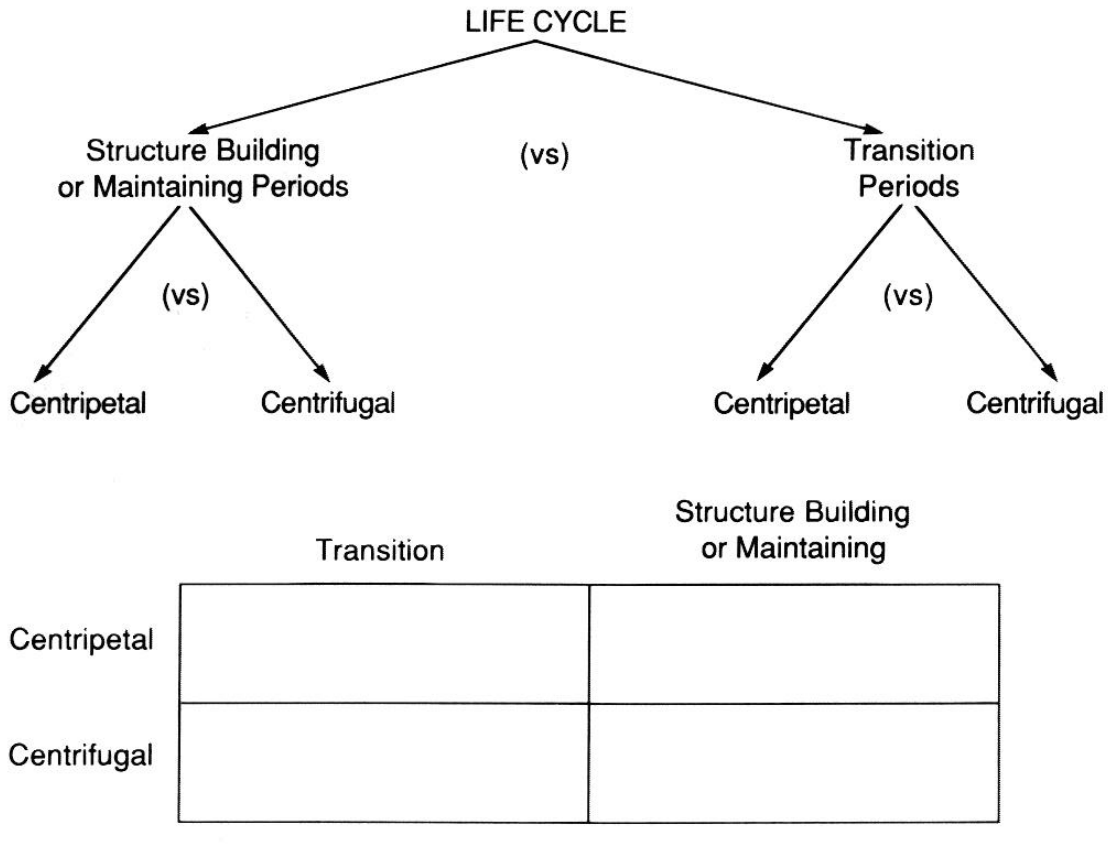

Figure 5.
Periods in the family and individual life cycles.

The notion of centripetal and centrifugal modes is useful in linking the illness life cycle to the individual and family life cycles. In general, chronic disease exerts a centripetal pull on the family system. In family developmental models, centripetal periods begin with the addition of a new family member (infant), which propels the family into a prolonged period of socialization of and to children. In an analogous way, the occurrence of chronic illness in a family resembles the addition of a new infant 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, it can derail the family from its natural momentum. 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 extrafamilial autonomy and individuation are 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. Family dynamics as well as disease severity will influence whether the family's reversion to a centripetal life structure is a temporary detour within their general outward movement or a permanent, involutional shift. A moderately fused or enmeshed family frequently faces the transition to a more autonomous period with trepidation. A chronic illness provides a sanctioned reason to return to the "safety" of the prior centripetal period. For some family members, the giving up of the building of a new life structure that is already in progress can be more devastating than when the family is still in a more centripetal period in which future plans may be at a more preliminary stage, less formulated, or less clearly decided upon.

Disease onset that coincides with a centripetal period in the family life cycle (early child rearing) can have several important consequences. At a minimum, it can foster a prolongation of this period. At worst, the family can become permanently stuck at this phase of development. In this instance, the inward pull of the illness and the phase of the life cycle coincide. The risk here is their tendency to amplify one another. For families that functioned in a marginal way before an illness begins, this kind of mutual reinforcement can trigger a runaway process leading to overt family dysfunction. Minuchin, Rosman, and Baker's (23, 24) research of "psychosomatic" families has documented this process in several common childhood illnesses.

When a parent develops a chronic disease during this centripetal child-rearing phase of development, a family's ability to

stay on course is severely taxed. For psychosocially milder diseases, efficient role reallocation may suffice. A recent case illustrates this point.

Case Example

Tom and his wife, Sally, presented for treatment 6 months after Tom had sustained a severe burn injury to both hands that required skin grafting. A year of recuperation was necessary before Tom would be able to return to his job, which required physical labor and full use of his hands. Prior to this injury, his wife had been at home full-time raising their two children, ages 3 and 5. In this case, although Tom was temporarily handicapped in terms of his career, he was physically fit to assume the role of house-husband. Initially, both Tom and Sally remained at home using his disability income to "get by." When Sally expressed an interest in finding a job to lessen financial pressures, Tom resisted, and manageable marital strain caused by his injury flared into dysfunctional conflict.

Sufficient resources were available in the system to accommodate the illness and ongoing childrearing tasks. Their definition of marriage lacked the necessary role flexibility to master the problem. Treatment focused on rethinking his masculine and monolithic definition of "family provider," a definition that had, in fact, emerged in full force during this centripetal phase of the family life cycle.

If the disease affecting a parent is more debilitating (traumatic brain injury, cervical spinal cord injury), its impact on the childrearing family is twofold. The ill parent becomes for the family like another child with "special needs," competing with the real children for potentially scarce family resources. Second, a parent is "lost," and the semblence of a single-parent family is created. For acute onset illnesses, both events can occur simultaneously. In this circumstance, family resources may be inadequate to meet the combined child-rearing and caretaking demands. This situation is ripe for the emergence of a parentified child or the reenlistment into active parenting of a grandparent.

If we look at chronic diseases in a more refined way through the lens of the typology and time phases of illness, it is readily apparent that the degree of centripetal/centrifugal pull varies enormously. This variability has important effects on the family life cycle independent of family dynamics. The tendency for a disease to interact centripetally with a family grows as the level of incapacitation or risk of death due to the illness increases. Progressive diseases over time are inherently more centripetal in terms of their effect on families than are constant-course illnesses. The ongoing addition of new demands as an illness progresses keeps a family's energy focused inwardly. After a modus operandi has been forged, a constant-course disease (excluding those with severe incapacitation) permits a family to enter or resume a more centrifugal phase of the life cycle. The added centripetal pull exerted by a progressive disease increases the risk of reversing normal family disengagement or freezing a family into a permanent state of fusion.

Case Example

Mr. L, age 54, has become increasingly depressed as a result of severe and progressive complications of his adult-onset diabetes that had emerged over the past 5 years. These complications included a leg amputation and renal failure that recently required the instituting of home dialysis four times a day. For 20 years, Mr. L had had an uncomplicated, constant course, allowing him to lead a full active life. He was an excellent athlete and engaged in a number of recreational group sports. Short- and long-term family planning had never focused around his illness. This optimistic attitude was reinforced by the fact that two people in Mrs. L's family of origin had had diabetes without complications. Their only child, a son age 26, had uneventfully left home after high school. He had recently married. Mr. and Mrs. L had a stable marriage in which both maintained many outside, independent interests. In short, the family had moved smoothly through the transition to a more centrifugal phase of the family's life cycle.

His disease's transformation to a progressive course, coupled with the incapacitating and life-shortening nature of his complications, had reversed the normal process of family disengagement. His wife took a second job that necessitated her quitting her hobbies and civic involvements. Their son and his wife moved back home to help his mother take care of his father and the house. Mr. L, disabled for work and his athletic social network, felt himself to be a burden to everyone and blocked in his own midlife development.

The essential goal of family treatment in developmental terms centered on reversing some of the system's centripetal overreaction back to a more realistic balance. For Mr. L, this meant a reworking of his life structure to accommodate his real limitations while maximizing a return to his basically independent style. For Mrs. L and her son, this meant developing realistic expectations for Mr. L and reestablishing key aspects of their autonomy within an illness/family system.

Relapsing illnesses alternate between periods of drawing a family inwardly and periods of release from the immediate demands of disease. However, the on-call state of preparedness dictated by many such illnesses keeps some part of the family in a centripetal mode despite medically asymptomatic periods. Again, this may hinder the natural flow between phases of the family life cycle.

One way to think about the time phases of illness is that they represent to the family a progression from a centripetal

crisis phase to a more centrifugal, chronic phase. The terminal phase, if it occurs, forces most families back into a more centripetal mode. In other words, the so-called "illness life structure," developed by a family to accommodate each phase in the illness life cycle, is colored by each time phase's inherent centripetal/centrifugal nature. For example, in a family in which the onset of the illness has coincided with a centrifugal phase of development, the transition to the chronic phase permits a family to resume more of its original inertia. One cannot overemphasize the need for clinicians to be mindful of the timing of the onset of a chronic illness with individual/ family transition and life structure-building/maintaining periods of development.

All *transitions* inherently involve the basic processes of termination and initiation. Arrivals, departures, and losses are common life events, during which there is an undercurrent of preoccupation with death and finiteness (19). 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, one might expect that issues related to previous, current, and 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 in 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. If a clinician adopts a longitudinal, developmental perspective, he or she will stay attuned to future transitions and their overlap with each other.

An example can highlight the importance of the illness in relation to future developmental transitions.

Case Example

Imagine a family in which the father, a carpenter and primary financial provider, develops multiple sclerosis. At first, his level of impairment is mild and stabilized. This allows him to continue part-time work. Because their children are all teenagers, his wife is able to undertake part-time work to help maintain financial stability. The oldest son, age 15, seems relatively unaffected. Two years later, father experiences a rapid progression of his illness, leaving him totally disabled. His son, now 17, has dreams of going away to college and being educated for a career in science. The specter of financial hardship and the perceived need for a "man in the family" creates a serious dilemma of choice for the son and the family.

In this case, there is a fundamental clash between developmental issues of separation/individuation and the ongoing demands of progressive, chronic disability upon the family. This vignette demonstrates the potential clash between simultaneous transition periods: the illness transition to a more incapaciting and progressive course, the adolescent son's transition to early adulthood, and the family's transition from the stage of "living with teenagers" to "launching young adults." Also, this example illustrates the significance of the type of illness. An illness that was less incapacitating or relapsing (as opposed to a progressive or constant-course disease) may interfere less with this young man's separation from his family of origin. If his father had an intermittently incapacitating illness, like disc disease, the son might have moved out but tailored his choices to remain close by and available during acute flare-ups.

The onset of a chronic illness may cause a different kind of disruption if it coincides with a *life structure-building/maintaining period* in individual or family development. These periods are characterized by the living out of a certain life structure that represents the outgrowth of the rethinking, formulation, and change of the preceding transition period. The cohesive bonds of the individual/family are oriented toward protecting the current life structure. Diseases with only a mild level of psychosocial severity (nonfatal, or mild incapacitation, nonprogressive) may require of the individual/family some revision of their life structure, but not a radical restructuring that would necessitate a more basic return to a transitional phase of development. A chronic illness with a critical threshold of psychosocial severity will demand the reestablishment of a transitional form of life at a time when individual/family inertia tends to preserve the momentum of a stable period. This transition will be highly centripetal in nature because the illness will, like the addition of a newborn, require a period of socialization. An individual's or family's level of adaptability is a prime factor in the successful navigation of this kind of crisis. In this situation, the concept of family adaptability is referred to in its broadest sense—the ability of a family to transform its entire life structure to a prolonged transitional state.

For instance, in our previous example, father's multiple sclerosis rapidly progressed while the oldest son was in a transition period in his own development. The nature of the strain in developmental terms would be quite different if his father's disease progression had occurred when this young man was 26, had already left home, finished college, secured a first job, married, and had his first child. In the latter scenario, the oldest son's life structure is in a centripetal, structure-maintaining period within his newly formed nuclear family. To fully accommodate the needs of his family of origin could require a monumental shift of his developmental priorities. When this illness crisis coincided with a developmental transition period (age 17), although a dilemma of choice existed, the son was available and less fettered by commitments in progress. Later, at age 26, he has made developmental choices and is in the process of living them out. Not only has he made commitments, but also they are centripetal in nature—focused on his newly formed family. To serve the demands of an illness transition, the son might need to shift his previously stable life structure back to a transitional state;

and the shift would happen "out of phase" with the flow of his individual and nuclear family's development. One precarious way to resolve this dilemma of divided loyalties may be the merging of the two households, thereby creating a single, super-large, centripetal family system.

This discussion raises several key clinical points. From a systems viewpoint, at the time of a chronic illness diagnosis it is important to know the phase of the family life cycle and the stage of individual development of all family members, not just the ill member. This is important information for several reasons. First, chronic disease in one family member can profoundly affect developmental goals of another member. For instance, a disabled infant can be a serious roadblock to a mother's mastery of childrearing, or a life-threatening illness in a young adult can interfere with the spouse's task of beginning the phase of parenthood. Second, family members frequently do not adapt uniformly to chronic illness. Each family member's ability to adapt and the rate at which he or she does so is directly related to each individual's own developmental stage and his or her role in the family (18). The oldest son in the previous example illustrates this point.

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 (16, 26). As untimely events, chronic diseases can severely disrupt the usual sense of continuity and rhythm of the life cycle. Levinson's research showed that the timing in the life cycle of an unexpected event, like a chronic illness, will shape the form of adaptation and the event's influence on subsequent development.

This discussion suggests that the notion of "out-of-phase" illnesses can be conceptualized in a more refined way. First, as described earlier, diseases have a centripetal influence on most families. In this sense, they are naturally "out of phase" with families in or in transition toward a more centrifugal period. From this vantage point, illnesses can be more disruptive to families in a centrifugal period of the development. Second, the onset of chronic disease tends to create a period of transition, the length or intensity of which depends upon the psychosocial type and phase of the illness. This forced transition is particularly "out of phase" if it coincides with a life structure-building/maintaining period in the individual or family's life cycle. Third, if the 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, a family 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 a family's consciousness, constantly impinging upon their attempts to get back "in phase" developmentally. Finally, the transition from the crisis to the chronic phase of the illness life cycle is often the key juncture at which the intensity of the family's socialization to living with chronic disease can be relaxed. In this sense, it offers a ldquo;window of opportunity" for the family to correct its developmental course.

Some investigators believe that chronic diseases that occur in the childrearing period can be most devastating because of their potential impact on family financial and childrearing responsibilities (16). Again, the actual impact will depend on the type of illness and the pre-illness roles of each family member.

In the face of chronic disease, an over-arching goal is for a family to deal with the developmental demands presented by the illness without the need for family members to sacrifice their own or the family's development as a system. Therefore, it is vital to ask what life plans the family or individual members had to cancel, postpone, or alter as a result of the diagnosis. It is useful to know whose plans are most and least affected. By asking a family when and under what conditions they will resume plans put on hold or address future developmental tasks, a clinician can anticipate developmental crises related to "independence from" versus "subjugation to" the chronic illness.

CONCLUSION

This article has attempted to provide a conceptual base for thinking about the system created at the interface of chronic illness with the family and individual life cycles. The description of a psychosocial typology and time phases of illness is a necessary, preliminary step to the creation of a common language to bridge the worlds of illness, individual, and family development. This developmental landscape is marked by periods of transition, periods of living out decisions and commitments, periods of family centeredness, and periods less dictated by family group tasks. What emerges is the notion of three intertwined lines of development during which there is a continual interplay of life structures needed to carry out individual, family, and illness, phase-specific, developmental tasks. Families' intergenerational paradigms related to chronic disease, crisis, and loss play upon these three interwoven developmental threads and add their own texture and pattern.

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