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Anticipatory Loss: A Family Systems Developmental Framework*

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This article provides a family-systems developmental framework for anticipatory loss in situations of physical illness, disability, and long-term psychiatric disorders, and offers a conceptual base for theory building, clinical practice, and research. A family systems-illness model that integrates psychosocial types and phases of illness with family variables, in particular, developmental patterns and beliefs systems, provides a foundation to rethink and expand our approaches to threatened loss.

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THE anticipation of loss in physical illness can be as challenging and painful for families as the death of a family

member. There has been relatively little attention given to the process of families anticipating future loss, and how their experience with protracted, threatened loss evolves with illness, individual and family development. Most literature on impending loss has focused on individual bereavement in the terminal phase of illness, when loss is imminent and certain. Overlooked are the enormous challenges to families over the course of disabling and life-threatening illness as they must live with uncertainty in the face of tragedy. A myriad of feelings and transactions associated with anticipatory loss complicate all dimensions of family life over time. This article offers a clinical framework to address, simultaneously, the interweaving of family efforts to sustain hope, cope with varying degrees of uncertainty, and prepare for loss over the entire course of an illness. This framework is developed from the assessment and treatment experience of the author and colleagues with over 400 families at a center specializing in providing systems-based services to families fac-

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ing chronic and life-threatening disorders in a child or adult member.

Lindemann (23) first described the phenomenon of "anticipatory grief" in his study of spousal adaptation to wartime separation, noting the essential signs of "true" grief experienced in preparation for bereavement. Subsequent research has focused on the effects of anticipatory grief on parents with terminally ill children and on key survivors (for example, spouses) of terminally ill adults (8, 12, 14-16, 25, 28-30, 41). Research has yielded inconsistent and often contradictory findings about both the value of time in which to anticipate loss and the kinds of coping strategies that are most helpful to long-term adaptation (13).

In the family-systems literature, the scant attention to loss has focused on the impact of prior unresolved losses on later family life (5, 9, 17, 27, 47), or redefining family boundaries in the context of ambiguous loss (4). The threat of loss touches more closely on the existential fact of our own mortality as an anticipated future event we may need to deny (2).

This article offers a systemic, interactional view of anticipatory loss over the entire course of an illness, which includes the mutual influence of family dynamics with: (a) family members' threatened loss of the ill member, (b) the ill member's anticipation of losing his or her family, and (c) the ill member's expectation of disability and/or death. The threat of loss needs to encompass the "person," the relationships with the ill member, and the intact family unit.

As distinct from the concept of anticipatory grief, which refers narrowly to individual emotions in the terminal phase, the experience of anticipatory loss involves a range of intensified emotional and interactional responses over the course of an illness. Feelings may include: separation anxiety, existential aloneness, denial, sadness, disappointment, anger, resentment, guilt,

exhaustion, and desperation. Emotional expression often fluctuates between these more difficult feelings and others such as a heightened sense of being alive, life's preciousness, intimacy, appreciation for "routine" daily events, and hope. There may be intense ambivalence toward the ill member, vacillating closeness and distance, and fantasies of escape from an unbearable situation. Especially with chronic illnesses involving long-term threatened loss, families often become hypervigilant and overprotective toward other family members as well as the patient. They may repeatedly rehearse the process of loss, and imagined scenarios of family suffering and hardship. These complex emotions can powerfully influence families' dynamics as they try to adapt to threatened loss.

A systems-oriented model that views the experience of anticipatory loss within a developmental framework clarifies how the meaning of possible loss evolves over time with changing life-cycle demands (36-38). Also, the salience of anticipatory loss varies depending on members' transgenerational experiences with actual and threatened loss. A family's experience of threatened loss varies with the kind of illness, its psychosocial demands over time, and the degree of uncertainty about prognosis. Because the quality and degree of anticipatory loss varies with the developmental phases of illness (35), it is essential to differentiate between a family's expectation of *inevitable* loss in the terminal stage of an illness and its awareness of the *possibility* at an earlier point. It is also crucial to assess anxieties about *disability* and *suffering* as distinct from *death*, since patients and families often express their greatest fears about helplessness in the face of uncontrollable suffering. As distinct from families in acute grief, such families earlier-on are faced with seemingly incompatible psychosocial tasks. They try to sustain vital membership for a person who is ex-

pected to become disabled with efforts to integration by reallocating role functions. These are easily overlooked, at time of diagnosis.

Finally, belief systems show how families view and threatening situations. Attributed to disability and of competence to influence events will affect how they face of threatened loss. Feelings of blame, shame, and affect their view of the and the meanings attached to loss, and seriously impede

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FAMILY SYSTEMS-ILLNESS

The Family Systems-Illness model developed by the author (35) is a useful framework for understanding family experience of anticipatory loss. The model distinguishes three dimensions: 1) "psychosocial" 2) major phases in the illness and 3) key family-systems. The first dimension, illness, vary in terms of: *onset* (acute vs. chronic); *course* (progressive vs. cyclical); *outcome* (fatal vs. nonfatal); or possible sudden death (short vs. long longevity); and *incapacity*

pected to become disabled or die, simultaneously with efforts to maintain family integration by reallocating the ill member's role functions. These critical distinctions are easily overlooked, particularly at the time of diagnosis.

Finally, belief systems powerfully shape how families view and respond to life-threatening situations. The meanings ascribed to disability and death and a sense of competence to influence the outcome of events will affect how families act in the face of threatened loss. Unresolved issues of blame, shame, and guilt can strongly affect their view of the cause of an illness and the meanings attached to anticipated loss, and seriously impede adaptation (40).

Recent studies by Wortman and Silver (48) indicate that traditional assumptions about healthy mourning are largely myth. Their research strongly suggests a much broader range of nonpathological grief reactions and casts doubt on stage theories of loss (19). Likewise, this discussion is based on the awareness that there are many effective coping strategies to deal with threatened loss. The aim of this article is to provide a framework for clinical assessment and research that will improve decision making and effective intervention for a range of situations faced by families dealing with anticipatory loss.

FAMILY SYSTEMS-ILLNESS MODEL

The Family Systems-Illness model developed by the author (35, 36, 38, 39) provides a useful framework for understanding the family experience of anticipatory loss. The model distinguishes three separate dimensions: 1) "psychosocial types" of illnesses, 2) major phases in their natural history, and 3) key family-systems variables. On the first dimension, illness patterning can vary in terms of: *onset* (acute vs. gradual); *course* (progressive vs. constant vs. relapsing); *outcome* (fatal vs. shortened life span or possible sudden death vs. no effect on longevity); and *incapacitation* (none vs.

mild vs. moderate vs. severe). To identify the core psychosocial themes in the unfolding of chronic disorders, the second dimension delineates three major phases: 1) *initial crisis*, 2) *chronic*, and 3) *terminal*, each linked by *critical transitions*. A family-systems assessment, as the third dimension, highlights the importance of various components of family life (development, belief systems, cohesion, adaptability, communication) in relation to specific types of disorders at a specific phase of the "illness life cycle." The Family Systems-Illness model (see Figure 1) enables clinicians to characterize the practical and emotional demands of any illness, and do it in relation to family interactional patterns.

Illness Timeline and Threatened Loss

The psychosocial types and phases of illness provide a timeline of potential nodal points of loss, including disability and death. Families begin to develop their own timelines at initial diagnosis. Discussions with health providers about the nature of the disorder, its prognosis, and prescriptions for management constitute a "framing event" for family members. Generally, this is a highly emotional and vulnerable period. Families face loss of "normal" life as it was before a diagnosis as they face threatened further loss through disability and/or death. This hypervigilant, anxious, trance-like state makes families highly receptive to intended and unintended messages about how to navigate the uncertainties that confront them. What is actually said, unstated, or left unclear about the prognosis by clinicians is critical. Who is included and excluded from these conversations influence how the family frames the experience. One family, accustomed to open frank discussion, described how the physician came to the mother's hospital room and took the family members to a separate room to inform them that the mother had cancer and to discuss the diagnosis. At this vulnerable moment, the

INTERFACE OF CHRONIC ILLNESS AND THE FAMILY

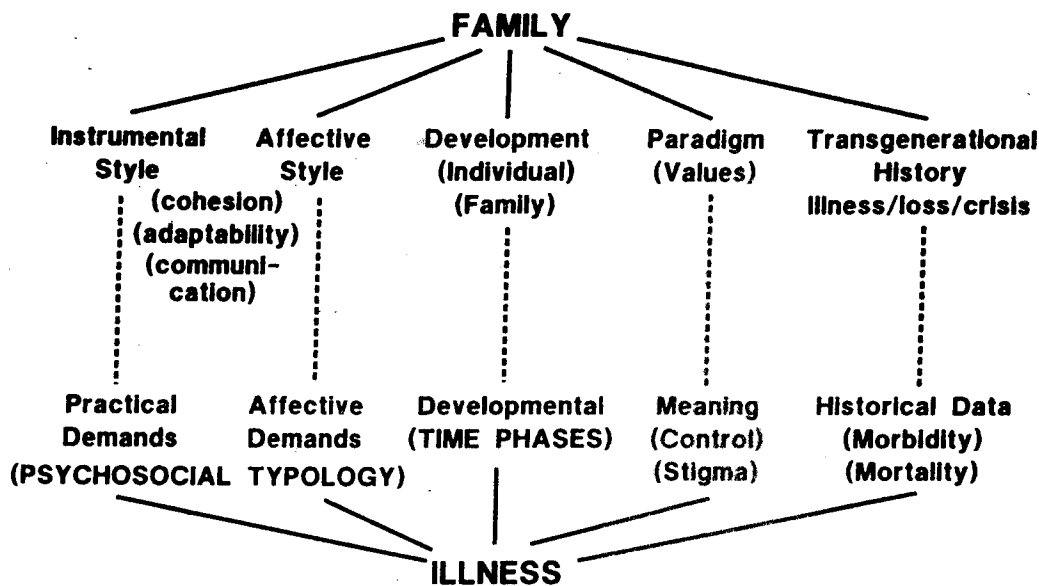


FIG. 1. Family systems-illness model: Interface of chronic disorders and the family.

family felt they were being instructed implicitly to exclude the mother in any discussion of her cancer.

Further, different families may hear the same discussion through very different historical/ethnic/cultural filters that can lead to conflictual and dysfunctional patterns later. Beliefs about the likelihood and timing of further disability and death strongly influence the relationship rules established in the face of threatened loss. In one family, the husband had a benign skin cancer removed and was reassured by the dermatologist that he need have no further worry about the growth. His wife's father had died from malignant melanoma a year after reassurance by his physician that he had removed a "benign" tumor. Her traumatic experience, unknown to the physician, led her to distrust the prognosis and live in terrified anticipation of her husband's demise. Therefore, it is extremely useful to ask each family member to discuss expectations about the anticipated course and outcome.

Progressive diseases, such as Alzheimer's (3) or multiple sclerosis, involve a number of losses. For Alzheimer's disease, although the timing of these losses is ambiguous, their inevitability is not. Family members anticipate and grieve each milestone as it is passed. Under disabling conditions, at key illness transitions, family functions may need modifications in order to shift to a new phase of adaptation. Clinicians should be sensitive to nodal points that may require discontinuous change for the family. For instance, one family tried at all costs to preserve the deteriorating father's role functions in order to maintain its strong belief in mastery. As disability increased, successful adaptation required acceptance of that which could not be changed.

Both the "if" and "when" of death have enormous impact on the family. Most studies of anticipatory loss, by focusing on terminal illness, have not addressed the "if" aspect, and have narrowed the "when" aspect to the last phase. At diagnosis most illnesses are uncertain on both counts. The

only question is the *and when* anticipatory loss is salient. For instance, a patient's lung cancer is tremendous fear absence. Every appointment, every ambiguous apprehension. The loss often shatters a family surfaces their worst means that the best to eliminate the possibility second attempts are succeed. The ambiguity between remission and anticipatory loss includes 20 years after a vague symptom can fears of recurrence are

Relapsing Illness disease, can flare up. Stable or low-symptoms with periods of exacerbation related to anticipatory loss the front and back strained by both the tension between crisis and ongoing uncertainty. Anticipatory recurrence may life-threatening crises heart attack, hemiparesis may preoccupy a family those crises that can out warning, and recur avert catastrophe. (Standing diabetes, warning signs develop hypoglycemia, result in illness. She and her husband episode could endanger small children, as well.

Frequently, families against life-threatening disease, when a patient attack, the family reaction may shift to one to protect against

only question is the *degree* of uncertainty and *when* anticipatory loss will become salient. For instance, when a family member's lung cancer is in remission, there is tremendous fear about a possible recurrence. Every appointment with the physician, every ambiguous symptom brings apprehension. The loss of the first remission often shatters a family's hope for a cure and surfaces their worst fears. Medically, it means that the best treatment has failed to eliminate the possibility of early death, and second attempts are even less likely to succeed. The ambiguous boundary between remission and cure stokes embers of anticipatory loss indefinitely. Even for families 20 years after treatment for cancer, a vague symptom can immediately rekindle fears of recurrence and death.

Relapsing Illnesses, like asthma or heart disease, can flare up or cause sudden death. Stable or low-symptom periods alternate with periods of exacerbation so that issues related to anticipatory loss hover between the front and back burner. Families are strained by both the frequency of transition between crisis and noncrisis, and the ongoing uncertainty of when a life-threatening recurrence may strike. In the event of life-threatening crises (for example, angina/heart attack, hemophilia), anticipated loss may preoccupy a family. Families fear most those crises that can arise suddenly, without warning, and require immediate help to avert catastrophe. One woman with longstanding diabetes, abruptly and without warning signs developed severe episodes of hypoglycemia, resulting in loss of consciousness. She and her husband feared that an episode could endanger the safety of their small children, as well as end her life.

Frequently, family rules shift to protect against life-threatening situations. For instance, when a parent has had a heart attack, the family rule of open communication may shift to one of conflict avoidance to protect against a fatal recurrence. Be-

cause dangerous relapses can often be triggered by emotional upheaval, family members, particularly the well spouse, need explicit guidance about when recovery is sufficient to allow them to resume their normal disagreements, sexual life, and so on.

Relationship between Psychological and Physical Loss

Illnesses vary in terms of the balance between expected physical and psychological disability. Psychological loss involves a range of cognitive deficits that impair participation in family life. For disorders like severe stroke, psychological death occurs long before physical death (3, 4). Psychological loss is especially painful for a family because it is associated with progressive loss of intimacy. With physical decline, intimacy can suffer if the family withdraws emotionally. Premature distancing can occur when family members are torn between their wishes to sustain intimacy and "let go" emotionally of a member they expect to die. All relationships are predicated on the existential dilemma of choosing intimacy in the face of eventual separation/loss. Life-threatening illness heightens this universal form of anticipatory loss.

Boss and her colleagues (3, 4) describe endpoint situations where an ill member becomes psychologically dead to the family but remains physically alive, as in Alzheimer's disease. She asserts that uncertainties about the illness trajectory push families either to reorganize without the affected member, or to minimize the demands/existence of the illness and unrealistically expect the ill member to maintain usual family responsibilities. The timing of such a family decision depends both on the type, degree, and timing of anticipated loss, and on family stylistic variables such as cohesion and adaptability. For instance, a highly cohesive family may have less tolerance for ambiguity in the face of threatened loss. The need to maintain a cohesive family

unit can lead to prematurely extruding the ill member or to tenacious denial. It is useful to inquire about the ill member's continued participation in family rituals and to note communication patterns that bypass the ill member.

Illness Phases and Developmental Tasks

Some family developmental tasks in the initial *crisis phase* facilitate family coping with long-term anticipatory loss. Families must grieve the loss of customary life as a family unit prior to the illness. In progressive and life-threatening disorders, families must accept expected hardship and the possibility of further disability or death. A family must learn to live "in limbo" and grieve for the ambiguities they must endure over the long term. A family's efforts to resist acceptance of chronicity may express their wish to elude living with threatened loss or "death over their shoulder." Coping with threatened loss for an indeterminate period makes it much harder for a family to define present and future structural and emotional boundaries. Helping families establish functional patterns early on promotes later coping and adaptation to loss.

Facing loss can shatter a family's myth that life-threatening illnesses only happen to others. A family's loss of their sense of control can be one of the most debilitating experiences, leading to frenetic or immobilized behavior. In this period of intense uncertainty, families desperately need to reestablish a belief (even if illusory) in their control of the situation. Assisting families to prioritize tasks and encouraging direct actions such as gathering information about the illness and community resources is especially useful in helping them reestablish a sense of mastery. It is very helpful to promote patient and family involvement in self-help groups for particular disorders. When possible, educating families about significant versus minor physical symptoms can help avert unnecessary alarm.

Helping families distinguish the expected emotional roller coaster from their fears of craziness can lower reactivity at this stage.

The *chronic or "long-haul" phase* presents different dilemmas for families. With caregiving demands, exhaustion and ambivalence are common as financial and emotional resources become depleted. The emotional tide of anticipation can shift from a fear to a wish for death, fraught with enormous guilt and shame that is often not discussed. Clinicians need to distinguish between normative ambivalence that arises in the context of an extended ordeal versus preexisting conflict in the relationship that has become heightened in the face of possible loss. For long-term disorders, customary patterns of intimacy for couples become skewed by discrepancies between the ill member and well spouse/caretaker. Emotions often remain underground and contribute to "survivor guilt." As one young husband lamented about his wife's cancer, "It was hard enough two years ago to absorb that, even if Ann was cured, her radiation treatment would make pregnancy impossible. Now I find it unbearable that her continued slow, losing battle with cancer makes it impossible to go for our dreams like other couples our age." Psychoeducational family interventions that normalize such emotions related to threatened loss can help prevent cycles of blame, shame, and guilt.

Medical care for life-threatening illnesses is often provided in specialty clinics, where patients and families dealing with similar disorders may develop significant relationships, even in the clinic waiting area. Progression, relapse, or death of another patient can trigger fears of "Will I (we) be next" and deflate family morale. It is useful for clinicians to inquire about such contacts and offer family consultations.

The boundary between the chronic and the *terminal phase*, when death is no longer an "if" but an inevitability, is often ambigu-

ous. Once in the terminal question that remains time to prepare. Medical the imperative of a "turned" philosophy lay these "natural" transitions possible to induce a transition for cancer. Such interventions designed be difficult to distinguish attempts to comfort a medical training tends to avoid communication to avoid about the prognosis uncertainty. This "wait" often generates height ambiguity that confuse stage of the illness, as i

Mr. and Mrs. L were readmitted at rehospitalization for 10-years duration, because sudden refusal to visit hospital. Three prior attempts had not worked. This time a new physician and a specialist family had never openly discussed possibility of death. The doctor needed change feel worse and thought but her physician made "doing well" and had untried treatments (which recognized as longshots) oncologist revealed that continued, aggressive be undermined by agreement with the family. The doctor's physician blocked stage of anticipatory hours before her death coma, that the physician with the family the dying.

When families are faced with anticipatory loss in the final phase, quality as much as quantity becomes a priority. (

uous. Once in the terminal phase, the only question that remains is the amount of time to prepare. Medical technology and the imperative of a "leave-no-stone-unturned" philosophy often reverse or delay these "natural" transitions. It is now possible to induce a third or fourth remission for cancer. Such persistent medical interventions designed to prolong life can be difficult to distinguish from caregiving attempts to comfort a dying patient. Also, medical training tends to promote ambiguous communication to families, to be cautious about the prognosis, or not to admit uncertainty. This "wait-and-see" attitude often generates heightened anxiety and ambiguity that confuses a family about the stage of the illness, as in the following case:

Mr. and Mrs. L were referred for consultation at rehospitalization for Mrs. L's lymphoma of 10-years duration, because of their daughter's sudden refusal to visit her mother in the hospital. Three prior recurrences had been easily treated. This time a number of attempts had not worked. With a highly optimistic physician and a stable illness course, the family had never openly discussed the possibility of death. The daughter's behavior signaled a needed change. Mrs. L continued to feel worse and thought she might be dying, but her physician maintained that she was "doing well" and had a number of as yet untried treatments (which the consultant recognized as longshots). Discussion with the oncologist revealed his steadfast belief in continued, aggressive treatment that would be undermined by any discussion of death with the family. The family's loyal belief in their physician blocked transition to a final stage of anticipatory grief. It was only 48 hours before her death, when Mrs. L was in a coma, that the physician agreed to discuss with the family the fact that Mrs. L was dying.

When families are coping with anticipatory loss in the final phase of an illness, the *quality* as much as the quantity of time becomes a priority. Clinicians need to ex-

plore a family's fears about the process of dying as well as the loss itself. The anticipation of a family member's increasing pain and suffering is often of even more concern than death. This is especially common in longstanding progressive disorders when the anticipation of death has been rehearsed many times. Reassurance early on about effective means of pain control, and informed discussion with the family as to the ill member's wishes about life-saving heroics, can alleviate a major source of anguish.

In the terminal phase, families typically are depleted from their protracted efforts to save a member's life. Clinicians need to help patient and family accept the ultimate hopelessness of the situation and the transition from curative to palliative care. This transition is fraught with possibilities for blame, shame, and guilt. The family may blame the medical team for failing to provide a cure, especially if physicians had earlier given an overly optimistic prognosis. The patient and family members may blame themselves or one another for having lost their battle with threatened loss. This is particularly true for families guided by a strong sense of personal responsibility and control, as in the following case:

Jeff (age 30) had metastatic cancer for 2 years and now was terminally ill. He was fiercely independent, professionally successful, and had vowed to cure himself, unlike his father, a "failure" who had been divorced by his mother, and who later had committed suicide. When Jeff developed brain metastases and became demented and unmanageable at home, his wife was left with no alternative but to place her husband in Hospice. She was burdened by intense guilt in assuming responsibility for his failed cure, and for the fact that he would die in an "institution," a sign of weakness like his father's. Couples therapy focused on these issues to unlink their sense of failure from the inevitability of death.

Clinicians can function as a guide for

families, helping them gently relinquish their prior hopes for cure, initiate a humane plan for palliative care, and instill hope by developing a pathway for the experience of death. Their task is to join with the family at a time when members are preoccupied with thoughts of a final separation.

In the terminal phase, the anticipation of the "when" of loss is narrowed to a day-to-day experience. Families may need assistance to redefine hope as present-focused rather than future-oriented. The patient and family need mutual understanding of unpredictable mood swings, and both need the courage and strength to "live in the moment." The patient hopes for compassion for unpredictable responses to pain and its relief, and not to be abandoned while still alive. Exhausted family members may need coaching that the dying member's effort to detach from the struggles of daily life is not rejection of the family or a rebuke of them for not having done enough. Clinicians now play a critical role in bridging the ever-widening gap between the patient and family. They can help family members to stay involved with the patient while pacing themselves for the final separation. Once death's imminence has been accepted by patients and families, clinicians can more openly deal with practical arrangements, such as funeral and will, and unfinished relationship issues. The family's dilemma is in certain respects isomorphic with the clinician's involvement in a time-limited form of therapy, needing to set immediate objectives and planned termination. They learn both to expect and not need another visit to accomplish goals.

Patients live in a world of diminishing concerns that center on control of pain and suffering, and hopes for having meaningful person(s) with them in their fading hours. The family's task is to share final moments and then to experience being left behind. There may be shame owing to a sense of

abandonment or relief at the termination of a burden or complicated relationship. There is tremendous variation among families and cultures as to tolerance and experience with saying goodbye. Clinicians need to be mindful of the wide range of normative responses in helping families through this process.

THE FAMILY LIFE CYCLE

A family's experience of threatened loss can best be understood through a life-cycle perspective, particularly transgenerational encounters with threatened/actual loss and timing of life-threatening illness within the individual and family life cycles (36, 38).

The Past: Transgenerational Issues

Genogram information related to prior family encounters with death, disability, threatened loss, and living with ambiguity are particularly important (17, 24, 36, 47). It is useful to track patterns of coping to prior situations of anticipated loss. In addition to illness events, asking about family experiences with other forms of uncertainty or loss such as poverty, divorce, violence, abandonment, or dangerous occupations (for example, military, law enforcement) provides valuable information about family hardiness in the face of adversity. Historical inquiry can clarify differences among family members in terms of areas of knowledge and inexperience, and expected sense of competence or helplessness in the present encounter with anticipated loss. Bowlby (6) has described the powerful impact early life experiences with attachment and loss have in predicting later difficulty with loss.

A history of unresolved, traumatic, or unexpected loss may generate catastrophic fear when one is confronted with threatened loss. This may be expressed in overprotectiveness toward the ill member or other family members, or in distancing and cut-off. One man who had lost his first wife to

breast cancer, star divorced from his s of her diagnosis cancer, despite th case. The risks o have been emphas a history of bein tracted illness ca could never again such an ordeal.

Present and Future Cycle

Anticipatory losses depending or future family tives. The impact system's oscillati periods of high far childrearing, and more family sepa with adolescents o For instance, a fan old daughter when brain tumor that shift gears to pull t

On-Time Versus C

The onset of ser late adulthood, wl ing, the integration own personal an anticipation of dea sal tasks (17, 21, disabling or life-t curs earlier, it is chronological and time, spouse and t cial preparation a later, as peers a losses. The ill mer to feel robbed o normal life span couples, the threa that it occurs sim childrearing and c are forced to col

breast cancer, started an affair and filed for divorce from his second wife within weeks of her diagnosis and surgery for breast cancer, despite the good prognosis in her case. The risks of "unfinished business" have been emphasized for sudden loss. Yet a history of being a caregiver in a protracted illness can leave fears that one could never again endure *the process* of such an ordeal.

Present and Future Timing with the Life Cycle

Anticipatory loss poses different complications depending upon its fit with current or future family developmental imperatives. The impact will vary with a family system's oscillation between centripetal periods of high family cohesion, as in early childrearing, and centrifugal periods of more family separateness, as in families with adolescents or young adults (1, 10). For instance, a family launching a 20-year-old daughter when she develops a disabling brain tumor that may prove fatal, must shift gears to pull together.

On-Time Versus Off-Time

The onset of serious illness is expected in late adulthood, when the quest for meaning, the integration and acceptance of one's own personal and family life, and the anticipation of death are normative universal tasks (17, 21, 22, 26, 36, 47). When a disabling or life-threatening disorder occurs earlier, it is "out of phase" in both chronological and social time. When off-time, spouse and family lack the psychosocial preparation and rehearsal that occurs later, as peers are experiencing similar losses. The ill member and family are likely to feel robbed of their expectation of a normal life span. In the case of young couples, the threat of loss is out of phase in that it occurs simultaneously with hopes of childrearing and career development. They are forced to confront prematurely life's

painful fact of intimacy in the face of eventual loss. Although for both spouses a serious illness breaks through denial of death and the promise of a full life span, preparation for disability and death is not on the horizon for the well spouse. The hard fact is that the family life cycle with the ill spouse will be severely altered and possibly abbreviated. As one young woman whose husband had metastatic cancer confided, "As long as Jim has cancer we have no future." Suffering is compounded for couples when peers distance themselves because they want to avoid having to envision the possibility of loss of their own spouse or child. These issues heighten discrepancies between the well and ill spouse and isolate the family.

Life-Cycle Transition Periods

In all life cycle models (7, 11, 21), developmental transitions involve beginnings and endings, as in births, young-adult launching, retirement, divorce, and death. Commonly, preoccupations about death, life's limits, and anticipation of separation and loss surface at such times. The diagnosis of a serious illness superimposes the illness life cycle onto that of the individual and family. One of the family's primary developmental tasks is to accommodate to the anticipation of further disability and possibly untimely death (36). Families in life-cycle transitions may be more vulnerable to the emotional upheaval generated by anticipatory loss associated with illness. For example, suppose a family is in the stage of launching a young adult when the father has a serious heart attack. The threat of the father's death may more heavily influence young adult members in transition to alter their life decisions in ways that compromise their own independent strivings.

With long-term threatened loss, as families move through normative life-cycle transitions, there may be a resurgence of prior feelings of anticipatory loss families thought

were "worked through." Also, at times of transition, developmental tasks of the next life stage may need to be altered, delayed, or given up if they are unrealistic or impossible to achieve. At each transition, intense grieving can occur over opportunities and experiences that may have been anticipated but must now be relinquished in a more final way. Family members often need to grieve the loss of future hopes and dreams. For instance, when a mother learns of her daughter's diagnosis with a terminal form of cancer, she must grieve the loss of anticipated experiences ranging from school graduations, the daughter's wedding, and her own grandparenthood. Clinicians should inquire about losses related to future life stages and explore options for alternative positive experiences.

Issues Related to Childhood Versus Adult Onset Illness

Threatened loss will impact families in new ways as they encounter developmental tasks at each stage of the life cycle. Such differences can be illustrated by examining timing issues in childhood versus adult-onset disorders as they affect the marital life cycle.

Childhood-Onset, Congenital, and Inherited Disorders: With such disorders, a child's socialization and belief system are shaped by continual interplay of developmental milestones with limitations and future risks of the illness. With many inherited disorders, family beliefs about mastery and the rules for social interaction are shaped over generations to synchronize with anticipatory loss (37). For example, with hemophilia, life-threatening bleeding episodes can be triggered by trauma, intense affect, or extended periods of stress. Because the possibility of sudden death is ever present, parents often teach affected children a finely tuned form of mastery over their bodies that is juxtaposed with fear of social interaction. Emotions are carefully monitored in the interest of self-

preservation. Anticipation of loss guides this interweaving of belief system and developmental processes.

For hereditary or childhood-onset disorders, the developmental experience with threatened loss is brought to adult relationships. Couples develop their relationship with the factor of possible loss overtly acknowledged or covertly overshadowing their commitment. It is important for clinicians to promote communication about the impact of possible disability and premature death on such areas as childrearing, career, and divisions of labor so that the couple can develop the flexibility necessary to adapt to the added strains of a life-threatening illness.

In long-term illnesses, such as diabetes and hemophilia, concerns about future loss become embedded in life-cycle planning in more subtle and covert ways, as illustrated in the following case:

Greg, a 45-year-old man with life-long hemophilia, was referred for severe depression. Extensive disability required his using crutches to walk. He had been divorced 3 years earlier, and his only daughter had just left home for college. Evaluation revealed that his mother's family had a 200-year history of hemophilia, involving scores of cases. A brother had died in childhood after a traumatic injury, and only one member with hemophilia had lived beyond age 50. When asked about how he had conceived his life from childhood, he stated that he had felt if he could survive the higher risks of trauma in childhood (his brother being a vivid reminder), that he had enough time to marry, raise children; but, given the statistics and his lengthy family history, life beyond 45 seemed unlikely. After 40, he began to view his life as "pre-dead." He had no vision or plans for life beyond 50 except in anticipation of death.

This case demonstrates how someone can structure their entire life cycle to conform to an expectation of disability and death at a particular life phase. The timing

of Greg's divorce vaguely conscious from having to deal with the burden and dying over the end of the mother's launching left depression and suicide his hopeless outlook both the potential loss becoming a need for a prevention. Greg had a version that was inevitable and terrible and of uncertain away process accelerated a point in his intervention that transgenerational personal illness indicated the time of intervention could help a way that acknowledge disability and early include meaningful relationships within a context of taint.

Adult Onset

Serious illness in a couple's relationship is often a foundation of their relationship. For well-functioning relationships, onset occurs later in life. If strains are counter to the relationship base. If exist prior to the illness, loss will more likely pull them farther apart.

The type of illness in response to threats of disability or a disease that subsequently remains disabled with diabetes according to negative outcomes of socialization. In the

of Greg's divorce coincided with an only vaguely conscious plan to spare his wife from having to deal with his becoming a burden and dying, and gave him control over the end of the relationship. His daughter's launching left him alone with his own depression and suicidal thoughts reflecting his hopeless outlook. The case highlights both the potential danger of anticipatory loss becoming a runaway process and the need for a preventive clinical framework. Greg had a version of anticipatory loss that was inevitable and timed, rather than possible and of uncertain timing. Also, the runaway process accelerated at the most vulnerable point in his life cycle. An earlier intervention that took stock of how his transgenerational experience influenced his personal illness timeline could have predicted the time of highest risk. Early intervention could help plan for life after 40 in a way that acknowledged the possibility of disability and early death but did not preclude meaningful life goals and relationships within a context of heightened uncertainty.

Adult Onset

Serious illness that occurs early in a couple's relationship is particularly stressful because they are still forming the foundation of their long-term relationship. For well-functioning couples, if disease-onset occurs later in the family life cycle, strains are counterbalanced by a firmer relationship base. If dysfunctional patterns exist prior to the illness, then the threat of loss will more likely drive the couple farther apart.

The type of illness and timeframe of anticipated loss influence how a couple responds to threats to their life plans. With an illness such as diabetes, the possibility of disability or a shortened lifespan frequently remains distant. Often the person with diabetes accommodates to uncertain negative outcomes through denial and minimization. In the process of forming an

intimate relationship, the well partner will need to be educated about diabetes. The ability of the partner with diabetes to inform the well spouse can be blocked by fears about deterioration, abandonment, and death, which are sensitive, loaded subjects for both partners. Often issues related to anticipatory loss become obscured in pronouncements like, "It's my illness and I'll handle it myself."

Another common nodal point occurs with a couple's decision about having children. The couple must consider risks of pregnancy complications for both an ill mother and the unborn child. Other fears include: 1) genetic transmission to offspring who will carry the burdens of anticipatory loss; 2) anticipation of loss of a "dream child" who may contract the illness at some point; 3) anticipation of illness complications that would interfere with effective parenting; 4) fears that the ill spouse might not survive to rear children to adulthood; and 5) associated financial and psychosocial burdens for the surviving/well spouse.

BELIEF SYSTEMS

In the face of possible loss, creating a meaning for an illness that preserves a sense of competency is a primary task for a family (31, 33). In this regard, a family's beliefs about what and who can influence the course of events is fundamental. Whether a family views the locus of control over health/illness as internal, in the hands of powerful others, or as a matter of chance, will affect how they interpret illness events, their health-seeking behaviors, and their involvements in caregiving (20, 37, 46).

Clinicians should evaluate family members' ideas about what caused an illness and their beliefs about what might influence the course or outcome. Beliefs that invoke blame, shame, or guilt block a normalizing process for the family. They are sufficiently toxic that, unless resolved, almost invariably preclude establishing a functional family-illness system. In the con-

text of a life-threatening illness, the blamed family member is implicitly held accountable for negligence or even potential murder if the patient dies. Decisions about treatment can become tension-filled when every new stage of loss escalates the cycle of blame or guilt. A mother who feels blamed by her husband for their son's leukemia may be less able to stop low-probability experimental treatment than the angry, blaming husband. For a family, ambiguities blur what behaviors can affect the odds of a tragic outcome, increasing the likelihood of blaming attributions whenever disease progression can be linked to errors of omission or commission. It is crucial for clinicians to help families obtain clearer medical prognoses and management guidelines. In my clinical experience, in situations of threatened loss, women are more likely than men to be the target of attributions involving blame, shame, or guilt, because of societal role expectations that they have the primary caretaker responsibilities for children, husband, aging parents, and extended family.

For childhood disorders, parents and siblings (especially those close in age to the ill child and when rivalry is strong) are at heightened risk of guilt. They may feel guilty for their being spared physical suffering and threatened death. Parents ruminate about possible negligence as a causal factor. For some members, especially siblings, this feeling can be expressed as a general somatic preoccupation or catastrophic fear of suffering the same fate. A child whose apparent influenza turns out to be leukemia, can trigger family panic if any other member shows the mildest respiratory symptoms. Family members may become overprotective of all their children. In other cases, guilt can surface in self-destructive behaviors (for example, alcoholism, recklessness).

In my clinical experience, families with the strongest, at times extreme, beliefs

about personal responsibility, and those with the most severely dysfunctional patterns tend to overemphasize psychosocial factors in the cause or outcome of an illness. For highly internal locus-of-control families, a belief in personal responsibility guides all facets of life, including "high-stake" situations of threatened loss. A relative lack of acknowledgment of "outrageous fortune" as a factor in an illness can create a powerful nidus for blame, shame, and guilt. For such a family, disability or death implies a failure of will or effort. Anticipatory loss becomes loaded with a second life-versus-death struggle: that of willpower and, possibly, the family's belief system. This sort of family will tend to hold on tenaciously to an ill member (32). Families guided by an externally oriented belief system centered on "fate," risk premature extrusion and grieving for the ill member.

Making peace with self, family, and world is a fundamental task in coping with threatened loss, especially in the terminal phase. Several kinds of beliefs complicate this normative process. Foremost, unresolved issues of blame, shame, or guilt seriously compromise movement toward closure and acceptance. Second, some families' beliefs about mastery are rigidly defined as an ability to control the biological unfolding and outcome of an illness. Rather, a more flexible definition of competence involves active participation in the overall process. To sustain a family value in personal control during a progressive or terminal phase of an illness, participation in a successful process of letting go needs to replace mastery over biology. The difference between a family experiencing a loss with a sense of competency versus defeat is connected to this kind of flexibility in its belief system. Clinicians need to be mindful that families with the strongest and most rigid beliefs about personal responsibility may function very well during earlier stages of threatened loss, but are extremely vulnerable if

an illness progresses "We understand going to try and be distinguished from thing."

Larger System Value

Historically, pre-middle-class values achievement and mastery that especially promote probability and effort as a necessity. From national psychology (42) to internalize and individual or family can interact powerfully for a family facing consequences of a disability and death with a profound sense of failure. This negative experience can alter a generation. Clinicians against advocating philosophy that the loss cost the family took on the illness.

These cultural values the orientation toward dominates our health professional training. In situations, the anticipations of failure tend to tendency either to patients and their relentless quest for training needs to both the technology (34). This will promote are helpful in the domains have failed. guard against blaming family for not do patient.

an illness progresses. An attitude that conveys "We understand the risks, and we're going to try and beat this thing" needs to be distinguished from "We have to beat this thing."

Larger System Values

Historically, prevailing American, male, middle-class values emphasize individual achievement and mastery. We live in an era that especially promotes personal responsibility and effort as the road out of adversity. From national policy-making to popular psychology (42, 43), there is a tendency to internalize and localize problems in the individual or family. This societal value can interact powerfully with belief systems for a family facing threatened loss. The consequences of a "losing" battle with disability and death can become infused with a profound sense of public shame and failure. This negatively interpreted experience can alter a family's paradigm for generations. Clinicians need to guard against advocating too strongly a philosophy that the loss could be prevented if only the family took enough responsibility for the illness.

These cultural attitudes dovetail with the orientation toward saving lives that dominates our health-care system and professional training. For most health professionals, the anticipation of loss holds attributions of failure that contribute to their tendency either to withdraw from dying patients and their families or pursue a relentless quest for a cure. Professional training needs to emphasize the value of both the technological and caregiving roles (34). This will promote interventions that are helpful in the dying process when treatments have failed, and will help clinicians guard against blaming themselves or the family for not doing enough to save a patient.

Societal Stigma: The Example of AIDS

AIDS dramatically illustrates how the process of family coping with anticipatory loss and bereavement is severely compromised by societal stigma. The beliefs/metaphors attached to AIDS (44) suggest that a restoration of health can only occur after a "moral cleansing" and proper atonement for immorality. Thus, larger system attitudes that victimize families can rival unresolved family problems as a potential cause of interminable grief linked to family guilt or shame. Threatened loss is too often experienced in a context of secrecy that fosters isolation in the face of an ignominious death. Clinicians can help to remove such blocks, to promote positive rituals, and facilitate community support for patients and their families.

CONCLUSION

Overemphasis on anticipatory loss can itself become emotionally disabling if not counterbalanced by ways to harness that experience to improve the quality of life. In this regard, clinicians can be extremely helpful in assisting families to achieve a healthy balance. For illnesses with long-range risks, families can maintain mastery in the face of uncertainty by enhancing the following capacities: 1) acknowledge the possibility of loss, 2) sustain hope, 3) build flexibility into family life-cycle planning that conserves and adjusts major goals (for example, childrearing) and circumvents the forces of uncertainty. Clinicians can help families agree under what conditions further family discussion is useful, and who would be appropriate to include.

In situations of anticipatory loss, we must be cautious about judging the relative usefulness of positive illusions, minimization, or repression versus direct confrontation with and acceptance of painful realities. In many clinical situations both are needed, and the skilled clinician must thread the needle supporting both the use-

fulness of exaggerated hope and the need for treatment to control the illness or a new complication. From a life-cycle perspective, illness, individual, or family transitions are critical times to examine issues of threatened loss and weigh them in light of other developmental considerations. Open discussion and shared decision making at these junctures will help prevent later blame-guilt cycles if loss occurs. A young adult whose father has cancer in remission may have difficulty leaving home partly out of fear of never seeing the ill parent again. Promoting frank discussion of feelings between parents and their young adults can be useful. Furthermore, there is greater incentive and importance for a family to confront the realities of an illness when preventive action or medical treatment can affect the outcome.

On the other hand, most of us cannot tolerate an unrelenting encounter with loss. There is a need for mental and physical respite. Taylor (45) has described the normal, healthy need for positive illusions, and its importance in successful coping and adaptation. The healthy use of minimization or selective focus on the positive, timely uses of humor, should be distinguished from the traditional view of defenses like denial, regarded as pathological.

A brush with death provides an opportunity to confront catastrophic fears about loss. This can lead to family members' developing a better appreciation and perspective on life that results in clearer priorities. Active creation of opportunities can replace procrastination and passive waiting for the "right moment." Threatened loss, by emphasizing life's fragility and preciousness, provides families with an opportunity to heal unresolved issues and develop more immediate, caring relationships. For illnesses in a more advanced stage, clinicians should help families emphasize quality of life by defining goals that are attainable

more immediately and that enrich their everyday lives.

Recent writings (18) in the family therapy field have underscored the lack of rituals for many families dealing with loss. Threatened loss often heightens awareness that each family gathering and ritual may be the last together. Clinicians can help families dealing with threatened loss by promoting the timely creation and use of rituals of celebration and inclusion. A family reunion can invigorate a family and serve to coalesce its healing energies to support the ill member and key caretakers. In the context of threatened loss, traditional celebrations offer an opportunity to affirm and improve *all* family relationships. Emotionally distant and cut-off members can be reconnected to family life.

Finally, clinicians working with these families need to consider their own experiences and feelings about loss. Such factors as our transgenerational and family history of threatened or actual loss, our health beliefs, and our current life-cycle stage, will influence our ability to work effectively with families facing loss.

Fears about our own vulnerability are easily triggered when working with families coping with off-time illnesses. This is especially likely if the patient and family are at the same stage of the life cycle as the therapist. Self-awareness is particularly important if one has the same disorder or is at high risk of illnesses involving loss (for example, a strong family history of cancer or heart disease). Because these situations are so compelling, clinicians who work with a family for an extended period tend to shape their hopes and beliefs to fit with those of the family. This can lead to excessive optimism and forgetting that loss is really possible. Finally, our own unresolved issues related to actual or threatened losses and fears about our own mortality can lead to maintaining excessive emotional distance, avoiding important, often painful

discussions related to becoming overinvolved in the family. As we come to realize our ability to control and work through losses, we can work through the excruciating dilemma of living with loss.

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