

## **Parental illness and disability: a family systems framework**

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Coping with the strains and uncertainties of parental illness and disability can be a monumental challenge. The Family Systems-Illness Model offers a psychosocial map to address this challenge and make the inevitable strains more manageable. Attending to the longitudinal psychosocial pattern of a condition within a multigenerational, life cycle and belief system context can provide the kind of structure – a common language that facilitates collaborative, creative problem solving and quality of life for families where a parent has a serious health problem. Some of the major challenges in families facing parental illness are addressed.

Families enter the world of illness and disability without a psychosocial map. Clinical attention to parenting and illness has primarily focused on situations of an ill or disabled child, while parental illness has remained a largely unexplored territory. Appropriate clinical intervention, family education, and national policies to support these families is severely lacking.

To master the challenges families need, first, a psychosocial understanding of the condition in systems terms. This means learning the expected pattern of practical and emotional demands over the course of the disorder, including a timeline for disease-related developmental tasks associated with different phases of the disorder as it unfolds. Second, they need to gain a systemic understanding of themselves as a functional unit. Third, an appreciation of individual, couple and family life cycles helps them to stay attuned to the changing fit between the demands of a chronic disorder and emerging developmental issues for the family unit and each member. Finally, families need to understand the beliefs and multigenerational

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legacies that guide their constructions of meanings about health problems and their relationship to caregiving systems.

How can we organize this large and complex landscape in a manner useful to families and clinical practice? This paper provides an overview of a conceptual framework that can serve as a guide for families coping with parental illness or disability.

### **Overview of Family Systems-Illness Model**

With chronic disorders, a biopsychosocial orientation should be conceptualized from a systems perspective, with the family as the interactive focal point. To enable us to think systemically about the interface of any chronic condition and the family, the model casts the disorder itself in systems terms according to its pattern of psychosocial demands over time. The unfolding of a chronic disorder is viewed in developmental context, involving the intertwining of three evolutionary threads: the illness, individual and family life cycles.

The Family Systems-Illness Model (Rolland, 1984, 1987a, 1987b, 1990, 1994a, 1998) provides a useful framework for evaluation, formulation and intervention with families dealing with chronic illness

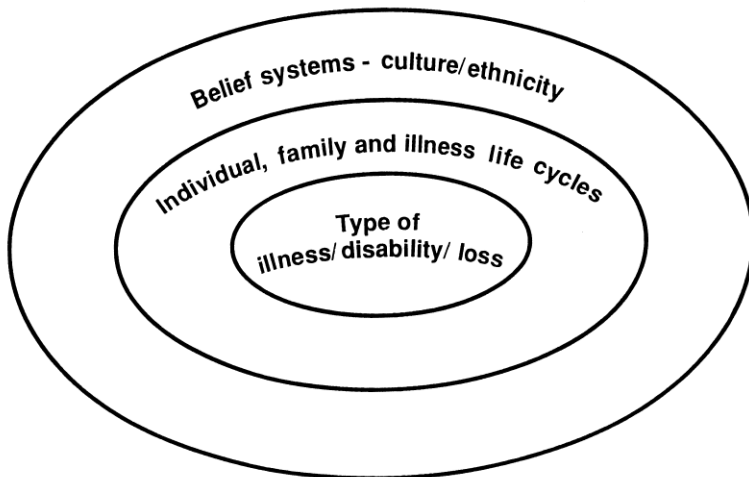


Figure 1. The Family Systems-Illness Model

*Source:* Rolland, 1994a

and disability. The model is based on a strength-oriented perspective viewing family relationships as a resource, and emphasizing the possibilities for resilience and growth, not just their liabilities and risks (Walsh, 1996, 1998).

The model addresses three dimensions: (1) 'psychosocial types' of illness and disability; (2) major developmental phases in their natural history; and (3) key family system variables. It attends to the expected psychosocial demands of a disorder through its various phases, family systems dynamics that emphasize family and individual life cycles, multigenerational patterns, and belief systems (including influences of culture, ethnicity and gender) (Figure 1). The model emphasizes the goodness of fit between the psychosocial demands of the disorder and the strengths and vulnerabilities of a family.

### **Psychosocial types of illness**

Standard disease classification is based on purely biological criteria, clustered to establish a medical diagnosis and treatment plan, rather than the psychosocial demands on patients and their families. I have proposed a different classification schema that provides a better link between the biological and psychosocial worlds, clarifying the relationship between chronic illness and the family (Rolland, 1984, 1987, 1994a). Chronic conditions can be grouped according to key biological similarities and differences with distinct psychosocial demands for the patient and family. This typology defines meaningful and useful categories with similar psychosocial demands for a wide array of chronic illnesses affecting individuals across the life span. Illness patterning can vary in terms of *onset*, *course*, *outcome*, *incapacitation* and the *level of uncertainty* about its trajectory.

#### *Onset*

Illnesses can be divided into those which have either an acute onset, such as strokes, or gradual onset, such as Huntington's Disease. For acute onset illnesses, affective and practical changes are compressed into a short time, requiring more rapid mobilization of crisis management skills. Families need to be helped to tolerate highly charged emotional situations, exchange roles flexibly, problem solve efficiently and utilize outside resources.

### Course

The course of chronic diseases can take three general trajectories: progressive, constant or relapsing/episodic. With a *progressive* disease such as multiple sclerosis, disability worsens in a stepwise or gradual way. The family must live with perpetual symptoms and the prospect of continual role change as the disease progresses. Family members experience growing strain and exhaustion, with few periods of relief from demands of the illness, and by new caretaking and financial challenges over time.

With a *constant* course illness an initial event is followed by a stable biological course, as after a single heart attack or spinal cord injury. Typically, after an initial period of recovery, there persists a clear-cut deficit, or limitation. The family is faced with a semi-permanent 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.

A *relapsing* or *episodic* course illness, for example, disc problems and asthma, is distinguished by the alternation of stable low symptom periods with periods of flare-up or exacerbation. Families are strained by both the frequency of transitions between crisis and non-crisis, and the ongoing uncertainty of *when* a recurrence will occur. This requires family flexibility to alternate between two forms of family organization. The wide psychological discrepancy between periods of normalcy versus flare-up is particularly taxing.

### Outcome

The extent to which a chronic illness leads to death or shortens one's life span has a profound psychosocial impact. The continuum ranges from illnesses that do not typically affect the life span, such as arthritis to those that are progressive and usually fatal, such as metastatic cancer. An intermediate, more unpredictable category includes both illnesses that shorten the life span such as heart disease, and those with the possibility of sudden death such as haemophilia. Most crucial factors are family members' *initial expectation* of whether a disease is likely to cause death and the degree to which they experience anticipatory loss (Rolland, 1990).

### *Incapacitation*

Disability can involve impairment of cognition (e.g. Alzheimer's disease), sensation (e.g. blindness), movement (e.g. stroke with paralysis), stamina (e.g. heart disease), disfiguring conditions (e.g. mastectomy), and those associated with social stigma (e.g. AIDS). The extent, kind, and timing of incapacitation will affect the degree of family stress. For instance, the combined cognitive and motor deficits caused by a major stroke necessitate greater family role reallocation than the others. With some illnesses, like stroke, disability is often worst at the beginning. 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.

The *predictability* of an illness, and the degree of uncertainty about the specific way or rate at which it unfolds, overlays all other variables. For illnesses with highly unpredictable courses, such as multiple sclerosis, family coping and future planning are hindered by anticipatory anxiety and ambiguity about what is to come and how much time they have before the condition worsens. Families able to put long-term uncertainty into perspective are best prepared to avoid the risks of exhaustion and dysfunction.

By combining the kinds of onset, course, outcome and incapacitation, and level of uncertainty, we generate a typology that clusters illnesses according to similarities and differences in patterns that pose differing psychosocial demands.

### **Time phases of illness**

Too often discussions of 'coping with cancer' or 'managing disability' approach illness as a static state, and fail to appreciate the dynamic unfolding of illness process over time. The concept of time phases provides a way for clinicians to think longitudinally and to understand chronic illness as an ongoing process with landmarks, transitions and changing demands. Each phase has its own psychosocial developmental tasks that require significantly different family strengths, attitudes or changes from a family. To capture the core psychosocial themes in the natural history of chronic disorders, three major phases can be described: *crisis*, *chronic*, and *terminal* (Figure 2).

The *crisis* phase includes any symptomatic period before diagnosis

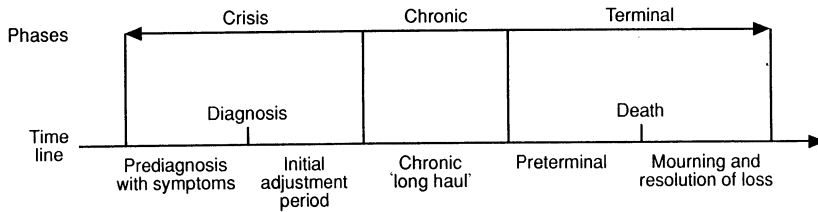


Figure 2. Time line and phases of illness

Source: Rolland, 1994a.

and the initial period of readjustment and treatment plan. This initial period of socialization to chronic illness holds a number of key developmental tasks for the ill parent and family (Moos, 1984), which include: creating a meaning for the disorder that preserves a sense of mastery; grieving the loss of the pre-illness family identity; acceptance of permanency of the condition; undergoing short-term crisis reorganization, while developing family flexibility in the face of uncertainty and threatened loss; learning to live with illness-related symptoms and treatments; and forging a working relationship with professionals and institutional settings.

During this initial crisis period health professionals have enormous influence over a family's sense of competence and approach to accomplishing these developmental tasks. Initial meetings and advice given at the time of diagnosis can be thought of as a 'framing event'. Because family members are so vulnerable at this point, clinicians need to be extremely sensitive in their interactions and aware of messages conveyed by their behaviour. Who is included or excluded (e.g. the patient) from a discussion can be interpreted by the family as a message conveying how a family should communicate for the duration of the illness. For instance, if a clinician meets parents separately from adolescents to give them information about the illness diagnosis and prognosis, the parents may assume they are being instructed implicitly to protect their adolescents from any discussion of the illness.

The *chronic* phase can be marked by constancy, progression or episodic change. It has been referred to as 'the long haul', or 'day-to-day living with chronic illness' phase. Salient issues include: pacing and avoiding burnout, relationship skews between the patient and other family members, sustaining autonomy and preserving or

redefining individual and family developmental goals within the constraints of the illness; and sustaining intimacy in the face of threatened loss. Family effort to maintain the semblance of a normal life is a key task of this period. If the illness is fatal, this is a time of 'living in limbo'. For certain highly debilitating but not clearly fatal illnesses, such as a massive stroke, the family can feel saddled with an exhausting problem 'without end'. Encouraging maximal autonomy for *all* family members in the face of protracted adversity helps to offset these trapped, helpless feelings.

In the *terminal* phase of an illness the inevitability of death becomes apparent and dominates family life. The family must cope with issues of separation, death, mourning and family reorganization beyond the loss (Walsh and McGoldrick, 1991). Families adapt best to this phase when they are able to shift their view of mastery from controlling the illness to a successful process of 'letting go'. Optimal coping involves emotional openness as well as dealing with the myriad practical tasks. Families can be helped to see this phase as an opportunity to share precious time together, acknowledge the impending loss, deal with unfinished business, say goodbyes, and begin the process of family reorganization. The parents and key family members need to decide about such things as a living will, involvement of hospice, wishes about a funeral, and provision for the surviving parent and children.

Critical *transition periods* link the three time phases, when families re-evaluate the fit of their previous life structure with new illness-related developmental demands. Unfinished business can complicate or block movement forward. Families can become permanently frozen in an adaptive structure that has outlived its utility (Penn, 1983). For example, the usefulness of pulling together in the crisis phase can become maladaptive and stifling in a long chronic phase.

In sum, the time phases (crisis, chronic and terminal) can be considered as broad developmental periods in the natural history of chronic disease. Each period has certain basic tasks independent of the type of illness. Each 'type' of illness has specific supplementary tasks. The psychosocial demands of any condition can be thought about in relation to each phase of the disorder, and to different components of family functioning (e.g. communication, problem solving, role flexibility). This framework can guide periodic family consultations and 'psychosocial checkups' as salient issues and priorities surface and change over time. At a larger systems level, it provides a lens for clinicians to analyse shifts in relationships between

healthcare institutions, professionals, the patient and family members.

It also informs evaluation of general functioning and illness-specific family dynamics such as: the interface of the illness with individual and family development; the family's multigenerational history of coping with illness, loss and other adversity; the family's health/illness belief system; the meaning of the illness to the family; social support and use of community resources; and the family's capacity to manage illness-related crises or perform home-based medical care.

### **Interface of individual, family and illness development**

When a condition is chronic, the dimension of time becomes a central reference point. The family and each member face the formidable challenge of focusing simultaneously on the present and the future, on mastering the practical and emotional tasks of the immediate situation while charting a course for dealing with the complexities and uncertainties of their problem in an unknown future. This task is facilitated by placing the unfolding chronic condition in a developmental framework that integrates three evolutionary threads: the illness, the individual and the family life cycles (Rolland, 1987a, 1994a). It is essential to consider the interaction of individual and family development. Because an illness is part of a person's life, it will affect the development of that person and various family members in distinct ways depending on a number of factors, including age of onset of the illness, the core commitments in the affected person and each family member's life at that time, and the stage of the family life cycle. Life cycle models can facilitate thinking proactively about the timing and nature of strains on the family unit and each member over the course of a chronic condition.

Illness, individual and family development have in common the notion of phases, each with its own developmental tasks. Carter and McGoldrick (1998) have divided the family life cycle into six phases, where marker events (e.g. marriage, birth of first child, adolescence, children leaving home) herald the transition from one phase to the next. In addition, the family life cycle can be viewed as oscillating between phases where family developmental tasks require intense bonding or relatively higher cohesion, as in early childrearing, versus phases such as families with adolescents, during



which the external family boundary is loosened, often emphasizing personal identity and autonomy (Combrinck-Graham, 1985). Levinson (1978, 1986), in his description of individual adult development, describes how individuals' and families' life structures can move between periods of life structure transition and building/stability. Transition periods are sometimes the most vulnerable because previous individual, family and illness life structures are reappraised in the light of new developmental tasks that may require major discontinuous change rather than minor alterations (Hoffman, 1989). The primary goal of a life structure-building/maintaining period is to form a life structure and enrich life within it based on the key choices which an individual/family made during the preceding transition period.

These unifying concepts provide a base to think about the fit among illness, individual and family development. Each phase in these three kinds of life cycle poses tasks and challenges that move through periods of being more or less in sync with each other. In my model, I distinguish: (1) the phases of the family life cycle, particularly the kind and degree of cohesion required; (2) the alternation of transition and life structure-building/maintaining periods in the family and individual life cycles; and (3) periods of higher and lower psychosocial demands over the course of a chronic illness or disability.

Generally, illness and disability tend to push individual and family developmental processes towards transition and increased cohesion. The degree of these effects varies enormously in different types and phases of health problems. In clinical assessment, basic questions are: What is the fit between the psychosocial demands of a condition and family and individual life structures and developmental tasks at a particular point in the life cycle? How will this fit change as the course of the illness unfolds in relation to the family life cycle and the development of each member?

When a parent develops a chronic disease during the childrearing phases of the life cycle, a family's ability to stay on course is most severely taxed. For more serious conditions, the impact of the illness is like the addition of a new infant member, one with 'special needs' that will compete with those of the real children for potentially scarce family resources that are diminished by parental loss. Moreover, in two-parent families, the well parent must juggle child-rearing demands with caregiving to their spouse. In psychosocially milder health problems, efficient reallocation of roles may suffice.

## **Health beliefs**

At the time of a medical diagnosis, a primary developmental challenge for a family is to create a meaning for the illness experience that promotes a sense of competency and mastery (Kleinman, 1988; Rolland, 1994a, 1998; Wright *et al.*, 1996; Wynne *et al.*, 1992). In the initial crisis phase, it is useful for clinicians to enquire about key beliefs that shape families' illness narratives and coping strategies. This means gaining an understanding of a family's overall belief system, of family beliefs brought into play by the strains of a chronic disorder over time, and of meanings associated with the condition itself. A thorough assessment includes tracking beliefs about: (1) normality; (2) the mind-body relationship; (3) control and mastery; (4) optimism/pessimism; (5) rules of communication; (6) meanings attached by a family, ethnic group, religion or wider culture to symptoms (e.g. chronic pain) (Griffith and Griffith, 1994), types of illness (e.g. life-threatening), or specific diseases (e.g. AIDS); (7) assumptions about what caused an illness and what will influence its course and outcome; (8) multigenerational legacies, stories and scripts (Byng-Hall, 1988) that shape a family's health beliefs and response to illness (Seaburn *et al.*, 1992); (9) ethnic, cultural and gender-related beliefs about expected roles and behaviour (McGoldrick *et al.*, 1996); (10) family rituals, particularly related to healing and loss (Imber-Black, 1991); and (11) anticipated nodal points in the individual, family and illness life cycles when health beliefs will be strained or need to shift. A clinician should also consider the fit of health beliefs within the family and its various sub-systems (including spouse/partner, extended family) and between the family and the healthcare system and wider culture (Rolland, 1998).

## **Major challenges in families with parental illness**

Using this overview of the Family Systems-Illness Model, I will address some key family and couples issues specific to the impact of a parent's illness.

As with any other life challenge, illness and disability offer the opportunity for growth of all family relationships and the risk of deterioration and distance. The disorder is an uninvited guest that must be incorporated into family life. The type of condition will

determine the demandingness of this 'intruder'. A severe disability such as a spinal cord injury always impinges on a family. A cancer in remission may not necessitate day-to-day pragmatic issues, but the undercurrent of threatened loss can still affect all aspects of their lives.

### **Life cycle issues**

When illness strikes a parent in the childrearing phase of the life cycle, this crisis is more challenging because it occurs 'off-time' in terms of chronological and social expectation and parenting needs of children. Particularly with health problems that occur 'off-time' or earlier in the life cycle, serious strains can develop because the possibilities for meeting normal individual and family goals can become very skewed. In a preventive manner, I find it useful to think about both the timing of onset of the illness in the life cycles and the major life cycle transitions looming ahead. Typically, with conditions that involve threatened loss, major transitions will bring latent concerns back to the surface. At life cycle transitions, families generally need to openly and more directly discuss issues of threatened loss and how the disorder may require added flexibility or revisions of normative developmental goals. The following case illustrates this point:

The father, a carpenter and primary financial supporter of his family, had emphysema and recently suffered a mild heart attack. At first, his level of impairment was mild and stable, allowing him to continue part-time work. Because their children were all teenagers, his wife was able to take a part-time job to help maintain financial stability. The oldest son, aged 15, seemed relatively unaffected. Two years later, the father experienced a second more life-threatening heart attack and became totally disabled. His son, now 17, had dreams of going away to college. The spectre of financial hardship and the perceived need for a 'man in the family' created a serious dilemma of choice for the son and the family. The son's grades plummeted and he began to drink heavily, leading his school to refer him to the local mental health clinic.

In this case, there was 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 incapacitating and progressive course, the adolescent son's transition to early adulthood, and the

family's transition from the living with teenagers to launching young adults stage. Issues of threatened loss also surface. The son expressed fears that if he left home he might never see his father alive again. In other situations, adolescents distance from an ill parent in pseudo-autonomy, minimizing the need for parenting or impact of loss. They may stay at friends' houses or leave home early in order to get away from the illness. These adolescents may later carry guilt about normative 'selfishness' in adolescence, when a parent was sick and needy and they did not do enough. This dynamic can be further complicated if there is normative father/son conflict in adolescence and where a father's death at that stage leaves a son with unresolved issues that get played out in repeated conflict with male authorities and self-destructive acts (e.g. drinking, being fired after conflict with boss).

As this case vividly illustrates, individual, family or illness developmental transitions are times when open discussion of issues of loss or threatened loss can help to prevent crises. This example also shows the significance of the type of illness. An illness that was less disabling, progressive and life-threatening might have interfered less with this young man's separation from his family of origin.

If one partner has disabilities, shared role responsibilities for child-rearing need to be discussed in the context of real limitations and changing phases of the various life cycles. The following case illustrates:

Jim, aged 45, and Nancy, aged 48, have been married for fifteen years, and have an 11-year-old daughter, Janet. Jim has had multiple sclerosis for twenty-eight years, marked by gradual progression. He uses a walker to get around their apartment and a wheelchair outside the home. His coordination is markedly impaired, particularly fine motor skills. When fatigued or physically ill, his disability worsens. He is legally blind but can read and work on a computer enhanced for the physically impaired. His keen intellect, warm personality and strong will are unaffected. Nancy works full-time as a paralegal.

When Jim and Nancy became parents, they were not prepared for the transition from a lower stress family system of two relatively autonomous adults to the considerable demands of an inwardly focused, cohesive family unit with an infant. They believed in mutual and equitable parenting. During prenatal visits, the physician minimized the limitations which the illness might pose. As Nancy said, 'I too desperately wanted to preserve the glossy picture of raising a child together, so I didn't question things,' but added, 'Jim's limits, that normally don't come into play, got accentuated.' For instance, their baby had a period of colic in the first few months. The

paediatrician told Nancy that their baby was not getting enough food, and suggested that timely and efficient bottle-feeding was needed. Jim could feed Janet, but, because of his coordination difficulties he was slow. The paediatrician's definition of the problem created a dilemma: Jim's disability would prevent 'efficient' feeding and exacerbate the colic. Jim argued with Nancy that 'I can do it fine, my own way'. Nancy was torn between her need to be a good mother and her wish to protect her husband from disappointment. Jim felt inadequate, and their glossy picture of mutual infant care was tarnished. This experience highlighted a painful transition in the context of a chronic illness that they had mastered in the previous phase of the life cycle.

However, Jim learned to anticipate complexities related to his daughter's future development. For instance, he realized that his visual impairment would make it difficult to read bedtime stories to Janet. Instead, he began a ritual of making up bedtime stories that side-stepped his disability while preserving special time with his daughter before sleep.

For Nancy and Jim, heightened skew in the relationship was inevitable by having a child. Given the limits imposed by his illness, she had to carry the bulk of home-making, breadwinning and childcare responsibilities. It has been crucial to the well-being of family relationships that they actively seek ways to maintain a balance, so that Nancy does not carry responsibility for all parts of family life and develop resentment. Although Jim may be limited in his physical capabilities, he can handle any of the family's emotional needs, and is a tender and loving father. To keep a balance has required open, direct communication and a willingness to challenge gender-role stereotypes.

As Janet has matured and become more autonomous, Jim's disabilities interfere less frequently. Since the age of 5, she has increasingly helped with certain aspects of caregiving and household chores, thereby diminishing the strain on her parents. Furthermore, as Janet approaches adolescence, the parents are sensitive enough to respond to questions and her growing level of understanding about the uncertainties and possible future losses related to her father's disease.

## **Family communication**

### *Strengthening couple relationships*

The foundation for family adaptation to parental health problems is heavily dependent upon how spouses or partners incorporate an illness or disability into their relationship. In general, how well parents handle communication and skew in their own relationship is a strong predictor of children's adaptation. I will highlight several

areas that strongly affect parenting dynamics. To master the challenges of chronic conditions, couples must meet the complexities of maintaining a viable, balanced mutual relationship with the dynamics of patient-caretaker; and to cope with the uncertainties of planning and achieving normative life goals in the face of threatened loss. A serious health problem challenges couples' relationship rules and established boundaries.

There is no love without loss (Lifton, 1975). Couples' willingness to address this basic fact is a key to healthy adaptation. Couples can learn to use the awareness that all relationships are time-limited to live more fully in the present, and enjoy what they have now despite imperfections, rather than postpone fulfilment based on an illusion of infinite time.

### *Couple communication*

A long-term health problem powerfully challenges a couple's communication skills. Sensitive, open, direct communication about a range of issues is essential to coping well with chronic disorders. A couple's comfort zone and degree of openness will drive the rest of the system. Levels of personal disclosure that may have been functional prior to a disorder often become insufficient. Identifying and normalizing difficult feelings, establishing clear illness boundaries and rebalancing relationship skews all require effective communication.

Important discussions for couples include: understanding the illness and its psychosocial demands over time; beliefs about who or what caused the disorder and what can affect its course; how to live with threatened loss; personal and relationship priorities; the roles of patient and caregiver; ways to maintain a balanced, mutual relationship; and wills and advance directives concerning a possible terminal phase. One couple facing the husband's terminal cancer found the quality of their relationship enormously enhanced by early discussions about limiting life-saving efforts in the terminal phase. It gave the husband a sense of control over his death that reduced unbearable uncertainties and enabled him to focus his energies on living. It reduced fears for his wife about having to make future life and death decisions while not knowing his true feelings. Given the unfolding of the condition and changes in personal and parenting priorities over time, no single discussion should be considered a 'once-and-for-all' decision. For instance,

one couple had agreed not to prolong the dying process if the cancer became terminal. However, when faced with that situation, the parents reconsidered the decision in order to try to prolong the father's life another year until their son had graduated from high school.

Communication is commonly blocked by tentativeness in exploring new territory, concerns about hurting the ill parent or worsening the condition, or fears that relationships will not survive openness in certain areas. If certain topics are going to be restricted, parents should consider the consequences and reach a mutual decision.

Shameful thoughts and feelings are a major impediment to openness. Normalizing such feelings as intense anger, ambivalence, death wishes or escape fantasies can help to counteract secrecy, shame and well partner/survivor guilt. Family members need to be reassured that having intense and seemingly irrational emotions is natural in situations of illness and disability. The ill person may in a moment of desperation or intense pain wish someone else could be in their shoes. One woman with intractable pain yelled at her husband, 'I wish you could feel what this pain is like for five minutes.' At a moment of exhaustion and exasperation a caregiver may yell, 'I wish you would die now, so I can get on with my life!' This may be expressed towards a partner in ways that under other circumstances would be labelled as pathologically cruel. In these situations, heightened emotions and reactivity are inevitable. Family members function best when they are able to tolerate strong emotions and can forgive each other for hurtful comments made in the heat of the moment. Both parents and children ought to feel entitled to have and express their own intense emotions. At the same time, they may need help in not becoming reactive to each other's outbursts. Clinicians can help family members to redirect their anger from the ill parent to the illness. Externalization is helpful in this regard (White and Epston, 1990).

### **Parent-child communication**

Parents struggle over how much, if anything, their children should be told about a serious medical condition. Obviously, with more visible disorders (e.g. spinal cord injury) or where home treatments are noticeable (home dialysis), some form of explanation is necessary. Unqualified reassurance and blocking of further communication

about a major illness can cause serious emotional problems for a child. This may often manifest as a symptom that is ascribed to an unrelated issue, as in the following case.

Mrs L called the child psychiatry clinic concerned that her daughter Janice, aged 5, had been compulsively masturbating for the past three months, and that this was an indication of sexual abuse. When the child assessment revealed no evidence of abuse, the therapist enquired about other recent stressful events in the family. Only at that point did the mother reveal that her husband had had most of his stomach removed nine months earlier due to stomach cancer, and, three months ago, he had been re-hospitalized for further tests that proved 'inconclusive'. She reported that after his surgery they had told the children only that 'Daddy had a tummy ache, so the doctors removed Daddy's stomach so he'd feel better.'

Mrs L was concerned about her husband's health, stating, 'I think about it constantly!' When asked if they ever talked together about these concerns, Mrs L replied, 'After the surgery he was adamant that he did not want ever to talk about it. He went back to work almost immediately, and has insisted everything is fine.' When asked whether this medical crisis had any impact on the children, especially Janice, Mrs L responded, 'Well, she doesn't tell me about any worries. But now that you ask, at dinner every night, when we say grace, Janice prays out loud for daddy's stomach.' No one in the family ever commented on this. Based on the assessment that Janice's compulsive behaviour was linked to worry and confusion about her father's cancer in the context of closed family communication, a family intervention focused on opening communication patterns in the system resulted in a rapid resolution of the presenting problem.

This case highlights the uncanny ability of children to sense danger and threat of loss despite secretive communication. Ill parents need to confront their own vulnerability and sense of devastation that they may not see their children into adulthood. A parent, unable to express his or her own fears of loss, may project that worry on to a child through overprotective behaviour. We must not underestimate a child's resilience and need to learn about, understand and come to terms with adversity. Children need to know they will be secure and cared for no matter what happens. Blocked communication only fuels anxieties. When age-appropriate open communication is established, parents can inform children about realistic and exaggerated fears about a parent's condition. Catastrophic fears and fantasies held silently are far more destructive than realistic concerns that are aired and relieved by and with parents.



### **Rebalancing family skews**

When a serious health problem becomes part of a family, inevitable skews develop (Rolland, 1994b). I would like to highlight several that most strongly affect childrearing dynamics.

#### *My problem versus our challenge*

When illness strikes, it is important to help couples to see 'the problem' as both partners' and, by extension, the family's dilemma/challenge. If 'the problem' of living with illness or disability is defined as the exclusive domain of the ill parent's, then serious imbalances with power and control often develop, leading to resentment, guilt, distancing and general erosion of intimacy. Significant couple and family interactions become skewed by this premise. When the condition becomes defined as the affected parent's problem, he or she may exert power and control through the role of 'sick person', or may feel deficient, underfunctioning and at fault because of a chronic disorder. Helping a family to view the affected parent's condition as 'our challenge' helps to prevent development of other family skews and promotes resiliency.

Most framing events foster a fundamental split between the patient, well partner and ultimately other family members. The highly technological medical focus on the patient's condition near diagnosis promotes a definition of the problem as the ill partner's. Optimal couple and family functioning depends largely on the ability of both parents to gain a shared, psychosocial perspective.

If the condition is framed as a family issue, psychosocial impact is defined in terms that acknowledge physical and psychosocial burdens and include the illness-related roles of all family members. Parents and children are more empowered when they can see their predicament in a balanced way as a family issue shared by all members.

By introducing this concept of 'our challenge' early on, clinicians provide an opportunity for parents to examine cultural and multigenerational beliefs about the rights and privileges of ill and well family members. In one situation, a well spouse came from a family where she saw her mother tend to her father's chronic respiratory disease while never asking anything from him in return. She and her sisters were instructed not to bother their father with their needs. For this woman, powerful multigenerational scripts dictated

extremely skewed gender-based role relations of a daughter and wife with the caregiver/well parent's burden going unacknowledged. Chronic illness belonged to the husband, with other female family members accommodating as selfless caregivers. The psychosocial experience and needs of all family members were subordinated to the biological condition of the father. This also highlights the importance of asking both parents about multigenerational family legacies and learned differences concerning illness, loss and crisis.

### *Boundary illness and family*

A major risk for parents and children is that their relationships become completely identified with an illness or disability. This is particularly difficult as families emerge from the initial crisis phase, which may have been medically intensive and necessitated a period of immersion in learning about the condition. When the illness takes over the entire fabric of family relationships, living 'a normal life' is externalized outside the family with 'illness' inside it. To help counteract this split, therapists can help family members to learn how to circumscribe the time and space occupied by the condition in their relationships. There are some simple strategies to keep the illness in its place. Where possible, parents should delineate times that are devoted to self-care and caregiving or discussing the illness, and times that are preserved for other activities and discussions that don't get overrun by the disorder.

Families need explicit guidance about when an initial 'near miss' life-threatening crisis has passed. For instance, with sudden-onset conditions such as heart attacks, an initial period of reduced emotional and physical stress for the affected parent may be necessary, but may also leave families with fears about another life-threatening episode. In such situations, family members may ritualistically cling to medical advice intended for a time-limited period. The freedom to talk about emotional issues or express anger are often blocked indefinitely to avoid a lethal recurrence. Escalating destructive interactions can easily happen.

### *Triangulation*

Another major risk is that a chronic disorder can become a powerful third member in a couple's relationship. In some relationships

governed by unresolved struggles for control, an illness or disability can serve as a powerful ally for the ill parent to gain the upper hand. For one couple with longstanding gender-related struggles, the wife's chronic back pain legitimized her demands for her spouse to do more of the parenting. The danger with a health problem serving as the rationale for change is that change often remains dependent on continued symptoms or the threat of loss. In these situations, children are more likely to become triangulated into the parents' conflict and/or learn maladaptive ways of using physical and psychosomatic symptoms as a way to gain attention or control. When families see parental illness as a collective challenge, this helps to counteract the dangers of triangulation where the disorder may be used by the ill member or caregiver against other family members around issues of control, entitlement or sacrifice.

#### *Caregiver-spousal/parental roles*

One of the most challenging issues for parents is how to maintain a functionally balanced mutual relationship, given the skews inherent in long-term caregiving and dependency needs of the ill partner. Early education about physical and emotional demands of a condition over time offers a psychosocial map that clarifies the degree and timing of caregiving needs. Professional guidelines as to which aspects of caregiving the affected parent can do unassisted are extremely helpful. In addition, clinicians can help the well parent to express limits beyond which outside family or professional help will be needed.

Conditions that involve cognitive impairment are often the most devastating, because intimacy is changed for ever. As one daughter put it in describing her father who had a stroke, 'Daddy's not the same person anymore.' The old relationship had been lost. This is often a profound crisis when new relationships have to be figured out, and where the possibilities for closeness are often very different, limited and skewed. Family members often struggle with ambivalent feelings about whether to continue to invest in a revised version of closeness or redefine the relationship in basically caregiving terms. A therapist can counteract either/or thinking by highlighting areas of spousal and parent-child relationships that may be unaffected.

*Role shifts*

Dramatic role shifts can also present problems for parents. In one situation, the husband had sustained an injury that required a long period of rehabilitation at home before he could return to work. Until the injury, this couple had had clearly defined, traditional roles where he supported the family financially and she raised the children, an arrangement that had been satisfying for both. When he remained at home, he became involved with childcare and parenting functions that had previously been his wife's territory. His style of parenting was more authoritarian than hers. Intense conflict and struggles over control and turf emerged as previous differences in parenting surfaced more forcefully.

*Children as caregivers*

Families coping with chronic conditions need to apply flexible definitions of normal involvement of children in caregiving and childrearing responsibilities. Understanding the pattern of psychosocial demands of a condition over time can help parents to decide about the realistic need to include their children in helping with caregiving and other family responsibilities. Flexibly moving in and out of such roles is greatly facilitated when the whole family understands the trajectory of a disorder. In relapsing conditions, where disability is intermittent, it is easier and less risky to assign responsibilities to older children, because the time frame of such role changes can be bounded by the duration of a flare-up. Knowing the timing of treatments and length of recovery reduces ambiguity and facilitates family caregiving that may involve children. In progressive, life-threatening, and more severely disabling conditions a parent's limitations are always present and increasing. In these situations, it is more likely that a lasting shift in role functions may occur and create a permanent parentified child. Conditions that involve cognitive impairment are perhaps the most difficult, because a child experiences the parent reduced to a confused and childlike state. With a fatal illness such as metastatic cancer, older children may adaptively need to gradually assume certain responsibilities in order to buffer the transition to life without one parent.

Key tasks involve the determination of role shifts and sensitivity to issues of fairness, and balancing competing priorities of a child's or an adolescent's development. Questions raised include: Have parents

realistically assessed the need for role reallocation? In two-parent households, have the parents first considered changing their balance of responsibilities? In families governed by strict and traditional gender-defined roles, this step may be bypassed. If a mother becomes ill, responsibilities may be automatically transferred to an oldest daughter without first examining how father and brothers might do their part. If a father becomes disabled, an oldest son may feel pressured to drop out of high school and find work to support the family rather than see his mother take a job outside the home to which his father is now confined. In such situations, clinicians can facilitate parents' renegotiation of rigid role definitions to fit the demands of a chronic disorder and encourage more flexible gender roles. Fathers may develop enhanced nurturing abilities and closeness with their children when a mother's illness crisis brings out untapped potential.

When children must assume new responsibilities, families should be encouraged to discuss issues of balance, flexibility and shared responsibility. Balance means that if a child needs to provide caregiving to a parent, it is important for the ill parent to still remain a parent to the child. One mother with a spinal cord injury maintained her role as listener and adviser to her children despite needing extensive caregiving support from them. To the extent possible, added responsibilities should be shared equitably among all family members. It is important not to split role assignments so that one child is designated as responsible and the others remain free of responsibility. Burdens should be shared and altered flexibly as natural shifts in demands on different siblings occur. This reduces the chance of resentment and promotes family problem solving that will maximally preserve each member's individual developmental goals. It also counteracts splits of good/bad child among siblings when they are helped to share caregiving challenges as a team. Establishing time boundaries for added responsibilities, especially caregiving, will counteract a child's feelings of being trapped and permanently stuck in a parental role.

### *Crisis and rescue procedures*

Children should be familiar with how to handle crisis or rescue procedures in an emergency. Frequently, parents do not include children in these matters out of a desire to protect them and minimize anxiety. This can often have the opposite effect. One 7-year-old child, whose mother had diabetes, was terrified that he would be

caught alone with his mother when she had a hypoglycemic reaction and might die while he stood by helplessly. In fact, this child had seen his mother in an extreme reaction accompanied by an epileptic seizure, saved by an older teenage son's intervention. This younger child needed to learn what caused hypoglycemia; how to give sugary foods; how, in an emergency, to administer an injection of glucose; how to protect his mother if she had a seizure; and how to place an emergency telephone call and report a medical crisis. By comparison, most children with diabetes give self-injections by his age.

A child's familiarity with crisis procedures needs to be distinguished from a loss of 'childhood'. Again, most useful is parents' mindfulness to maintaining boundaries between times of medical crisis that may necessitate a child temporarily assuming more adult roles and times when such sharing of responsibilities is unwarranted.

### **Extended family resources**

It is useful for clinicians to assess and facilitate mobilizing extended kin resources for the children. If grandparents and other extended family are nearby and healthy, they may be available to help. The extent of inclusion of an ill parent's own parents needs to be carefully considered in terms of the rebalance of power which this may imply. Such a solution may be inadvisable if it causes an adult to feel infantilized, overly dependent or dominated by a historically 'controlling' parent, who may also be seen by a spouse as an intrusive in-law. On the other hand, it may provide a second chance to form a satisfying relationship if members can rise to the occasion. One lone mother, in a year-long recovery from a serious accident, reluctantly allowed her mother to move into the household to cook and care for her and her children. This nurturing healed old wounds from having felt neglected in favour of her brother. Adults are often surprised that intergenerational relationships can change dramatically in mid- and later life. When families consider this option, I encourage full discussion of the implications by the parents separately, between the parents and the grandparents, and by the entire family unit.

### **Other challenges**

Seriously ill parents need to be careful about certain risks in relating to their children. Those with life-threatening illnesses, in

anticipation that they may suffer an untimely death, may push their children too quickly towards independence. Conversely, they might spoil a child out of guilt that they are not being a good enough parent or that they will not be alive for very long. This is especially common with disorders that require much self-care, so that the demands of the illness conflict with those of parenting. This may also occur when a parent's illness is hereditary and the affected parent experiences guilt because of the future suffering that their children may have to endure. Parents may overprotect their children out of fears that the world is an unsafe place. This pattern is most likely when an illness or disability is seen as having been caused by neglect or a victimizing experience.

In lone-parent and lower income households, these problems may be magnified. A parent may use a child as a sounding-board or a comforter if no one else is available, and, if disabled, may need to rely more on children to assume a wide range of responsibilities. In these situations, children are apt to be reluctant to 'burden' a lone parent with their own needs and therefore suppress them. Children may have particular fears about being orphaned. Thus it is important to assess potential involvement and support by a non-custodial parent and members of the extended family, including aunts, uncles and godparents.

In lower income households, severe financial strains may force an older child to drop out of school and go to work just to help the family survive. One second grader, caught for stealing food at a grocery store near school during lunchtime, said, 'My mommy is sick and needs food, so I bring her lunch every day.'

### **Belief systems**

Beliefs about normality, mind-body relationship and control, what caused an illness or can affect its course, meanings or narratives developed around a health problem, and cultural/ethnic or gender-related beliefs are particularly significant. Therapeutically, I am most interested in supporting beliefs that sustain hope and empower families instead of those that foster blame, shame or guilt.

Families adapt best when they can create a narrative about an illness or disability that is empowering, sustains hope, and affirms their relationship. To discover whether a family has a normative perspective, I urge clinicians to ask both parents how they think other average and healthy families would handle their situation.

Another critical issue for families is each member's beliefs about what caused or can affect the outcome of a condition. Beliefs that involve blame of oneself or another family member are particularly toxic. In the face of a life-threatening illness, children often worry that they caused their parent's condition. One daughter feared that her temperamental outbursts had caused her father's heart attack. In such a situation, she is holding herself psychologically accountable for potential murder if her father were to have a fatal recurrence. Occasionally, a parent may blame a child by saying, 'Your screaming and misbehaving gave me a heart attack.' Early intervention is vital in these situations, as these kinds of blaming beliefs are inevitably destructive.

## Conclusion

Living well with the strains and uncertainties of parental illness and disability can be a monumental challenge. The Family Systems-Illness Model offers a way to address this challenge and make the inevitable strains more manageable. Attending to the longitudinal psychosocial pattern of a condition within a multigenerational, life cycle and belief system context can provide this kind of structure – a common language that facilitates collaborative, creative problem solving and quality of life for families facing serious health problems.

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