

The Developmental Challenges of Chronic Illness

Helping Patients and Families Cope

Most families must face chronic illness in a family member at some time during the life cycle. Chronic illness is increasing in prevalence and has replaced acute illness as the major cause of morbidity and mortality in the United States (1). Half of all people over age 65 and one fourth of those between ages 45 and 65 are limited in their activities by at least one chronic condition (2). As the elderly population grows, this burden of chronic illness increases, and families must play an even greater role in their care. (See Chapter 13 on caring for the elderly.) The experience of chronic illness affects families in profound ways, and how well the family adapts to chronic illness can influence the course of the illness (3). This chapter presents a comprehensive psychoeducational approach to working with families with chronic physical illness, to assess their needs and assist them in coping with illness. (Other chapters deal with family-oriented approach to chronic mental illness including depression, Chapter 17, and alcohol abuse, Chapter 18.)

Families, not health care providers, are the primary caretakers for patients with chronic illness. They are the ones that help most with the physical demands of an illness, ranging from preparing special meals for a family member with heart disease, to assisting with insulin administration for a diabetic, to running a home dialysis machine. In addition, families are usually the major source of emotional and social support; someone to share the frustrations, discouragements, and despair of living with chronic illness.

Chronic illness affects all aspects of family life. Old and familiar patterns of family life are changed forever, shared activities are given up, and family roles and responsibilities must often change. Most patients

and their families cope well with the stresses and demands of chronic illness, and tend to pull together and become closer (4). Some families may become too close or enmeshed, by assuming too much responsibility and care for an ill member, they may inhibit his or her autonomy and independence. Other families may pull apart under the stress of chronic illness and even disintegrate through divorce (5), institutionalization, or death. The spouses of chronically ill patients often have as much subjective distress as the patients themselves (6). It is easy for health care providers focused on the "patient" to overlook the spouse's distress and not attend to their physical and emotional needs (7). The failure of health professionals to address the needs of family members as well as patients can lead to a downward cycle: the family becomes more distressed and is less able to respond to the needs of the patient, who may then deteriorate physically and emotionally, and put more stress and demands upon the family, leading finally to burnout of the family. By addressing the needs and stresses of the family as well as the patient, the physician can help promote the healthiest functioning of all concerned. This can be best done by establishing a partnership with the families and supporting them as coproviders of care.

Characteristics of Families with Chronic Illness

From their work with families with different chronic illnesses, Steinglass and his colleagues have described four common characteristics of these families (8):

1. **The illness and its demands tend to dominate family life, and other family needs are neglected.** This response is initially adaptive as the family copes with the crisis, but leads to family disruption over the long term.
2. **Family coalitions between the patient and one or more family members develop, or previous coalitions are intensified by the chronic illness.** For example, a mother may become overinvolved in the care of her ill child and the father may withdraw or be excluded (9).
3. **The family's coping response often becomes rigid, and the family fears that any change may adversely affect the family and their current adjustment.**
4. **Families tend to isolate themselves in coping with the illness demands.**

The primary task for families with chronic illness is to create a balance between the needs of the individual with the illness and those of the rest of the family. The following example illustrates some of the problems and challenges of coping with a serious chronic illness.

Jim Strong had not felt well since he was in his mid-twenties, but it was not until he was 32 and lost part of his vision in one eye, that the diagnosis of multiple sclerosis was made. He had attributed his chronic fatigue and depression to his dissatisfaction and stresses working as a machinist on an assembly line. His primary care physician had initially diagnosed his leg weakness and gait disturbance as a herniated lumbar disc. He and his 30-year-old wife, Harriet, had undergone sex therapy for his impotence. Although therapy helped their sexual relationship, his erections did not return. Their four and six year old boys did not understand what was happening to their father who no longer wrestled with them after work or carried them around on his shoulders. The youngest, Timmy, began having behavior problems at nursery school.

Jim and Harriet's relief at knowing what was "wrong" was balanced by the lack of effective treatment and poor prognosis. Over the next few years, Jim was in and out of the hospital with acute exacerbations of the illness. Initially he recovered from each new neurological deficit, and he and his family maintained hope that he would stabilize. However, gradually he became more disabled and had to quit his job when he could no longer safely work on the assembly line. Harriet returned to work as a librarian, and Jim stayed at home to care for the children after school. With reduced income and the loss of medical insurance from Jim's job, the family was forced to move out of their home and into a smaller apartment.

With time, family life revolved more and more around Jim's illness. There was no longer time or money for going out to movies or restaurants, and many of their friends stopped asking them over for meals. Jim was self-conscious about using a walker in public and stopped going out to the grocery store or to the children's school. Harriet worried constantly about Jim's health and encouraged him to rest as much as possible. At the same time she resented how little housework he did, and felt physically and emotionally burdened by all of her responsibilities. She began developing migraine headaches that occasionally incapacitated her.

This case illustrates many of the challenges of chronic illness and the importance of assessing the patient in the context of the family.

A careful assessment of the patient and the family and their adaptation to the chronic illness is crucial to helping all parties cope with the illness. This assessment occurs over many visits with the patient and family, but usually requires convening the entire family at least once. This family conference is useful at the time of the diagnosis of the illness, or during the initial hospitalization (see Chapter 21). Meeting with the entire family is also helpful early in the chronic phase of the illness, when the initial crisis is over, and the family has settled into the day to day demands of living with chronic illness.

From his work with chronically ill patients and their families, Rolland (10) has developed a clinically useful family systems model of chronic illness. We have organized our assessment of the illness and the family around this model.

Chronic Illness and Its Psychosocial Demands

Physicians are well trained in assessing and managing the biomedical aspects of chronic illness: monitoring blood sugar control, adjusting medication, identifying and treating complications, but are less well prepared to deal with the psychosocial aspects of illness. Each illness is viewed idiosyncratically with different kinds of stresses for each illness. Rolland's psychosocial typology of chronic illness organizes their similarities and allows for important distinctions across illnesses. The typology calls for an assessment of the following areas:

- 1. Onset: Did the illness begin suddenly or gradually?** Illnesses with acute onset such as strokes or spinal cord injuries require rapid mobilization of resources and put enormous acute stress on a family. Illnesses with gradual onset such as lupus or arthritis allow families more time to adapt, but may create great uncertainty and anxiety.
- 2. Course: Is the illness progressive, constant or relapsing?** For slowly progressive diseases such as chronic obstructive pulmonary disease or AIDS, there is a gradual increase in stress on the family with the need for continual adaptation and role changes. With constant course illnesses, such as strokes or amputations, the family attempts to cope with a stable change. Illnesses with relapses such as hemophilia or asthma require that the family shift back and forth from crisis orientation to chronic adaptation. These illnesses demand the most flexibility.
- 3. Prognosis: Is the illness rapidly fatal, does it shorten life span, or is there a risk of sudden death?** Obviously fatal illnesses, such as amyotrophic lateral sclerosis (ALS) or terminal cancer, require that the family cope with impending death. Illnesses where there is a risk of sudden death such as coronary artery disease add an additional stress of unpredictability and constant vigilance.
- 4. Disability: How severe are the handicaps and incapacitation associated with the illness?** The degree to which the disability affects the roles and responsibilities of the patient in the family will influence how the family adapts. A physically disabling illness in a man who works as a laborer will be much more difficult for both the patient and family to cope with than a similar disability in a school teacher. Loss of cognitive abilities (such as in dementia or some strokes) is one of the most difficult burdens for the family (11).

From using this assessment, one can quickly assess the likely stresses and demands that the family faces with a chronic illness. For example, because the onset of multiple sclerosis (MS) is often gradual, there may be confusion, anxiety and sometimes denial initially, and then a diagnosis is

for families is its unpredictability. Patients may do very well for months or years, and then there can be a sudden worsening which will later improve. The stepwise decline that commonly occurs in MS challenges the family over the long haul, and eventually many families become overburdened and cannot care for the patient at home. Other difficult aspects of the disease are the personality changes that occur in some patients. Spouses may describe the patient as "no longer the person I married." This loss of the patient's identity or personality makes coping with all the other demands of the illness particularly difficult.

Assessing Family Functioning and Health Beliefs

This section focuses on those aspects of the family that are particularly important to assess in caring for the chronically ill.

Family Development

1. Where is the family in the family life cycle? The normal developmental tasks of a family will influence and be influenced by chronic illness (12). The impact of serious illness of a parent will be very different depending upon whether the children are very young, adolescent, or adult. Illnesses that are completely unexpected or "out of phase" such as cancer in children or multiple sclerosis in young adult, are usually the most disruptive to normal family development and the most difficult to cope with.

2. How are the developmental tasks that the family is dealing with affecting the chronic illness and vice versa? The direction a family is moving in its life cycle, whether it is pulling together ("centripetal") as during the childbearing years, or pulling apart ("centrifugal"), as when children are leaving home (13), will influence on how it deals with chronic illness. If a chronic illness occurs when a family is in a centripetal phase of development, such as families with a chronically ill child, the additional pull of the illness may lead to enmeshment in which families overreact to each other and discourage personal autonomy (12). Minnichin and colleagues (14) have described psychosomatic families of children with diabetes, asthma and anorexia nervosa, in which an extreme form of this pattern of overinvolvement exacerbates the illness.

When a chronic illness occurs when a family is in a centrifugal period, such as adolescence, the care of the chronic illness can be particularly disruptive and conflict with normal development. The patient may be

adolescent" illness and has demonstrated how it can impede the adolescent's personal growth and individuation. At the next visit Dr. K explored the impact of Timmy's illness on family developmental issues.

Dr. K knew the Strong family well from being their family physician for ten years and delivering their two children. He knew that they had developed a strong marital relationship prior to having children, but had initially had some problems parenting their first child. Jim was very strict about discipline, just as his father had been with him, and Harriet tried to compensate by being very lenient. With some brief primary care counseling, they were both able to assume more balanced roles in disciplining.

After the multiple sclerosis was diagnosed, Jim and Harriet became preoccupied with Jim's health, and Timmy, the youngest son, responded by having behavioral problems both at nursery school and at home. Jim again felt that Harriet was too lenient with Timmy and became very strict and authoritarian. Timmy's behavior worsened until they brought him to Dr. K for help. In one session, Dr. K helped the parents find ways to pay special attention to both children in the midst of all the illness-related stresses. This reduced the need for either child to resort to misbehavior to get their parents' attention.

From his work with the Strong's, Dr. K learned how the demands of a chronic illness can compete with the developmental tasks of a healthy family with young children.

Family Strengths and Supports

1. What are the family's strengths and sources of support? Identifying and utilizing the strengths in families, helps the family and the health care provider feel a sense of control in managing the illness. Smilksteins' (16) acronym SCEEM (Social, Cultural, Educational, Economic, Medical) is a helpful way to remember potential sources of support for families.

2. What has helped the family to cope with crises in the past? Reviewing past crises helps identify what kinds of coping strategies have been used before and may be useful dealing with the illness.

3. How adaptable is the family to change? Has the family been able to make the necessary changes in role functioning with this illness? What are the signs of their ability to do so?

4. Does the family accept outsiders, especially health care providers, into the family to help? Some families close ranks around an ill member and are suspicious of health care providers, while other families become excessively dependent upon the health care system. This style may represent the family's way of accepting help or dealing with the illness. It may be the result of a previous experience with the

Dr. K met with the Strong's every three or four months to review Jim's medical condition and see how the family was doing. During an early session, Dr. K had the family list and discuss their strengths. These strengths were:

1. a loving and caring marital relationship
2. equal sharing of family responsibilities
3. flexibility in family roles
4. a small group of close friends
5. a supportive extended family, many of whom lived in the area
6. a good working relationship with health care professionals

Dr. K encouraged them to draw upon these strengths and support when they developed difficulties.

Family Health Beliefs

The family's beliefs about the illness, their sense of control over it, and their attitudes toward health professionals will strongly affect how they cope with the illness (17).

1. What does each family member think caused the illness? The family's beliefs about the etiology of the illness can have a powerful effect upon their response to the illness. These health beliefs are usually a combination of the family's medical knowledge about disease (e.g., an understanding of cardiac risk factors), the family's view of health and illness, and their cultural beliefs. Some common beliefs about the etiology of illness include:

- Fate or bad luck
- Blaming the individual who is ill: for not taking care of him or herself, (smoking, lack of exercise) or for misdeeds (an illegitimate birth, divorce).
- Blaming other family members: "Your drinking made me ill," "I get chest pain whenever we fight."
- Genes: "Cancer runs in our family."
- Religion: "It's God's will."

Health beliefs may be quite idiosyncratic and specific to the disease in question. Thus a woman may believe that illness in general is largely a matter of chance, but that her husband developed heart disease because of stress at work.

2. What do family members believe they or others can do to improve the patient's health? A family's sense of control or mastery of an illness may be quite different than their beliefs about its etiology. A family may believe that the illness is the result of past misdeeds, but that there is nothing they can do to control the illness; or that the illness occurred by chance, but the individual is responsible for maintaining health. Families will also have different beliefs

about how much influence the physician or medicine in general has on the illness. Some families will expect the physician to be responsible for the illness and even blame the physician when the illness is diagnosed or worsens.

After his diagnosis, Jim read extensively about multiple sclerosis, especially its etiology and treatment. He became especially concerned whether he had been exposed to heavy metals in his job. When a coworker also developed MS, he solicited Dr. K's help in getting an occupational health expert to study the plant he worked in.

Harriet became interested in dietary treatments for MS. For six months, Jim tried a gluten free diet. Although it was time consuming, expensive, and not always very tasty, the couple felt that at least they were doing something to try to get better. Although Dr. K informed them that there was no solid evidence that such a diet would help, he told them it could do no harm and was worth a try.

Multigenerational Patterns of Coping with Illness

How have previous generations responded to serious chronic physical or mental illness? The ways in which individuals and families cope with chronic illness is often passed down from one generation to another. There may be family myths, expectations, or rituals that surround illness and go back many years. An understanding of how previous generations have dealt with illness will help to predict the future adaptations. This information can be elicited by obtaining a family genogram oriented to illness and illness related events and behaviors. Although this can be done with the patient alone, he or she is often unaware of all the multigenerational patterns, so other family members' input can be valuable.

Obtaining an illness oriented genogram can be introduced by saying, "It would help me to learn more about your family history of illness, and how your family has coped with previous illnesses." Ask about all illnesses in the family going back at least three generations: how they were diagnosed, how the family reacted, what happened to the family member and the rest of the family. Look for repeating patterns, such as denial of the illness, over or underfunctioning of the ill person, and family coalitions that develop around the illness.

The Strong's' genogram revealed that Harriet's maternal grandfather had suffered a severe stroke in his early 30s and had been cared for by her grandmother for over 20 years. She had an excessively close relationship with her daughter, Harriet's mother, who did not leave home and get married until after her father died. Harriet feared that Jim would become similarly dependent upon her, and she did not want to become a martyr as her grandmother had. She also worried about the impact of Jim's illness on their children's

Other Stresses and Demands on the Family

What other kinds of stresses or strains is the family dealing with? A chronic illness is a major stress on families, but families commonly face numerous stresses simultaneously. Additional stressful life events will influence the family's ability to cope with the chronic illness. Ask about specific stressors including:

- recent deaths, hospitalizations, other serious illness
- marital distress or recent divorce
- financial or work problems, especially unemployment or the threat of unemployment
- recent moves; change in residence, job, schools

Even positive life events or normal life cycle changes can be quite stressful, such as a new baby, a recent marriage or a job promotion.

Shortly before Jim's MS was diagnosed, he was promoted at work to a supervisor on the assembly line. Although the job provided more income, it involved more responsibilities and required that he walk up and down the line, trouble shooting any problems that arose. As his illness progressed and he became more disabled, the job got more stressful and exhausting, until he could no longer safely do his work. Unfortunately, there were no sedentary jobs he could transfer to, so he was considered disabled and laid off.

Helping Families Cope with Chronic Illness: A Psychoeducational Approach

We base our family-oriented approach to chronic illness on the psychoeducational model (18). This approach assumes that patients and their families do their best to cope with the demands of chronic illness and have many, perhaps untapped, resources. It emphasizes these strengths rather than the deficits of families, and tries to use them to help chronically ill patients and their families. Families are viewed as partners in the treatment process.

The two key elements of this approach are education and psychological support. The education involves providing information about the illness and teaching specific skills in dealing with a chronic illness. The psychological support involves providing empathy, an opportunity to share feelings, and an assessment of how the family is coping, including referrals of families that are having serious difficulties to mental health professionals.

Families with chronic illness often feel blamed by themselves, friends and neighbors, or health professionals for the difficulties that they experience. Thus they often

unacceptable in light of the patient's suffering. Encouraging the honest discussion of feelings at a family conference can have a very powerful and therapeutic effect upon the patient and family.

Sometimes a single experience of sharing feelings in a safe environment allows families to open up and communicate emotional reactions that have been suppressed for years. Families who are either over or under-reactive to these feelings may need to be referred for family therapy.

When meeting with the family, the physician can encourage open communication about their experience of living with chronic illness. Some ways to facilitate this communication include:

- a. Ask directly about their experience. "What has it been like for all of you to deal with your mother's illness day after day and week after week?"
- b. Elicit and empathize with feelings associated with the family's specific problems concerning the illness. When a family member describes a problem, ask "That sounds pretty tough, how do you feel about having to face that every day?"
- c. Normalize feelings of anger, guilt, and depression. "Dealing with a chronic illness like this can be very difficult. Most families I have cared for feel a great deal of frustration and sadness about what's happened. What's it been like in your family?"
- d. Inquire about common emotional responses. "Jim, do you ever get angry at Harriet for being healthy and able to do the things you cannot?" or "Harriet, how often do you feel guilty about being healthy when your husband has been so ill?"
- e. Ask the patient or a family member what kind of feelings they have seen in other family members. "Jim, how has Harriet dealt with your illness?" "Who in this family is the most upset about Jim's illness?"
- f. Do not try to "cheer up" the patient or other family members; help family members accept the patient's feelings and share their own experiences.

Jim: I am so discouraged! None of these treatments seem to help at all, and I keep getting weaker and weaker. Sometimes I just want to give up and stop everything.

Harriet: Don't say that, Jim. You haven't had as many relapses since you've been on Cytosol, and your vision seems a bit better.
Dr. K: Harriet, it sounds like it's difficult for you to hear how discouraged Jim is at times about his illness.

Attempts to cheer up someone who is discouraged or depressed can make that person feel misunderstood and more alone and depressed. Families who are able to share their emotional responses to an illness are more likely to give and receive emotional support from each other.

first time within a family conference. This can have a powerful therapeutic effect and may stimulate the family to be more open at home. Patients and family members go through stages of dealing with chronic illness that are often similar to those dealing with death: shock, denial, anger, bargaining, grief, and acceptance. However, each family member may be at different stages in dealing with or accepting the illness. Some may deny aspects of the illness or be angry while others are grieving, and a family member may go back and forth between stages. Because of the personal demands of illness, and this can create conflicts. For the Strongs, Harriet's efforts to get Jim to look at the bright side of this illness were partly because she was still trying to deny the seriousness of the illness, while Jim was normalizing these different responses to the illness.

4. Facilitate the family's involvement in the care of the patient through negotiations with the patient. Most families would like to assist the patient in the care of his or her illness, but sometimes the difficulty negotiating an optimal plan. Physicians may recognize the family has become either over or underinvolved in the patient's care.

- a. Encourage all appropriate family members to learn specific skills involved in the care of the patient. It may be particularly useful to have the patient teach his or her family how to do certain tasks such as having a spouse draw up the insulin syringes and learn to give injections if the patient is sick or begins to lose vision. Even when the family members do not take over a task, teaching them about specific procedures provides a way to educate them and communicate about the illness. For example, having a colostomy patient demonstrate how to change the colostomy bag can help to normalize the disability.
- b. Have the patient tell other family members how they can help. Except when he or she is incompetent, the patient should remain in charge of the illness. Problems arise when family members try to decide what is best for the patient or try to help in ways that are intrusive to the patient. Negotiating how the family can help in a family meeting or in a routine visit when another family member is present.

Dr. K: Jim, it sounds like getting dressed in the morning can be quite difficult. Would you like Harriet's help with any of it?

Jim: Yeah, I guess so.
Dr. K: Harriet, would you be willing to help Jim in the morning when he gets dressed?
Harriet: Of course, I offer to help him every morning but he just snaps at me.
Jim: Well, I'm not an invalid!

Dr. K: Jim, what kind of things would you want Harriet to help you with?

Jim: She could start by not treating me like I'm an invalid . . .

Dr. K: Let's start with things she can do to help.

Jim: The one thing I have trouble with is putting on my ankle brace.

Dr. K: Would you like Harriet to help you with this?

Jim: Sure.

Dr. K: Harriet would you be willing to help with this?

HARRIET: Of course.

Dr. K: Is there anything else you'd like her to help with?

Jim: No, I can handle the rest.

Dr. K: Are there things you would prefer that Harriet not do for you?

Jim: Yes, I don't like her hovering around me asking if she can help me get dressed.

Dr. K: Harriet, would you be willing just to help Jim with his brace and let him dress the rest of himself, no matter how long it takes him, and only give additional help if he asks for it.

HARRIET: If that's what he wants.

Jim: That's what I want.

Dr. K: It is important for Jim to remain as independent as possible. You may help him the most by letting him ask for help when he needs it and not offering it at other times.

6. Help the family to develop an appropriate balance between the demands of the ill member and the need for further growth and development for the patient and other family members. Encourage the family to normalize family life as much as possible and only change those aspects of family life that must be altered. This can help to minimize the impact of the illness. For example, it is usually better to maintain family routines and rituals, such as mealtimes, birthdays, and holidays. Family members should be encouraged to pay attention to their own needs. Often family members will view this as being selfish ("How can I think about myself when he/she is so sick?"). It can be explained that taking care of one's own needs is necessary in order to be able to care for the ill family member. Sometimes patients will encourage other family members to do things for themselves.

Dr. K: Jim, in the process of helping you with your illness, do you think Harriet is taking good care of herself?

Jim: No, and I worry about that. She used to have lunch with her friends every Wednesday and now she comes home to check on me. I wish she wouldn't sacrifice those lunches.

The challenge for the family is to find an appropriate balance between caring for the ill member and caring for the family and to put the illness in its appropriate place in the family's life. Families need to continually reassess this balance. **Because of this balance, more families are developing involvement, more families are dealing**

with serious chronic illness would benefit from supportive family counseling, and the physician should offer this to all such families. However, some families develop serious difficulties and family dysfunction. These families should be identified and referred for more intensive therapy. (Details for how to refer for family counseling are discussed in Chapter 22.) Common warning signs are listed below.

Warning Signs of Patient Dysfunction

1. Poor management or complications of the illness. This is often a result of poor compliance with the medical regimen and may result from lack of support or assistance from the family or may be a form of resistance to family overinvolvement.

2. Poor Coping. Poor coping with the illness can result in underfunctioning, such as exaggerating the disability, not participating in rehabilitation (e.g., the cardiac patient who won't do anything that "stresses" his heart) or reporting an increase in symptoms. Poor coping can also result in over functioning, such as denial of symptoms or illness, overdoing the rehabilitation (e.g., the cardiac patient who runs a marathon). The development of any serious psychiatric disorder, such as severe anxiety, depression, suicidal thinking, eating disorders (anorexia or bulimia) is an indication for referral.

Warning Signs of Dysfunction in Family Members

1. Illness or symptoms in other family members. These symptoms result from the stress of caring for an ill family member or be a way of competing for attention and care via health problems. The symptoms may be functional (e.g., tension headaches) or represent serious organic illness (e.g., development of angina).

2. Emotional disturbance in other family members. In addition to psychiatric problems such as depression and anxiety, these signs of poor coping may include school or work problems or chronic insomnia.

3. Family, marital, or sexual problems. Superficially these problems may appear unrelated to the chronic illness (e.g., sexual dysfunction in the parents of a diabetic child), but the illness often plays an important role.

As Jim's illness worsened, the stress on the couple and their relationship worsened. Jim became withdrawn and depressed, and Harriet's migraine headaches became incapacitating. Despite Dr. K's counseling during office visits, the couple fought more about Harriet's attempts to help Jim. Dr. K suggested that they might benefit from seeing a counselor on a more regular basis to deal with the tremendous stresses related to the illness. The couple agreed.

Chronic illness is a nearly universal part of the life course of families. It is often a crisis that severely stresses families and threatens to disrupt them. The shared experience of coping with chronic illness is also an opportunity for growth; to become closer and develop new and healthier patterns of interaction. Physicians have a unique opportunity to work with patients and families over the long course of chronic illness. Through careful assessment and planned intervention, the family-oriented physician can help families cope in healthy ways to chronic illness.

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