3 Families and chronic illness: Assumptions, assessment, and intervention

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OVERVIEW

This chapter presents certain basic assumptions about families with chronic illness. Guidelines for conducting a family assessment are outlined and examples of circular questions are given. Indications and contraindications for family intervention and concepts about the process of change are highlighted. General and specific interventions directed at the cognitive, affective, and behavioral levels of family functioning are described.

The family system influences the course of illness in a variety of ways. Thus, the family should be the context in which the challenges of coping with illness are resolved. Interventions target the whole family system since chronic illness cannot be treated solely by a physician or nurse. As Griffin (1980, p. 254) has written,

> Medical intervention is of paramount importance but even the implementation of medical treatment will eventually become the obligation of the family. After the medical program is outlined, it is the family who must see that procedures are followed sensibly, that medications are taken, and that diet and rehabilitation programs are observed. Family members quickly become experts on chronic illness suffered by one of them, and their daily observations usually provide reliable data for health professionals in attendance. Family

attitudes and actions are crucial in determining the course of the illness and contribute to remission or exacerbation of symptoms.

Working from the premise that *family* intervention is paramount, this chapter presents basic assumptions about families with chronic illness. Guidelines for conducting a family assessment and examples of circular questions are given. Indications and contraindications for family intervention and concepts about the process of change are highlighted. Specific family interviewing skills as well as particular types of interventions useful in work with families with chronic illness are addressed.

BASIC ASSUMPTIONS ABOUT FAMILIES WITH CHRONIC ILLNESS

Effective intervention with a family system is possible only after thorough family assessment. Nursing requires certain assumptions so that nurses can maximize opportunities for systemic change.

Assumption #1: There are Predictable Points of Family Stress

If a chronic disease symptom conflicts with a normal developmental milestone, stress is predictable. For example, families of children with Crohn's disease often experience stress when growth failure conflicts with the usual adolescent growth spurt; this can be particularly stressful if younger siblings become taller than the ill child. Another predictable stress point (Power and Orto, 1980) comes when a developmental milestone is not met or is delayed. A family may cope quite well with a child's congenital disability until it prevents the child from entering school at the usual time.

Assumption #2: Families Vary in Their Level of Tolerance for the Patient's Physical Condition

Families may tolerate some symptoms when they cannot accept others (Blazer, 1984). It is important to assess a family's tolerance level and not insist that family members cope with symptoms before they are ready to. One family may deal well with chronic pain, by seeking appropriate assistance and perceiving the situation as a challenge. Another family, however, may perceive chronic pain as an undue and unfair form of suffering; members may become angry and despondent, affectively blocking problem-solving efforts.

An adult child might successfully care for an elderly parent until that parent becomes incontinent of feces and urine, at which point care becomes intolerable. When the family's tolerance level is exceeded, other arrangements, such as institutionalization, must be considered.

Assumption #3: Families Under Stress Tend to Hold to Previously Proved Patterns of Behavior, Whether or Not They are Effective Under Current Circumstances

Some families minimize or deny problems which can be useful (Power and Orto, 1980). If, however, a father has had a recent stroke and requires extensive care, then the normal pattern of minimalization may not be effective. Family members will not fully appreciate or admit the amount of effort and time that will be required for his care.

Assumption #4: Families Usually Go Through a Grief-Loss Process Following the Diagnosis of a Disabling Condition

A chronic illness diagnosis represents a major family loss and adjustment that goes beyond the suffering of the patient, and produces different reactions. For example, a patient may openly mourn the loss of eyesight or memory. Family members, on the other hand, may be unable to openly express their feelings about the loss of the valued "normal" relative. Family members sometimes feel guilty for complaining about this change in their situation in light of the change the patient experiences.

Health professionals should not intervene prematurely in this grief process or insist that all family members cope with it in similar ways. In terms of intervention, nurses must not insist upon "required grieving" or impose on family members' specific grief techniques.

Assumption #5: Families Play a Significant Role in Encouraging or Discouraging Chronically Ill Members to Participate in Particular Therapies

Families can increase or hasten the rehabilitation process if they actively support and encourage prescribed therapies.

Assumption #6: Families React to Particular "Illness Behaviors"

Chronically ill patients often become dependent on other family members. However, family reactions to such expressions of dependency and helplessness vary. Some relatives become angry and fail to recognize the patient's real needs, while other members may overcompensate and foster dependence. Therefore, before intervening a nurse must first assess family reactions to displayed illness behaviors.

Assumption #7: Many Families Have Difficulty Adjusting to a Chronic Physical Illness Because of Incorrect or Inadequate Disease-Related Information

Families need up-to-date information regarding their member's illness, although such information may produce guilt or shame in family mem-

bers, or add to existing anxiety. Health care professionals should recognize that some families cannot comprehend the information given to them at first. Therefore, a nurse should assess not only family members' needs for information, but also their ability to comprehend and process it. The latter is critical if the family already has accurate information but persists in maladaptive behavior, despite intervention efforts.

Assumption #8: In Chronic Illness, Families Must Adjust to Changed Expectations of Each Other

Many of the changes in physical functioning brought on by chronic illness may subtly change expectations for family members. These changes often go unacknowledged and may contribute to family disruption. For example, a young mother confined to a wheelchair with multiple sclerosis often cannot adequately discipline her preschool children. All family members may realize this but never discuss it openly and may, therefore, retain unrealistic expectations.

Assumption #9: A Family's Perception of the Illness Event is the Greatest Influence Upon Ability to Cope

"Besides adjusting its structure in order to cope, a family also develops explanations of illness in order to bring some measure of certainty to the unknown, the unexplainable and the unjust" (Phipps and Desplat, 1984, p. 301). Some families perceive illness as a threat; others perceive it as a challenge; and still others see it as an enemy or test. Nurses must understand the family's perception of the illness before they attempt to intervene. Often, the most important goal of health care intervention is to change family members' perceptions of and thoughts about the illness event. In chronic illness the nurse's primary objective is to help the family adjust and adapt to the situation, not necessarily to accept it.

FAMILY ASSESSMENT

Family assessment is the evaluation of a family system. Although families are composed of individuals, a family assessment should focus less on the individual and more on the relationships and behaviors among *all* the individuals in the unit; thus, the family is viewed as a system of interacting members.

The nurse who conducts a family assessment assumes that individuals are best understood within their immediate social context. The nurse conceives of the individual as defining and being defined by that context (Sluzki, 1974). Relationships with family members and other meaningful members of the social environment are thus very important factors in family assessment.

If the nurse thinks "relationship" rather than "individual" then individual family members' behavior will be seen not in isolation, but in context. In interviewing family members as a group, the nurse can observe how they spontaneously interact and influence each other. Furthermore, the nurse can ask questions about the impact that family members have on one another. Although many variables of family functioning (e.g., roles and control) may also be assessed, the evaluation of relationships must remain the thrust of family assessment.

Family Assessment Models

The nurse may choose between family assessment frameworks. The model referred to in this chapter is the Calgary Family Assessment Model (CFAM) (Wright and Leahey, 1984), a multidimensional framework consisting of three major categories (structural, developmental, and functional). CFAM is based on a systems/cybernetics/communication theory foundation. This chapter will be devoted to the practical application of this model in family interviews.

HOW TO CONDUCT A FAMILY INTERVIEW

Before conducting a family interview, the nurse must have a clear conceptual framework. This will be influenced by her basic assumptions about families and chronic illness. The following guidelines are designed for family nurse interviewers and are an extension of the beginning family interviewing skills described by Wright and Leahey (1984). They are based on the theoretical foundation of a strategic/systemic approach to family interviewing (Haley, 1977; Watzlawick et al., 1974; Selvini-Palazzoli et al., 1980), and encourage a problem-solving, goal-oriented, time-limited approach to family interviewing.

Pre-Interview Guidelines

Developing hypotheses. Prior to meeting the family for the first time, the nurse should develop a basic hypothesis—a hunch or explanation about the family and the presenting problem in its relational context. Tomm (1984) defines hypothesis as a supposition generated to guide executive activity during the interview. Such assumptions orient the nurse's questioning and offer meaning to family behaviors. In short, hypotheses provide order for the interviewing process.

In dealing with families facing chronic illness, the nurse can generate hypotheses based on information gathered during hospital admission, visiting hours, or from the other staff. This information may consist of opinions, behavioral observations, or analogic (nonverbal) data. Fleuridas et al. (1986) suggest that hypotheses can also be based on prior experience with similar families, problems, symptoms, and situations. A

nurse's knowledge about developmental life-cycle stages and theory in general (systems, crisis, and so forth) can be connected to salient family information to generate a hypothesis. Guidelines for designing hypotheses are given in Table 3.1.

Table 3.1 Guidelines for Designing Hypotheses*

- Choose hypotheses that are useful.
- Generate the most helpful explanations of the family's behaviors at this particular time.
- Remember that there are no "right" or "true" explanations.
- Include all family components to make the hypothesis as systemic as possible.
- Link the hypothesis to the family's immediate concerns to keep the interview content relevant to their situation.
- Make the hypothesis different from the family's to help introduce new information into the system and to avoid entrapment into the family's solutions.
- Be as quick to discard unconfirmed or unhelpful hypotheses as to generate new ones.
- Do not necessarily share the hypothesis with the family.

*Adapted from Fleuridas et al., 1986.

The following example illustrates how alternate hypotheses can be generated prior to the first family meeting. A nurse working in an extended care facility noted that the family, especially the 9- and 10-year-old children, avoided visiting their 41-year-old mother with Huntington's disease, and that the patient's symptoms worsened around visiting days. The children seemed depressed and withdrawn every time they came to the nursing unit on their monthly visits. During case conferences, the staff wondered whether there might be a connection between the family's avoidance and the patient's flailing and head-banging. They generated several hypotheses to explain why the family might be avoiding the patient and why the patient's symptoms seemed to exacerbate around the time of the family visits.

One hypothesis pertained to the children's belief that head-banging and flailing were controllable. Perhaps the children felt that their mother was not trying to control herself so she could return home to care for them. This made them angry, so they avoided her. An alternative hypothesis concerned the children's conflicting loyalties toward their mother and the aunt who took care of them. Perhaps they felt that if they visited too often, their aunt might think they did not appreciate her care. Thus they spaced out their visits and acted depressed and withdrawn to demonstrate both loyalty to their aunt and affection for their mother.

Yet a third hypothesis involved the children's fears of developing Huntington's disease themselves. They avoided visiting and showed sadness because of their own expectations of contracting the disease.

Having generated several alternate hypotheses about the family and the problem in its relational context, the staff arranged a family meeting. The purpose of the interview was to seek validating information through assessment questions. Interventions would then be designed based on either confirmed hypotheses or those which seemed most salient.

Arranging a family meeting. Once a nurse decides that a particular situation would best be addressed using a family approach, she must make two important decisions: who should be present at the assessment, and where should the interview take place. These decisions are strongly influenced by the hypotheses.

The first decision is particularly critical. Although it is not necessary for every family member to be invited to the assessment, it is strongly recommended that nurses meet all members of the household at least once, preferably at the first interview. In this way the nurse can become familiar with family members' perceptions of the situation, making it less likely that the nurse will become aligned with one individual's perspective and thereby lose the *family* perspective.

Haley (1977, p. 10) states that to begin family work "by interviewing one person is to begin with a handicap." The more family members present, the more information it is possible for the nurse to gather. Sometimes the most significant accomplishment of a family assessment is bringing the whole family together simultaneously to discuss an important issue.

The nurse's second decision pertains to the interview setting. A family assessment can take place anywhere: in the family home (the kitchen, the living room, or the patient's bedroom), in the community health agency (in an interviewing room or an office), or elsewhere. There are advantages and disadvantages to conducting an initial assessment in any setting. Nurses should be flexible in choosing a setting that is appropriate for the specific purpose of the interview.

The concrete advantages to interviewing in the home have been delineated in part by Smoyak (1977). Family members of all ages are more easily able to attend. Opportunities for meeting significant but perhaps elusive family members, such as boarders or grandparents, are increased. The nurse can experience the family's social environment and observe firsthand the physical environment. Disadvantages to using the home setting for family interviews include the increased administrative and personal cost involved in traveling and the greater likelihood of interruptions. Home interviews also require increased interviewing skill from the nurse (Clark, 1978).

The greatest advantage to using the agency or hospital setting is

that, often, this is the nurse's base. This is where the nurse has initial contact with at least one family member face-to-face. The nurse can therefore capitalize on this opportunity and suggest a family interview. There are generally fewer telephone calls or visitor interruptions and the nurse can structure the interview more easily. The disadvantages of the work setting usually center around issues of context. Family members can be intimidated by such professional trappings as plush furniture or complicated equipment.

Interview Guidelines

Engagement. During the engagement or first stage of the family interview, the nurse must establish and maintain a therapeutic relationship with the family. Confrontation and interpretation too early in treatment may inhibit engagement (Gurman and Kniskern, 1981). To enhance engagement, the nurse must provide structure, be active, be empathic, and involve all members of the family group. Wright and Leahey (1984) have delineated specific skills for engaging families. One of the most helpful tools in this nursing situation is the genogram; its construction is a dynamic way of involving the family in defining its own structure (Holman, 1983).

Problem definition. During this phase of the family interview, the nurse should ask the family to define its main problem or complaint. Fleuridas et al. (1986) recommend that this be done by focusing on three time frames: past, present, and future. Within each time frame the nurse can ask questions pertaining to areas of difference, areas of agreement/disagreement, and explanations for or the meaning of the problem (Fleuridas et al., 1986). It is important to emphasize that "an effective systemic interview does not depend on the use of any one type of question or another, but on the knowledge of when, how, and to what purpose to use questions and techniques within the framework of a specific model" (Lipchik and DeShazer, 1986, p. 89).

Present. The nurse should ask each family member, including the children, to share their knowledge and understanding of the present situation. For example, the community health nurse working with a diabetic family could ask such questions as:

- What is the family's main concern *now* about John's diabetes?
- How is this concern a problem for the family *now* as compared to before?
- Who agrees with you that this is a problem?
- What is your explanation for this?

Past. In exploring the past, the nurse can again ask questions pertaining to:

- *Differences:* (How was John's behavior before his diabetes was diagnosed?)

- *Agreement/disagreement:* (Who agrees with dad that this was the main concern when the family lived in Seattle?)
- *Explanation/meaning:* (What do you think was the significance of John's decision to stop injecting his own insulin?)

Future. During the initial interview with a new family, the nurse must learn about the family's own hypotheses or beliefs about their problems (Tomm, 1984). In asking the family to explain their present situation, the nurse should consciously attempt to identify previously unrecognized connections. This might be done by asking such questions as:

- If Bill suddenly developed renal disease, how would things be different from the way they are now?
- Does Bill agree with you?
- If this were to happen, how would you explain the change in John's relationship with mom?

Children and adolescents might be reluctant to identify "problems" in the family; they may hesitate to disagree with their parents' description of the problem. Nurses may need to ask children what types of changes they would like to see in the family or how they would know if the problems went away. For example, one 7-year-old repeatedly denied that there were any difficulties surrounding his brother's diabetes and his mother's overinvolvement with the sick child. However, when the nurse asked what differences there would be in the family if his brother did not have diabetes, the 7-year-old said that he and his mother could go to hockey games after school. At the time of the family interview, the mother was reluctant to leave the house after the boys returned from school for fear that the older boy would have an insulin reaction.

In exploring the presenting problem, the nurse should obtain a clear and specific definition of the situation and identify any conflict among family members over the problem definition. If such conflict exists, then the nurse must clarify the problem further to help define the behaviors for which the family is seeking help. Rosenthal and Bergman (1986) suggest that during this stage of the initial interview the nurse should discover if the patient (whether family, couple, or individual) is committed to seeking change. In other words, is the patient a "customer" seeking the nurse's assistance to change or is the patient under duress?

Sequence of Interaction

After the problem is identified, the nurse must examine family interactions connected to it. This calls for a review of all the information obtained from the family in light of the hypotheses generated prior to the interview, and the development of additional questions. Questions focusing on interactional *behaviors* deal with three time frames: present, past, and future. Within each time frame, the nurse should once again

explore differences, agreements/disagreements, and explanations/meanings.

Present. In exploring the present situation, the nurse could ask: Who does what when? Then what happens? Who is the first to notice that something has been done?

The nurse can inquire about differences between individuals ("Who is better at getting grandmother to eat, Jose or Maria?") and between relationships ("Do your ex-husband and Sammy fight more or less than your ex-husband and Alan?"). In working with families with chronic illness, the nurse should explore differences before or after important events or milestones. For instance, the nurse could ask, "Do you worry more, less, or the same about your wife's health since her heart attack?"

In addition to exploring areas of difference, the nurse can explore areas of agreement/disagreement ("Who agrees with you that Jose is the most forgetful in attaching the SIDS monitor to the baby? Who disagrees with you?"). The nurse should also explore the family's explanation for the sequence of interaction ("How do you explain Jose's tendency to be most forgetful about the monitor? What does his behavior mean to you?").

Past. In exploring the past, the nurse uses the same types of questions to explore differences ("How was it different? How does that differ from now?"), agreement/disagreement ("Who agrees with Randy that dad is more involved in Cheryl's exercise regimen?"), and explanation/meaning ("What does it mean to you that after all this time, things between your wife and her mother have not changed?").

Future. By focusing on the future, the nurse instills hope for more adaptive interaction regarding the presenting problem. The nurse can ask questions pertaining to:

- *Differences:* "How would it be different if your grandmother didn't side with your father against your mother in managing Katrina's Crohn's disease?"
- *Agreement/disagreement:* "Do you think your father would agree that if your grandmother stayed out of the discussions things would be better?"
- *Explanation/meaning:* "Mom, tell me why you think it would be best for your husband to stop phoning his mother for advice about Katrina's Crohn's disease."

During the interview the nurse attempts to gain a systemic view of the problem and a description of the full cycle of repeated interactions. It is not important for the nurse to "understand" the problem but rather to be able to describe the sequence of the development of the problem over time and the current contextual view of the problem interaction.

Attempted Solutions

The next task for the interviewing nurse is to explore the family's attempted solutions to their problem. The process can begin with general questions ("How has your family tried to cope with Maria's refusal to dress herself properly?"). More specific questions should then be used to identify the least and most effective strategies for achieving desired effects, and when these strategies were employed ("What was least helpful in trying to get Maria to bathe? What was most effective?"). The nurse can ask if any successful elements in the solutions are still being employed and if they are not, why not. The same types of sequence of interaction questions focusing on difference, agreement/disagreement, and explanation/meaning can be used to explore the family's attempted solutions to the presenting problems.

In working with families with a chronically ill member, the nurse should be aware of any additional "helping agencies" involved in health care delivery. Therefore, it is important to ask appropriate questions: "What agencies have attempted to help you with this problem? What has been the most useful advice that you have received? Did you follow this advice? What has been the least helpful advice?" Leahey and Slive (1983) point out the usefulness of exploring the ideologies of the treatment systems; if there is unclear leadership or a confused hierarchy within the helping system, the family can be placed in a distressing situation, similar to that of a child whose parents continually disagree. Confusion among helping agencies can exacerbate the problem rather than alleviate it. In this way, the attempted solution (assistance by helping agencies) can become an entirely new problem.

Change Orientation

At some point during the interview, the nurse must establish what changes the family expects as an outcome of nursing intervention. Members may expect a large change, for instance, "My father will be able to walk without the aid of a cane," or a small but significant change, such as, "We will be able to leave our profoundly retarded daughter with a babysitter for one hour a week." In many cases, only a small change is necessary. "No matter how awful and how complex a situation, a small change in one person's behavior can lead to profound and far reaching differences in the behavior of all persons involved" (DeShazer et al., 1986, p. 209). Moreover, experienced nurses are aware that small changes can lead to further progress.

The nurse can clarify the family's change orientation with future/hypothetical questions, such as, "What would your parents do differently if they did not stay at home every evening with Jennifer?" The nurse can explore future/hypothetical areas of difference ("How would your parents' relationship be different if your mom allowed your aunt to take

care of Jennifer one evening a week?"), areas of agreement/disagreement ("Do you think your mom would agree that she and your dad would probably have little to talk about if they went out one evening a week?"), and explanation/meaning ("Tell me more about why you believe this would happen. What would this mean to you?").

If possible, the nurse should encourage the family to state the appearance of a specific new behavior that is incompatible with their presenting complaint ("We would like to have time for ourselves as a couple one evening a week without having to provide care for our daughter."). If the "small but significant" change is presented as *stopping* a problem behavior, then the nurse should help the family redefine the desired change "in terms of the *appearance* of a specific behavior incompatiable with the complaint" (Rosenthal and Bergman, 1986, AI. 2B).

Nurses working with families of the chronically ill often find that an expected change is too big or too vague ("We would like Tanya to feel good about herself even though she has had a colostomy."). Experienced clinical nurses know that "feeling good about onself" is very difficult to measure. The nurse could ask for a sign or for a statement defining the smallest concrete change that the patient could make on his way to the general goal. By asking for this degree of specificity about desired change early in the nurse/family relationship, it is more likely that the family and nurse can accomplish the desired change.

Planning

When a family assessment has been completed, nurses can decide whether or not to intervene. To make this decision they need to consider the family's level of functioning, their own skill level, and other resources available.

Indications for family intervention. Intervention is recommended under the following circumstances (Wright and Leahey, 1984):

- A family member presents with a chronic illness that has an obvious detrimental impact upon the other family members. For instance, a grandfather's Alzheimer's disease may result in the grandchildren being afraid of him, or a young child's acting-out behavior may be related to his mother's deterioration from multiple sclerosis.
- Family members contribute to an individual's symptoms or problems, as when lack of visitation from adult children exacerbates hypochondriasis in an elderly parent.
- One member's improvement leads to symptoms or deterioration in another family member, for example, when decreased asthma symptoms in one child correlate with increased abdominal pains in a sibling.
- A child or adolescent develops an emotional, behavioral, or physical

problem in the context of a family member's chronic illness. Perhaps a diabetic adolescent suddenly requests that his mother give him his daily insulin injections when he has been injecting himself for the past six months.

- A family member is first diagnosed with a chronic illness. If a family has no previous knowledge or experience with a particular illness, they will require information.
- A family member's condition deteriorates markedly. Whenever there is deterioration, family patterns will need restructuring and intervention as indicated.
- A chronically ill family member moves from a hospital or rehabilitation center back into the community.
- An important individual or family developmental milestone is missed or delayed, such as when an adolescent is unable to move out of the home at the anticipated time.
- The chronically ill patient dies. Even though the patient's death may be a relief, the family can be faced with a tremendous void where the caretaking role used to be.

If family intervention is to begin, and the family is not in immediate crisis, the authors recommend that sessions occur once every two weeks at most. Families, particularly those of the chronically ill, need time to incorporate interventions into entrenched patterns; too-frequent sessions may offer insufficient time for change. One cannot categorically state the optimal number of days, weeks, or months between sessions, but health care professionals should tailor visitation schedules to the needs of each client family.

Nurses' workplace context will also influence session duration and intensity. A rehabilitation nurse working with a family, for instance, might reduce session frequency the longer the patient is in the rehabilitation center. That would help avoid inadvertently fostering family dependence.

Contraindications for intervention. Family intervention is not always appropriate or required. The authors suggest the following contraindications for family intervention (Wright and Leahey, 1984):

- *All* family members request or state that they do not wish to be involved in recommended family sessions or interviews.
- The family states that all members prefer to work with another health care professional.

Generally, these contraindications are evident to the nurse following a thorough family assessment. Even when the climate for intervention seems favorable, the family might indicate a desire to terminate family treatment.

Intervention

To intervene effectively within a family system, nurses must understand some basic assumptions regarding families and chronic illness; the indicators and contraindicators for actual intervention; and some of the primary concepts of change. The authors (1984, p. 174) view change within families as a systems/cybernetic phenomenon.

> "That is, change within a family may occur within the cognitive, affective, or behavioral domains but change in any one domain will have an impact on the other domain. Interventions can be targeted at any or all of the three domains. However, we believe that the most profound and sustaining change will be that which occurs within the family's beliefs (cognition). In other words, as a family thinketh (they are so)!"

Concepts of change. Some of the major concepts of change (Wright & Leahey, 1984) are:

- Change depends upon context.
- Change depends upon the perception of the problem.
- Change depends upon realistic treatment goals.
- Understanding alone does not lead to change.
- Change does not necessarily occur equally in all family members.
- Directing change is the nurse's responsibility.
- Change can have myriad causes.

These concepts of change provide a theoretical guide for family intervention. As mentioned previously, a primary interventional goal for families with chronic illness is to change the family-created "reality" if it is problematic. Nurses can help family members interact in new ways by focusing particular techniques or interventions on the system's cognitive, affective, or behavioral domains. Such interventions can effect change by affecting family members' perceptions about the illness and about each other. Normally, nursing interventions are directed at challenging the meaning that families give to behavioral events. However, the nature of the problem for which help is sought—i.e., whether it is acute or chronic—will influence the receptivity of the family to seeing it as a problem for the family system rather than for the identified patient alone. An acute health problem, regardless of its origin (e.g., physical illness, accidental injury, etc.) by definition brings a state of disequilibrium to the family system in which it occurs. The crisis nature of the event can be useful in helping to make the family more amenable to a system intervention. On the other hand, a chronic problem in the identified patient around which the family has developed a homeostasis balance is less likely to be viewed by the

family as requiring treatment exclusively for the identified patient.

The nurse must remember that interventions do not begin at the intervention stage; they are part of the total interview process, from engagement to termination. The interventions used during the specific intervention stage are based upon ongoing assessment. Families who do not follow through with planned interventions may not be "resistant" due to pathology but rather to a lack of an adequate engagement period. Resistance may also indicate inadequate assessment, or the nurse might not recognize a family as being resistant due to the so-called suction phenomenon (Wright and Leahey, 1984).

Intervention skills. The intervention stage represents the core of the work with a family. It provides an appropriate context in which the family can make necessary changes. Once a thorough assessment has been completed, family intervention is indicated; particular intervention skills can then be utilized.

There are three basic types of intervention skills: perceptual, conceptual, and executive (see Table 3.2) (Wright and Leahey, 1984).

Types of interventions. Direct interventions focus on families' cognitive, affective, and/or behavioral levels of functioning, and request that a family do something different from what they have been doing. Obviously, these interventions are most effective with compliant families rather than noncompliant families. Most nurses assume that the family is compliant until given reason to think otherwise, for example, when members do not follow through with assignments or immediately state that everything has been tried before and nothing worked. The following interventions have been found to be most effective with compliant families and can be implemented singly or simultaneously.

Interventions directed at the cognitive level of family functioning. Interventions directed at the cognitive level of family functioning usually give new information or new ideas about a particular problem. If a family cannot solve problems, it may mean that members lack sufficient information. However, when they do have the information and do not change, the problem is different, and indirect interventions are probably indicated. Some of the more common *direct cognitive interventions* follow. Nurses can provide:

- Information about the chronic illness: its cause (e.g., genetic concern), progress over time, and present and potential handicaps.
- Suggestions about appropriate family responses to the illness. For example, the nurse can discuss the need for respite, the emotional effect of chronic illness on children, and the possible strain on a marriage. Also, the nurse can

explore with families what patient-related problems (e.g., incontinence of urine) might be most difficult for members to tolerate.
- Information about available community resources such as Meals on Wheels, rehabilitation services, and disease-specific support groups like those run by the American Diabetes Association. Information about specific equipment and/or prostheses is also very useful.
- Help with decision-making. Sometimes families need relief from the pressure of decision-making. In such circumstances the nurse should assume that responsibility, but only after the family has had the opportunity to decide for themselves. For example, it might be too painful for the family of an elderly person with a chronic illness to consider an auxiliary hospital or nursing home placement. Sometimes the nurse can recommend that the family consider such an alternative. The nurse should give a solid reason why this decision might benefit everyone concerned.

Any direct interventions which present information to families need to be presented in a context of support; this supporting atmosphere is, in some instances, even more important than the specific information provided.

Interventions directed at the affective level of family functioning. Interventions directed at the affective level are designed to modify the intense emotions that may be blocking a family's problem-solving efforts. One of the most useful interventions is validating members' emotional responses. This can alleviate feelings of isolation and loneliness by helping family members see the connection between their relative's illness and feelings of stress (Wright and Bell, 1981). For example, it is useful to show a family with a chronically ill member that it is normal for family processes to be slowed down by the illness.

Following a recent diagnosis of chronic illness, it is important to tell the family that they may feel out of control, or frightened, or sad for a period of time, but within a few months they will adjust and learn to cope. It is also important in this validation process to tell them that everybody is affected by what happens and that chronic illness is a family venture. Tucker (1984) suggests three common reactions of families to chronic illness:
- The family is overwhelmed and becomes a "disabled family."
- The family pretends that nothing has happened.
- The family balances between making an adjustment and coping well.

Many families react intensely to the initial diagnosis of chronic illness. Initially, fear, shock, and disbelief predominate; physical symptoms often appear in healthy family members. Denial is often used to cope with this initial shock; it can be a useful mechanism if it protects family members from decompensation and does not interfere with

Table 3.2 Intervention Skills

Perceptual/Conceptual	Executive
• Recognize that family systems are goal-directed and possess problem-solving abilities. For example: Believe that families are not only able to change but can also identify and implement methods for change; this helps the nurse avoid feeling overly responsible.	• Encourage family members to explore problem-solving alternatives. For example: "Mr. Sanchez, you've mentioned that your wife has become very tired lately caring for your elderly mother. Do you have any idea of what could be done to assist your wife?"
• Recognize that direct interventions will probably be most effective with compliant families, but less effective with noncompliant families.	• Intervene directly by instructing the family to do something *different.* It is expected that the family will comply.
• Recognize that direct interventions are normally focused on cognitive, affective, and/or behavioral levels of family function. It is not always necessary or even efficient to target interventions at all three levels of functioning simultaneously.	• Target direct interventions on any one or all three levels of functioning. For instance, a) cognitive—provide information to help the family perceive the chronic illness differently. b) affective—encourage different affective expression. c) behavioral—have family perform new tasks either within or outside the interview context.
• Recognize that lack of educational information can inhibit a family's attempts at problem-solving, while additional information can encourage members to devise their own solutions to problems.	• Enhance the family's knowledge and facilitate further problem-solving. For example, the nurse can provide information about the normal aging process to caretakers of an elderly parent. This type of direct intervention targets the family's cognitive level of functioning.
• Recognize that persistent and intense emotions can often hinder problem-solving. Families who predominantly experience such emotions as sadness and anger often cannot deal with problems until the emotional block is removed.	• Validate family members' emotions when appropriate, and suggest where feelings might be problematic. Example, suppressed grief over the loss of an arthritic mother's usual physical functioning may be relieved by mere confirmation of the normal grieving process. This type of direct intervention targets the family's affective level of functioning.
• Recognize that constraining repetitive behavior patterns can inhibit family creative problem-solving, and that some tasks can serve to initiate changes in the structure of the family and/or family rules.	• Assign tasks aimed at improving family functioning, e.g., instruct a mother and father with a leukemic child to have grandparents babysit for a day while they have time together. This type of direct intervention targets the family's behavioral level of functioning.
• Recognize that families are often reluctant or hesitant to discuss aspects of the future that will be affected by the chronic illness. Questions "What will happen in two years when it would have been the time for Scott to begin attending school?" might be difficult for the family to answer.	• Ask hypothetical or future-oriented questions as a way of raising sensitive core issues about chronic illness without suggesting specific family action.

treatment. If families talk about denial but behave adaptively, then the denial is not maladaptive. For example, if a young husband denies his wife's recent diagnosis of multiple sclerosis, but installs a ramp in their home for her wheelchair, then his denial is not maladaptive.

Often families with chronic illness experience intense anger, sometimes directed at the ill member because of the tremendous changes in family life that the illness has required. Overtly this anger does not last too long, if only because social norms make it unacceptable to be angry at people who are ill. At other times family members and patient may become angry at the health care system, often quite appropriately. They may feel that sufficient treatment or information is not being provided. The family's rational management of the situation and action toward making needed changes may markedly reduce the frequency of such negative responses.

Guilt is also common among families of the chronically ill. This reaction can be adaptive if it helps mobilize resources on behalf of the ill person. A useful distinction can be made between realistic and neurotic guilt.

Another emotion common in families facing chronic illness is sadness, a frequent sign of resignation and depression. This reaction may recur with every new crisis or when another developmental milestone is missed or delayed, although the pattern may become less frequent and less intense. Unfortunately, the social rituals that help families grieve after a death do not help alleviate the sense of loss associated with chronic illness, and no effective substitute is available.

Finally, there is an important point to make with regard to the affective functioning of families with chronic illness. That is, families may adapt, but they do not necessarily ever accept the chronic illness. Therefore, it is wise that nurses not demand acceptance from such families. Rather, health care professionals should simply acknowledge the fact that something sad, bad, or awful has happened, and that the family is entering a lifelong process of adapting (Tucker, 1984).

Interventions directed at the behavioral level of family functioning. Interventions targeted at the behavioral level can help family members interact more effectively and thus behave more positively in relation to one another. This goal can be accomplished by assigning specific behavioral tasks to some or all family members. Some tasks can be assigned as homework to be done between sessions, while others might be completed in the interviewing room so that the interaction can be observed.

Nurses working with families after an initial diagnosis of chronic illness must focus on the instrumental issues first, before dealing with the affective issues. This rule of thumb holds true unless a severe

blockage of affect interferes with family problem-solving. Interventions targeted at the behavioral level of family functioning require a nurse to:

- Encourage families not to make drastic adjustments in their daily life. Often families with chronic illness make major adjustments and changes immediately after diagnosis, so that they are living in a continual state of disruption (Power and Orto, 1980). Emphasize that family members continue with usual routines whenever possible and maintain their customary role responsibilities. At least one home visit is recommended when nursing a family with chronic illness in order to understand the instrumental implications within that environment. By making a home visit, the nurse can reassure the family of their own competence by stating, "Now that I have come to know your family somewhat better, I know you have the ability to cope with what is ahead of you, although it will be difficult sometimes."
- Encourage opportunities for respite. One of the caretaking family's most difficult tasks is allowing members adequate respite. Too frequently, family members feel guilty if they need or want to remove themselves from the caretaking role. Even the ill member must disengage himself from time to time from the usual caretaking and accept another person's assistance. Each family's need for respite varies. The factors affecting respite requirements include the severity of the chronic illness; availability of family members to care for the ill person; and financial resources. All of these factors must be considered and balanced before the health care professional recommends a respite schedule. Tucker (1984) reports that she advises families to buy a less expensive prosthesis and use the extra money for a family vacation. In this way, caretaking and coping are balanced. Such "time outs" or "time away" is essential for families facing excessive caretaking demands.

CHALLENGES FOR NURSES WORKING WITH FAMILIES OF THE CHRONICALLY ILL

Working with families with chronic illness poses particular nursing challenges. An awareness of possible pitfalls and problems helps nurses intervene more effectively into family systems. The first challenge pertains to nurses' understanding of reciprocal influences. She must recognize that, not only is the family a system with certain boundaries, but also that she forms a new system with the family (the nurse-family system). The nurse is, therefore, influenced by the family just as the family is influenced by the nurse. Reciprocity is an important concept to remember when working with families with chronic illness.

Because of the nature of chronic illness, nurses often have long-term relationships with patients in either rehabilitation settings or home care. Many times these relationships can be more rewarding than the brief relationships of acute care settings. However, extreme attachment

and dependency can hinder the nurse, patient, and family alike. If appropriate boundaries are not maintained (e.g., if the nurse does not have a strong social network and interests outside work), then working with chronically ill patients and their families may become exhausting and intrusive.

Nurses should also recognize the triangle that forms when they work with a family with chronic illness. The triangle consists of the patient, the family, and the health care system; all of these facets interact with and influence one another. At times, the nurse may be caught between the patient and other family members; this often happens when the nurse feels that both parties want her on their side.

A second challenge relates to the depression that has been observed in health care professionals working with families with chronic illness over a long period of time. Tucker (1984) relates a study completed at the University of Illinois which attempted to help nursing students cope with this depression. It was postulated that the depression arose from the students' inability to see any progress in the families' situations. The study involved showing nursing students videotapes of client families over time in order to make the progress visible. This had a positive influence on the nursing students and made them more optimistic about nursing the chronically ill and their families. Another finding in this study was the nurses' need to work with patients at all levels of dysfunction or disability, rather than with one particular population at one particular stage of illness.

A third challenge for nurses pertains to their entry into a family system where there is a chronically ill member. Nurses should not be overempathetic, or state that they understand the patient's dilemma or suffering. Instead, a nurse should ask the family to "teach" her what to consider and what to be aware of when working with families with chronic illness. Nurses *should not* say "I know what you are going through" but rather, "Teach me about what you're experiencing."

Finally, nurses should remember that families with chronic illness normally do not present with psychiatric problems and are frequently not pathological in their functioning. Rather, they are families who are adjusting and coping with a serious health problem that disrupts their usual pattern of functioning.

CONCLUSIONS

In conclusion, family interventions are as numerous and as varied as families themselves. However, interventions should be tailored to meet each family's specific needs and problems. They should always be based on sound assessment and a recognition of certain basic assumptions relevant to all families coping with chronic illness.

REFERENCES

Blazer, D. "The Management of Chronic Physical Illness," in *Role of the Family in the Rehabilitation of the Physically Disabled.* Edited by Blazer, D., and Siegler, I.C. Baltimore: University Park Press, 1984.

Clark, C. *Mental Health Aspects of Community Health Nursing.* New York: McGraw-Hill Book Co., 1978.

DeShazer, S., et al. "Brief Therapy: Focused Solution Development," *Family Process* 25(2):207–21, 1986.

Fleuridas, C., et al. "The Evolution of Circular Questions: Training Family Therapists," *Journal of Marital and Family Therapy* 12(2):113–27, 1986.

Griffin, J.Q. "Physical Illness in the Family," in *Family-Focused Care.* Edited by Miller, J.R., and Janosik, E.H. New York: McGraw-Hill Book Co., 1980.

Gurman, A., and Kniskern, D. "Family Therapy Outcome Research: Knowns and Unknowns," in *Handbook of Family Therapy.* Edited by Gurman, A.S., and Kniskern, D.P. New York: Brunner-Mazel, 1981.

Haley, J. *Problem-Solving Therapy.* San Francisco: Jossey-Bass, 1977.

Holman, A. *Family Assessment: Tools for Understanding and Intervention.* Beverly Hills, Calif.: Sage, 1983.

Leahey, M., and Slive, A. "Treating Families with Adolescents: An Ecological Approach," *Canadian Journal of Community Mental Health* 2:21-28, 1983.

Lipchik, E., and DeShazer, S. "The Purposeful Interview," *Journal of Strategic and Systemic Therapies* 5(1 & 2):88–99, 1986.

Phipps, E., and Desplat, P. "The Intertwining of the Family System in Huntington's Disease," *Family Systems Medicine* 2(3):298–308, 1984.

Power, P.W., and Orto, A.E.D., eds. "Approaches to Family Interventions," in *Role of the Family in the Rehabilitation of the Physically Disabled.* Baltimore: University Park Press, 1980.

Rosenthal, M., and Bergman, Z. "A Flow Chart Presenting the Decision-Making Process of the MRI Brief Therapy Centre," *Journal of Strategic and Systemic Therapies* 5(1 & 2):A1.1–A1.6, 1986.

Selvini-Palazzoli, M., et al. "Hypothesizing, Circularity and Neutrality: Three Guidelines for the Conductor of the Session," *Family Process* 19:3-12, 1980.

Sluzki, C. "On Training to Think Interactionally," *Social Science and Medicine* 8:483–85, 1974.

Smoyak, S. "Homes: A Natural Environment for Family Therapy," in *Distributive Nursing Practice: A Systems Approach to Community Health.* Edited by Hall, J., and Weaver, B. Philadelphia: J.B. Lippincott Co., 1977.

Tomm, K. "One Perspective on the Milan Systemic Approach Part II. Description of Session Format, Interviewing Style and Interventions," *Journal of Marital and Family Therapy* 10(2):253–71, 1984.

Tucker, S. Personal communication. Chicago: Northwestern University, 1984.

Watzlawick, P., et al. *Change.* New York: W.W. Norton & Co., 1974.

Wright, L.M., and Bell, J. "Nurses, Families and Illness: A New Combination," in *Treating Families with Special Needs.* Edited by Freeman, D., and Trute, B. Ottawa: The Canadian Association of Social Workers, 1981.

Wright, L.M., and Leahey, M. *Nurses and Families: A Guide to Family Assessment and Intervention.* Philadelphia: F. A. Davis Co., 1984.