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Families and life-threatening illness: Assumptions, assessment, and intervention

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OVERVIEW

This chapter presents basic assumptions about families with life-threatening illness. Guidelines for a systemic family assessment are outlined and examples of circular questions are given. To help nurses maximize change, specific interventions are described.

INTRODUCTION

Nursing assessments of and interventions with family systems are most often derived from beliefs, premises, and assumptions about human nature, the nature of human illness, and the nature and creation of therapeutic change. These beliefs enable nurses to determine the impact of life-threatening illness on the family and the influence of the family on the illness. Family responses during the assessment and intervention process perturb our beliefs, however, and modify our thoughts about the way families experience serious illness. Thus, the assumptions described in this chapter are based on research and clinical experience with families experiencing life-threatening illness. Ideas for assessment and intervention are also presented.
BASIC ASSUMPTIONS ABOUT FAMILIES WITH LIFE-THREATENING ILLNESS

Life-threatening illness challenges family stability, adaptability, resources, and, most intensely, beliefs and assumptions. It also challenges health professionals' beliefs about their ability to alleviate suffering and to cure. As a result, in both the family and treatment systems the “meaning” assigned to disease becomes paramount. The assumptions listed below are perhaps the most salient in this situation.

Assumption #1: The Diagnosis of Life-Threatening Illness Is a Social Contract

Diagnosis of a life-threatening condition combines clinical expertise, medical science, and intuition; however, it becomes meaningful only when placed in an interactional context. Diagnosis is a social event that occurs when one person (the medical or nursing expert) affixes a classification to another (the identified patient) (Glenn, 1984). At this point, the patient, family, and health care system enter into a contract regarding the problems. The diagnosis implies that a cluster of signs and/or symptoms exists, places those manifestations in context, gives them meaning, and suggests treatments. However, as nurses are only too aware, it is difficult to have all parties in the contract agree on all aspects of the diagnosis. Thus, a life-threatening diagnosis is subjected to “negotiations.” Initially, the patient may accept a diagnosis of myocardial infarction, but other family members may not; the patient, while accepting the label of the illness, may not agree with the proposed treatment. Not even the health care system presents a united front regarding management of the illness. The diagnosis is scrutinized by all parties involved.

Among the most powerful implications of any diagnosis are the patient’s and family’s conclusions about it. They will spend much time thinking about the origins of the illness and its implications. Complicating matters is the illness’s profound effects on those around the patient. Thus, families can experience confusion, anger, pleasure, or relief. Health care professionals who understand this broader context will be more sensitive to their anxiety and guilt and can better involve them in the management process.

Nurses need to review the circumstances surrounding the life-threatening diagnosis to help the family integrate the new information into their lives. Most families vividly remember how they received the diagnosis: who told them, what they were doing at the time, and how they reacted. Families are, of course, unique and complex, responding to life-threatening incidents or diagnoses differently. But all families need to discuss the circumstances and details of the diagnosis.
Assumption #2: A Life-Threatening Diagnosis Changes the Family's Life Trajectory

Before middle adulthood, few people think about their own deaths. Pattison (1977) suggests that serious consideration of that subject constitutes projection of "a trajectory of our life." A life-threatening diagnosis, a "crisis knowledge of death," changes the family life trajectory. Often, family members' reactions to the diagnosis are influenced by the type of dying trajectory the patient faces. Glaser and Strauss (1968) identified four types of dying trajectories:

- certain death at a known time
- certain death at an unknown time
- uncertain death but a known time when the questions will be resolved
- uncertain death and an unknown time when questions will be resolved.

Wright (1985) emphasizes that nurses are obligated to help patients and their families experience the crisis knowledge of death.

Assumption #3: Families Need to Review a Life-Threatening Event

When a family experiences a life-threatening event (for example, a member's coronary or cranial injury), that event becomes a kind of videotape that needs to be played, viewed, and discussed repeatedly, not unlike the circumstances surrounding a death. Many nurses have noted families' spontaneous references to tragic incidents during family nursing interviews. Further questioning revealed that they would almost be relieved to be able to describe the incident, regardless of how painful it might be. Life-threatening events impinge so deeply upon family members' cognitive and affective functioning that one method of regaining stability and reducing sensitivity to the event is to relive it through detailed description.

Assumption #4: Family Members' Reactions Influence the Course of a Life-Threatening Illness

Nurses and other health care professionals know that individuals' responses to life-threatening illness vary (for example, denial, anger). However, some family clinicians (Palazzoli, 1985) now propose that patients respond more to their family's responses to the illness than to the condition itself. This interactional phenomenon has seldom entered into previous efforts to understand the reciprocity between illness and family dynamics. The research of Reiss et al. (1986) suggests that affected families who are too emotionally close may precipitate death in the sick member. Death represents an "arrangement" between the family and the patient—the patient dies so that "the family may live." This is often an extreme but perhaps the only "reasonable" patient
response to the family's feelings of grief and burden. Rolland (1984) states that "some families' hope to resume a 'normal' life might only come through the death of their ill member" (p. 255).

In recognition of this, various studies have examined family outcomes when support interventions have been provided. For example, Morisky et al. (1983) offered impressive support for the efficacy of family interventions in individual hypertension. A five-year mortality survey demonstrated 57% lower mortality in groups receiving intervention, compared with control groups. One significant finding was that brief family intervention had as strong an effect as combined individual-plus-family interventions in terms of treatment compliance.

Family (typically spousal) support also affects the course of an illness. Barbarin and Tirado (1985) contributed greatly to family support research by discovering that a spouse's support works only in the context of a cohesive marriage.

Therefore, family reactions can significantly influence the decision to initiate or delay treatment, the perceptions of symptom or disease seriousness, compliance, and satisfaction with the treatment outcome (Weakland and Fisch, 1984). In extreme cases, the family may even influence the patient's will to live.

Assumption #5: Family Function is Often Altered by Life-Threatening Illness

Dealing with a life-threatening illness within a family commonly alters usual family functioning. Koch's (1985) study of 32 families of children with newly diagnosed cancer revealed these changes within families: increased negative affect, prohibition of emotional expression, new or exacerbated health and behavior problems following diagnosis, role changes, and increased emotional closeness among family members. Giaquinta (1980) specified 10 functional phases for families facing cancer. These phases (functional disruption, search for meaning, informing others) can be useful if health care professionals do not reify the particular phases as was done with Kübler-Ross's (1969) five stages of facing death. The effect an individual's life-threatening illness has on the family differs in intensity depending on the nature of the illness itself, the timing of the illness in the family life cycle, the openness of the family system, and the family position of the patient (Herz, 1980; Brown et al., 1982). However, in the Brown et al. study of patients with serious coronary problems, there was little evidence of any correlation between severity of illness and impairment of the patient's family functioning. Therefore, the nurse should actively investigate critical variables and then draw a conclusion.

When nurses assume particular models of family functioning to be
“true” rather than simply the observer’s (nurse’s) assumptions, they reduce their receptiveness to other possibilities or assumptions. Care providers must behave more like anthropologists, viewing the study of changes in families facing illness as a study of unmapped territory, rather than as an area to be explored using a preexisting map. Even after assessment, the territory is still not a map, nor the map the territory. Nurses can only behave as if that is so.

Assumption #6: Family Members’ Beliefs about a Life-Threatening Illness Influence How They and the Patient Cope with the Situation

Beliefs about the cause of a life-threatening illness can profoundly affect the ways a family copes with and responds to the crisis. Borhek and Curtis (1975) define a belief system as a set of related ideas (learned and shared) which are more or less permanent and to which individuals exhibit commitment. The authors’ experience has been that families are powerfully attached to their beliefs, and display more commitment to beliefs about life-threatening illness than about chronic illness because grave illness confronts beliefs about mortality. Therefore, some families perceive illness as a challenge, while others consider it a punishment or perceive it as a threat. One family whose adolescent had a life-threatening illness explained their ability to cope by saying “God knew that our family could handle it—other families would have fallen apart.”

Family beliefs significantly determine the impact of illness, the choice of coping patterns used, and ultimately physical and behavioral reactions (Wright and Bell, 1981). Sometimes these beliefs are held so strongly that family members appear more willing to invalidate data than to invalidate perceptions (Dell, 1986). This provides an additional challenge for family nurses.

**FAMILY NURSING ASSESSMENT**

The nurse must consider whether an assumption about families facing life-threatening illness applies to a given client. If it does apply, is the effect negative or positive? Rather than focus on particular assessment models, many of which are described elsewhere in this volume, to answer these questions, this chapter presents procedural ideas applicable to many assessment styles.

**Guidelines for Systemic Assessment**

The assessment process is predominantly based on a systemic model of interviewing (Palazzoli et al., 1980) developed by four Italian psychiatrists known as the Milan Associates. The model was originally developed through their work with families with psychosocial problems (for
example, anorexia nervosa), but it has proven useful in interviewing families with grave or chronic illness. This model proposes three guidelines: hypothesizing, circularity, and neutrality. Recently, Tomm (1987) has proposed a fourth guideline, strategizing. All four of these principles are interrelated.

In a systemic family interview, the nurse must be aware of personal assumptions about families and serious illness and remain open to feedback that might modify them. It is important to apply these assumptions individually, in the form of hypotheses, to each family. These unconfirmed hypotheses help organize information; they are affirmed or disaffirmed with information obtained through assessment. Generally, these hypotheses are the parameters or variables associated with specific family assessment models. The behavioral or actual executive skills necessary to explore them require the selection of linear or circular questions.

Circular questioning involves obtaining information about relationships (Palazzoli et al., 1980). The nurse must be able to respond to the elicited descriptions without judgment or blame. For example, if a family sees a connection between illness and punishment from God, the nurse's response must be neutral; this does not mean that the nurse must accept the family's reasoning. Information obtained by circular questioning will greatly assist the intervening nurse. Intervention is only necessary, however, if a particular belief interferes with the family's ability to solve problems or care for the ill member.

Strategizing refers to clinical decision making: evaluating the effects of past nursing actions, constructing new plans, anticipating possible consequences of various alternatives, and deciding how to proceed on the basis of ultimate therapeutic utility (Tomm, 1987).

Assessment Questions

*Lineal descriptive vs. circular descriptive.* Regardless of the particular model(s) chosen by the nurses, certain questions may create a recursive loop between nurse and family. There is also ongoing interaction between family functioning and illness (Weakland, 1977). Some questions aid understanding of the family system while others serve to effect change (Tomm, 1985; Tomm, 1987). The questions are usually lineal descriptive, such as problem-oriented questions. For example, when a family reviews a life-threatening event (Assumption #3), the nurse could ask: "How did the family learn about John's motorcycle accident? How were other family members informed? Where was John taken in the ambulance? How long was he in Emergency? What was explained to you at the time about John's condition? What do you now understand happened in the accident?" Such questions inform the nurse of the circumstances of a life-threatening accident and establish a therapeutic
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context for further review. The authors have found that many details need to be sifted in order for all to arrive at a “common crisis story.”

To reduce the family’s sensitivity to the tragic event and thus to effect change, the nurse should move from lineal descriptive to circular descriptive questions. For example, the nurse could ask, “Who in the family worried the most while John was in the emergency room?” (“Mother did because she didn’t think he’d live.”) “How did she show that she was the one worrying the most?” (“She kept asking the doctors and nurses ‘He’s going to be all right, isn’t he?’”) “What did your father do while your mother was so worried?” (“He stayed in the hospital cafeteria and drank gallons of coffee—he can’t be around sick people.”) Circular descriptive questions are directed more toward explanation, whereas lineal descriptive questions are more investigative. Both types are useful. Remember, though, that the effect on families of these two types of questions differs: lineal questions can have a moderate effect, whereas circular questions tend to have a liberating effect (Tomm, in press).

The primary distinction between circular questions and lineal questions lies in the notion that information reveals differences in relationships (Bateson, 1979). With circular questions, a relationship or connection is always sought between individuals, events, ideas, or beliefs.

Some questions are more difficult for nurses to ask because they confront the professionals’ own beliefs and philosophies. Nevertheless, it is important to assess each family’s ability to adjust to the change in their trajectory (Assumption #2). To sensitively assess the family systems, the nurse should begin with lineal descriptive questions about the circumstances surrounding the diagnosis. For example, “Who told your father about his diagnosis of cancer of the lung? How did your mother learn of the diagnosis?” By asking such questions, the nurse can assess not only how the medical system informed the family but also how the family shares “crisis information.” Next it is important to assess each family member’s reaction to the diagnosis. This can be done through such circular descriptive questions as: “Who in the family was most surprised by the diagnosis? Who in the family was most upset by the news? Who between your mother and father is the most optimistic about the future? How do you explain that your family has to cope with this situation while other families do not?” This helps the nurse target the family’s beliefs about illness.

Family members’ beliefs about the illness or event may be the most important factor to assess; their implications for nursing intervention are enormous. A family who believes a father’s lung cancer is due to smoking and who concludes that he caused his own illness will need dra-
matically different interventions than a family who attributes the cancer to an occupational hazard and blames an employer. In the former case, a family's reaction could be resentment and blame directed towards the ill relative. In the latter case, family reactions could be sorrow and sympathy and a projection of blame and anger onto the employer.

Circular descriptive questions such as the following are also useful in the evaluation of advice given to the family by relatives, friends, and community resources: “What is the worst advice that friends have given you? What is the best advice? What advice have you acted on?” These questions yield significant information about the types and sources of advice that the family values; they also give the nurse clues about what advice to avoid.

Once assessment through lineal and circular descriptive questions has been completed, the nurse can begin making critical clinical decisions regarding interventions. If assessment indicates that family functioning and/or problem solving is blocked (for example, if members blame themselves for the life-threatening illness), then family intervention is indicated.

FAMILY NURSING INTERVENTION

Nurses who provide family health care should target interventions at health promotion, treatment, management, and resolution of biopsychosocial problems. A myriad of helpful family interventions are available for families experiencing difficulties with a serious illness. This chapter presents those interventions that, based on research and the authors’ own clinical practice, seem most critical in such situations. Unfortunately, despite the large quantity of family and health care research, there are few studies of family interventions (Doherty, 1985).

Interventive Questions

One of the simplest but most powerful nursing interventions for families coping with life-threatening illness is the use of interventive questions. *Lineal strategic vs. circular reflexive questions.* Questions that serve as interventions are primarily of two types: lineal strategic and circular reflexive (Tomm, in press). The two types have vastly different effects on families: strategic questions tend to be constraining, while reflexive inquiries are generative—that is, they introduce new cognitive connections, creating the potential for behavioral change.

The following two interventive questions could be used in a situation where a young adult has been in a serious motorcycle accident with resultant head and spinal cord injuries:

- “Don’t you think that your continual blaming of your son for the
accident might discourage him from the rigorous physiotherapy he has to endure?” This question is lineal strategic. It takes a harsh, blaming, confrontational stance and gives a strong message or directive for change to the parents. The implication is that the nurse knows what is best for the family.

- “If you became even more critical of your son’s reckless motorcycle driving, do you think it would be more or less likely that he would continue with his rigorous physiotherapy exercises?” This question is more reflexive and is intended to facilitate change by mobilizing the parents to reflect on their actions. It allows the parents to choose their own position and thus respects family autonomy more. Strategic questions often imply a corrective intent while reflexive questions imply a facilitative intent.

One type of reflexive question, the future-oriented question, is particularly useful for work with families experiencing catastrophic illness. Families with serious health problems find it difficult to speculate on the future because they are so preoccupied with present difficulties and so fearful of the future. This attitude inhibits problem-solving efforts. Reflexive questions about the future can encourage a family to consider the future (Tomm, in press); questions to a family with a young son with serious burns might include: “What are you worried will happen if these skin grafts continue to be so painful for your son? What’s the worst thing that could happen?” To a father diagnosed with terminal lung cancer, the powerful and penetrating question was asked: “When you die, do you think it is more or less likely that your wife and son will fight as much as they do now?” Such questions help families discuss catastrophic expectations, which they can then affirm or disaffirm. They help establish awareness of important connections between family functioning and illness. In the above example, the father had always mediated between his wife and son and the nurse hypothesized that the father believed their fighting would worsen after he died. To the father’s surprise and delight, the son answered that he would not fight as much with his mother because that was his way of getting his father involved in decision making. While his father was ill, the son stated he was fighting more because he wanted his father involved in decisions.

In one family that seemed to conspire against mentioning the life-threatening diagnosis, members were asked a question focusing on outcome: “If things continue going the way they are now, what do you expect will become of your family in 6 months to a year?”

And finally, future-oriented questions—“What changes would you like to see in a month from now with regard to your mother’s care? And what about other family members?”—were used to open discussion about family goals with respect to the illness.
In the authors’ clinical experience, interventive questions alone have often been sufficient to effect change within families that have difficulty dealing with their crisis.

**Provide Information**

The context in which a nurse encounters a patient with a grave illness will help determine the amount of involvement with family members. However, family research and clinical experience in family nursing both indicate that families, regardless of setting, desire more information from nursing and medical personnel than is offered spontaneously. Families with a member in an intensive care unit seem to express the highest need for regular and current information on the client’s condition. The family has to be kept informed, especially when the patient’s condition worsens or death is imminent. One useful strategy is for the nurse to initiate regular telephone contact. This punctuates the usual nurse-family interaction in a dramatically different way. Instead of having the family call and request information (and the nurse caring for the family member frequently being unavailable), the nurse calls the family. This reduces family members’ anxiety and allows them to be absent from the hospital so they can meet other obligations and obtain rest (Bozett and Gibbons, 1983).

This strategy also helps reframe the family’s need for the nurse. Instead of labeling particular family members as “bothersome” or a “nuisance,” the nurse who initiates contact is more likely to perceive clients as appreciative and grateful. This reframe of family members’ behavior occurs because the nurse has assumed control of the dissemination of information. It also allows her to feel competent. When phoned spontaneously by family members, without having a chance to organize the necessary information, the nurse may feel out of control and/or incompetent.

Nurses can also provide information to families during regular visiting times. Hampe (1975) found that relatives do not expect nurses to be concerned about them; rather, they think the nurse’s responsibility is solely to the hospitalized patient. Ideally, the nurse should have short family meetings to assess their functioning and to explore the family’s perceptions of the situation. Assessment and interventive questions appropriate to the nurse’s chosen assessment model are helpful during these meetings.

**Promote Family Involvement in Care of the Ill Family Member**

Families with a member hospitalized due to a life-threatening illness or event often feel helpless. To reduce these negative feelings, the nurse needs to involve relatives in patient care. A few suggestions follow:

- Teach family members how to touch and hold the patient without
interfering with life support systems.
- Ask family members if they would like to feed the patient at scheduled mealtimes.
- Encourage different family members to adopt particular roles (for example, one to take daily calls from the nurse and one to prepare a favorite dish that is permissible on the patient’s diet).
- Encourage younger children to make gifts.

The primary goal of this intervention is to reduce family stress. Just being with the patient can help. Many intensive care units have rigid visiting times that often magnify family members’ anxiety by limiting the amount of time they can be with their loved one. The hospitalization of a family member makes many families feel powerless, out of control, and at the mercy of both the illness and health care personnel.

**Provide Consistent Care**

Ideally, primary nursing is provided for all hospitalized patients and their families. Family members should know the names of their primary nurses so they can call them in times of need. In some circumstances, however, someone other than the patient’s nurse, such as a family clinical nurse specialist or a psychiatric liaison nurse, may be responsive to family needs. In these situations, the family should also know these nurses by name and know how to contact them.

**Provide Opportunities to Discuss the Possibility of the Patient’s Death**

Families experiencing a catastrophic illness or event also have to face the possibility and eventual reality of the patient’s death. It is often emotionally challenging for nurses to arrange appropriate and therapeutic discussions between family and patient about the impending loss. Just as each person’s grief is unique, so is each person’s anticipation of grief. Some family members will deny, others will be resentful or angry, others will accept the situation. The anticipation of loss is a functional response, usually related to how other family members are preparing for it. Thus one family member’s denial may be more a relational than an intrapsychic phenomenon. Stein (1984) emphasizes this point when discussing the case of a patient with terminal metastatic cancer. He suggests asking the question: “In what context does the patient’s denial make sense?”

Another important intervention is for nurse, family, and physician to discuss the use or nonuse of life support systems. Nurses need to anticipate that most families cannot make such a critical decision the first time it is discussed. Also, families commonly change their minds. This decision brings to bear the full spectrum of familial, cultural, and religious beliefs.
These recommended interventions are by no means inclusive. However, the authors believe them to be crucial considerations in nursing practice with families experiencing the upheaval of a life-threatening illness or event.

CONCLUSIONS

Family health care, particularly in the event of life-threatening illness, is shaped by assumptions, family research, and clinical practice that enhance compliance with treatment, provide social support, and sustain motivation for health-promoting behavior even in the absence of extrinsic reinforcement (Barbarin and Tirado, 1985). Nurses, because of the variety of contexts in which they encounter patients, because of their availability, and because of the involvement with families that has traditionally been a part of their profession, have an immense opportunity to alleviate the intense family stress and anxiety associated with tragic illness or events.
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