Chapter 13 ·

Nurses, Families & Illness: A New Combination

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> We shall not cease from exploration
> And the end of all our exploring
> Will be to arrive where we started
> And know the place for the first time.
> T.S. Eliot

THE NEW ROLE: FAMILY NURSING IN HOSPITALS

Nurses, more than any other health care professionals, have unique opportunities to work with families. This is primarily due to the number and variety of contexts in which nurses provide health care such as hospitals, homes, and work settings. Since the majority of nurses are employed in hospital settings (78.7% according to Canadian Nursing Statistics 1977), one might predict that most family work by nurses occurs in this context. Surprisingly, however, this is not the case. More emphasis to family work is given within community health settings rather than in hospitals; although in actual practice, family nursing in the community is not fully realized.

There are many factors which have prohibited or inhibited nurses from doing more family work. However, at present, there is an exciting turnabout in most clinical areas to encourage family work. In hospitals, nurses for many years spent much time and energy "shooing" relatives away - fathers out of labour and delivery areas, parents out of pediatrics, and family members away from the bedside of critically ill or dying members. Now, with the help of changes in hospital policy, the nursing profession is inviting family members back to participate in significant *family* events. Fathers, and sometimes other members of the family, are invited to labour and delivery rooms; arrangements are made for parents to stay overnight with small children; and hospices are being created for terminally ill patients where families are indeed welcome and in many cases provide the majority of care to their ill family members. Nursing is definitely moving toward more family-centered care but it is still the "squeaky" families who seem to obtain the most "grease", e.g., the upset families; the hostile families; the complaining families.

Nursing needs to be more cognizant that all families with a hospitalized family member need information and support. The family literature indicates that families have a capacity to care for their members in times of crisis. However, the arrival of the illness seems to fracture the unity of some families with the result that some lose this ability (Peck, 1974). The nurse may be able to provide support directly to families or indirectly by assisting them to support their own members.

It is encouraging to witness the movement towards more family work in hospitals by nurses and their demands for more knowledge and practice of family assessment and family interviewing skills. However, these changes in practice will continue to be slow until nursing changes its *thinking* with regard to *who* is the patient. This change in thinking will result in recognition of the impact of illness on the family, the influence of family interaction to the "cause" of illness, and the reciprocity between the two.

THE NEW "PATIENT": THE FAMILY

General systems theory postulates that a change in one part of the system affects change in other parts as well. When this premise is applied to the family system, the impact of illness affects *all* family members. Thus, our previous notion that the individual is the patient would now be revised to consider the family as the "patient".

The amount of disruption to a family unit when there is illness depends on: 1) the timing of the illness in the life cycle; 2) the nature of the illness; 3) the openness of the family system at the onset of the crisis; and 4) the family position of the ill family member (Herz, 1980). Recovery is based on social, cultural, education, economic, and medical resources of the family and the ability to communicate their emotions of anxiety, guilt, and grief (Hill, 1958). The family members in hospital settings are not only in the process of coping with the physical and emotional impact of a seriously ill family member, but are also trying to cope with new roles and demands. They have functioned in familiar routines and specific roles, and now these particular interrelationships are disrupted - if only for a short time.

To assess the impact that the illness has had on a family, it is well to explore the family's cognition with respect to their perception of the illness event (Aquilera & Messick, 1976). The perceptions of the family play a central role in determining what impact the illness has, what coping patterns are used, and ultimately, what physical and behavioral reactions will occur. People think about illness in different ways. It can be seen as a threat, challenge, enemy, punishment, weakness, relief, harm and/or loss (Weisman, 1978). If a family perceives the illness as a harm or loss, for example, they may need to grieve the loss of function or ability. If the family perceives the illness as a challenge, they may focus on the positive aspects and try to master the situation, rather than focus on the negative risks involved (Lipowski, 1970).

Several studies illustrate that illness may have a significant impact on family development, structure and/or functioning. Crain et al. (1966) studied the effect that diabetes has on the parents and siblings of diabetic children. They found that diabetes produces an intrafamilial crisis that leads to less agreement between the parents on how to handle the child, more marital conflict, and lowered level of marital integration. The family's responses to serious or chronic disease can be a significant determinant for recovery, i.e., a family can hasten the healing process. A study by Litman (1966) of 100 patients with a severe orthopedic disability found that 73% of those with a "good" response to rehabilitation had been receiving "positive" reinforcement whereas 77% of those with a "poor" response did not obtain this encouragement from their families. Benjamin (1978) studied families in

which a child had recovered from an unexpected, acute, life-threatening illness. Subsequent family adjustment problems were observed such as a sense of helplessness, lack of control, and incomplete mourning experienced by parents. "Parental passivity, anxiety, and hypervigilance coupled with behavioral changes in the children set the stage for rapidly escalating over-activity and behavioral problems on the part of the children" (pp. 288).

When nurses begin to conceptualize the family as the "patient", the implications for clinical practice are numerous. Nurses in hospitals have a unique advantage in providing 24 hour care. This allows them to utilize the opportunities afforded by family visits. During the visiting period, the nurse can meet the patient's family or, better still, invite them to a family interview. This can be done by explaining that talking with families is a normal practice on the unit. Even a 15 minute interview could accomplish a great deal. By seeing the patient in his family context and observing family interaction, a greater understanding of the patient and the impact of illness on the family will be obtained (Northouse, 1980).

Opportunities are also available to emphasize the normalcy of their reactions to shock, confusion, and pressures which may be created by additional roles of parent, breadwinner, etc. (Atkinson et al., 1980). Many times families feel frightened, sad, and angry, but cannot connect these feelings to what has been happening to them. Validation by the nurse of a family member's affect can do much to alleviate a sense of aloneness by helping them make the connection between the experience of illness and their feelings of stress.

By making a special attempt in the family interview to answer questions and concerns, help them express their feelings, and include them in information or assist them to get information from the system, the nurse can provide the family with the tools for problem solving. Specifically, with regard to the family's perception of the illness, nurses can provide important information to help the family develop a realistic expectation about what the illness and treatment involves. Presented in a context of support, information about the illness, about procedures and their side effects, or information about what the family can do to prepare to adjust to the illness would be useful. In fact, the nature of the interaction itself might possibly be more important than the specific information provided (Cohen and Lazarus, 1980).

Additional resources may, at times, be necessary to provide assistance to families who seem unable to support their ill family member or who are having difficulties coping with the illness. The social worker, chaplain, volunteer, or family members of former patients with similar illness can all be utilized as additional support (Williams and Rice, 1977).

Therefore, while families can be a tremendous support system to the ill family member as he recuperates from illness, nurses can play an important role in maintaining and strengthening this vital support system. To conceptualize the family as the "patient" offers nurses in hospitals a wider view on one's lens for understanding the impact of illness on families and thus provides more intervention alternatives.

THE NEW CONNECTION: INFLUENCE OF FAMILY INTERACTION TO THE "CAUSE" OF ILLNESS

The influence of linear thinking on the etiological models of disease has created a classification of illness into those of purely psychological origins (termed mental); those with a mix between psychological origin and physical manifestations (termed psychosomatic); and those with physical origins and symptoms (termed organic). However, systemic thinkers are quick to see the fallacy of such a categorization. One cannot categorize disease or creations of mind or body when both are intimately and exquisitely linked together. However, the linear view of illness searches for factor A which causes factor B which equals factor C.

Perhaps it is this kind of thinking which limited our conceptualization of disease until the early 1950's. At that time, several researchers dared to depart from the accepted psychological and biological theories of schizophrenia to postulate that family communication, particularly the dysfunctional double bind pattern of interaction, produced disordered thought and behavior in family members (Bateson et al., 1956). Work in the area of double bind communication provided a new model of mental illness and had an enormous impact on the field of family therapy in particular, providing it with the scientific stature necessary for increased acceptance and practice. The result has been that while other psychological and biological theories of mental illness still exist to explain susceptibility, the family interactional theory has led to exciting developments in the understanding and treatment of schizophrenia (Selvini Palazzoli et al., 1978) and other dysfunctions. In a recent decade review of the family therapy literature, Olsen et al. (1980, pp. 973) confirms that, "marital and family therapy has gained credibility and emerged as a viable treatment approach for most mental health problems."

This new epistemology led others to examine the influence or contribution of family interaction to the "cause" of other types of illness. Anorexia nervosa has been successfully treated by Selvini Palazzoli (1974) using this new epistemology in a family approach. Salvador Minuchin and his colleagues (1975) reported that certain types of family structure were related to the development and maintenance of illness in children. These illnesses, which included asthma, diabetes, anorexia and chronic pain, were thought to play a major role in maintaining family homeostasis. These families were characterized by enmeshment, overprotectiveness, rigidity and lack of conflict resolution. Impressive treatment results were found when family structure was altered to more adaptive functioning.

Grolnick's (1972) review of the literature with 129 references concluded that, "family relationships do influence the onset and course of psychosomatic illness and of many organic illnesses" (pp. 478). Weakland (1976) coined the term "family somatics" and pointed to the need for increased practical application of the family interactional viewpoint to illness, even clearly organic pathology.

There, however, appears to be very little in the literature relating family interaction to what is classed as "organic illness". Very few studies of this nature have been published. One exception is a recent study by Steidl et al.

(1980) who reported family functioning was related to the patient's condition and adherence to treatment in a population of chronically ill patients on long-term dialysis. The specific areas of family functioning which were isolated included: strong parental coalition, respect for individuality in a context of closeness, and warm, affectionate and optimistic interactions. A positive relationship was found between the presence of these factors and the patient's condition and adherence to treatment.

The dearth of literature in this area is related to our lip service about "holistic", "integrated" health care which remains, in actuality, a dualistic model of treatment comprised of psychological vs. physical components, and individual vs. contextual components with no relationship between the parts. This model influences what we consider illness to be and "determines what we ask of, look for, and find in patients. In this way illness is *not* viewed, for the most part, as an inseparable part of the individual and his family." (Lewis et al., 1976, pp. 182, 183.) Unfortunately, nursing has not been immune from this fragmentation. However, it does appear that we are beginning to move away from the quest for single, specific causes of illness and are open to considering a complex of factors which influence each other in a circular fashion. Some of these factors are family-related.

Recently, a considerable body of evidence has accumulated which suggests that many serious illnesses, as well as being related to acknowledged physical causes, occur with some regularity following particular types of life experience. Holmes and Rahe (1967) developed a questionnaire to measure life events which required some degree of adaptation. The relationship of these life change events to illness was stated as follows: "It is postulated that life change events, by evoking adaptive efforts by the human organism that are faulty in kind or duration, lower body resistance and enhance the probability of disease occurrence" (Holmes and Masuda, 1973, pp. 172). It is interesting to note that approximately half of the 42 life change events may be related to family events or functions. In other words, it may not be change itself, but the context in which the change occurs that makes the event stressful, creating a ripple effect and affecting other important relationships.

A number of authors have suggested that family interaction can maintain illness (Anthony, 1970; Grolnick, 1972; Waring, 1977). Hoebel (1977) reported greater success in modifying high risk factors in coronary artery disease by changing family interaction which maintained the problem behavior rather than modifying the high risk factors themselves. Stern and Pascale (1979) have demonstrated that marital adjustment in patients with myocardial infarction may be a perpetuating factor in the course of their illness. Peck (1974) identified family dynamics which interfered with the rehabilitation of a disabled family member. However, Selvini Palazzoli et al. (1978) have begun to suggest that illness can serve a positive function or solution to impaired family interaction.

There is increasing evidence in the literature to support the connection of family interaction and illness. It is also evident that this idea is becoming more widely accepted but as yet has had limited impact in its application to nursing interventions.

SUMMARY

While nurses, families and illness may be a new combination in the health care system, it is hoped that once nurses internalize the belief that working with families is important, this combination will become less unique. As the uniqueness fades, more family nursing in hospitals will be provided which will reflect this new concept and be evidenced by knowledgeable family assessments and skillful family interviewing. It is exciting to not only observe, but be part of this evolution.

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