

# PARENTS OF HOSPITALIZED CHRONICALLY ILL CHILDREN: COMPETENCY IN QUESTION

Carole A. Robinson

Health care professionals are striving to offer family-centered care. In the care of a sick child, the family, and more specifically the parents, play an important role in promoting wellness. In fact, when a chronically ill child is cared for in the home, the parents fill the role of full-time, primary health care providers. Not only does illness become integrated as an on-going facet of daily living, but repeated hospitalizations often become a significant aspect of family life. As such, the parents' relationships with professional health care providers become a special part of the experience with illness.

This article is based on a research project that explored the views of parents of hospitalized chronically ill children. Through the in-depth interviews involved, it became evident that such parents often find themselves in complex, contradictory situations. They must retain a sense of the on-going care of the child, and they must relinquish the short-time care to professionals who are more accustomed to dealing with short-term, acute illnesses. The article also explores the use of "double bind" theory to show how the dilemma may be better understood and resolved. This is a new application of an old theory (Bateson, Jackson, Haley, and Weakland, 1956; 1963; Watzlawick, 1963). Double bind refers to a pattern of communication where individuals are caught in a system of sequenced messages that are contradictory and are associated with punishment. A "no-win" situation is created in that punishment is unavoidable. Bateson and colleagues (1956) originally proposed the theory as an explanatory device for the development of schizophrenia. The double bind has since been recognized as a facet of much normal human communication. Following years of empirical testing, the validity of the theory in relation to schizophrenia remains inconclusive; however, its clinical usefulness is clearly documented (Jones, 1977; Olson, 1972; Schuham, 1967; Watzlawick, 1963).

Double bind situations result in distress in relationships, and relationships in health care are no exception (Alexander, 1976; Bateson et al., 1956; Carter, 1981). This view of the dynamics operating between parents and professional health care providers offers a way of interpreting parental behaviours that are often

Carole A. Robinson, R.N., M.S.N., is Assistant Professor (Pediatric and Family Nursing), School of Nursing, University of British Columbia, Vancouver. The assistance of Sally Thorne, Assistant Professor at the UBC School of Nursing is gratefully acknowledged for her earlier collaboration on work regarding "interfering" families.

viewed as "interfering." Further, it directs nurses' efforts toward developing more satisfying, effective relationships with these parents.

### The Research Study

The data for this article were accumulated in a qualitative study of parents having a hospitalized, chronically ill child, which was carried out in a large, metropolitan children's hospital in Western Canada. These parents had assumed the role as primary health care providers, with regard to the day-to-day management of their children's illnesses, for periods ranging from 3 months to 21 years. All of the children were diagnosed as having different long-term illnesses such as muscular dystrophy, meningomyelocele, and toxoplasmosis. Intensive, long-term clinical work with several families that had a chronically ill child supported the formal interview data.

Kleinman's (1977, 1978) work in the area of cross-cultural medicine provided the conceptual framework for the study. He postulates that Western Society's view of the health care system, and of illness, has been dominated by the professional medical institutions and their focus on objective, scientific, biomedical explanations for illness. He proposes that the health care system is much more inclusive than these professional institutions and, in fact, that it "represents a total cultural organization of medically-relevant experiences, an integrated system of social (and personal) perceptions, use, and evaluation" (p.414). He conceptualizes the health care system as composed of three different but interacting sectors, which are socio-culturally shaped and defined by their own beliefs, roles, behaviours and institutions. The sectors are: The professional medical care system; a popular culture system, which is individual and family based; and, a folk care system.

Kleinman (1978) views all attempts to understand illness and treatment as "explanatory models", that differ among the sectors because of differing health value hierarchies. Individuals in the professional medical sector explain, understand, and respond to illness in terms of the biological and psychological phenomena of disease; whereas, the popular medical culture bases its explanatory models on personal and social experience. Kleinman, Eisenberg, and Good (1978) assert that neither the professional view nor the popular view of illness are sufficient to explain the phenomena. However, the dominance of the professional view of illness has resulted in a consistent disregard in both practice and research for the illness experience. Health professionals are coming to realize that an understanding of the client's explanatory model is necessary to the negotiation of mutually satisfying and efficacious care (Leininger, 1978). Kleinman (1978) states that "explanatory models can be objectively elicited as more or less formally structured coherent accounts of reality, though they may be and often are ambiguous and changing" (p.421).

As hospitalization is often a repeated aspect of long-term experience with illness, and because little is known about how it affects day-to-day family life, this study was designed to explore parents' views. The phenomenological paradigm of research methodology directed both the processes of data collection and data analysis (Knaak, 1984; Schwartz and Jacobs, 1979). Nine parents from six families participated. They were selected by virtue of being "expert witnesses" with regard to the research question (Pearsall, 1965).

The data were collected from the parents' accounts of their experiences during the children's hospitalizations. A semi-structured question guide adapted from Kleinman et al. (1978) was used to initiate interaction. Once data collection began, the researcher's questions were generated in response to the parents' explanations. This permitted in-depth exploration of the participants' perspectives. The researcher validated the accuracy of her understanding of the parents' experiences throughout the interview process. A total of fourteen interviews took place.

Verbatim transcripts of the parents' accounts were subjected to constant comparative analysis throughout the research process (Lofland, 1971). As it was the researcher's intent to present data that increase understanding of the shared aspects of the parents' perspectives, analysis resulted in a framework of themes that were common to the participants' accounts. The process is one of interpreting the phenomenon under study, through immersion in the construction of accounts (Davis, 1978), and thus, through intimate familiarity with the data (Lofland, 1971).

One of the common themes was the dilemma parents face about their competency as integral members of the health care team. All of the parents explained their experiences differently. However, at some point, all described being caught in the situation of not knowing what to do for their hospitalized children because it seemed that every attempt was denigrated or disregarded. The parents who had long-term experiences described the dilemma retrospectively, while the parents who were relatively new to the experience of chronic illness described actively being caught. Double bind theory has proven helpful in interpreting the dynamics from the parents' perspective.

### **The Beginning of the Double Bind**

When asked to describe and explain their experiences with hospitalization, the participating parents invariably began their stories by placing hospitalization in the context of their on-going experience with chronic illness. Thus, hospitalization is viewed in the context of day-to-day illness management. It cannot be seen as an isolated incident as would an acute episodic illness.

This is where the double bind begins. Parents recognize that

they are expected to be competent primary health care providers in the day-to-day management of illness problems of a chronically sick child. There are few resources available on a 24-hour basis. That is the reality of living with chronic illness. The problems require continuous attention. Parents must be competent. As they stated over and over, "There is no other choice - you manage because you have to." The professional medical system requires that parents be competent because it cannot assume daily management of the chronically ill. This expectation is reinforced by the inherent threat that if they are not, their child's health will suffer.

When parents decide, in consultation with professional health care providers, to admit their child to hospital, several points are critical. The first is that hospitalization is only one facet of the larger, continuing experience with illness. It is viewed in relation to the effect it has on the child's on-going long-term illness experience, and primarily its effect on those problems in daily living that arise from being sick (Kleinman, et al., 1978). The second point, a basic extension of the first, is that parents have a holistic understanding of their child, knowing the past experiences and anticipating likely future implications. A third point is that parents view hospitalization from their position as competent health care providers who take responsibility for the majority of the illness management for their child. Thus, they enter the realm of professional health care providers assuming that, for a short time, they will be relinquishing their job as primary health care providers. However - and this is a most important aspect for health care professionals to understand - they assume that the responsibility for managing the child's illness will be shared, and that mutually satisfying care will be negotiated.

Initially, the parents believed that their overall understanding of the child, the illness, and the home circumstances contributing to illness management would be recognized and valued in the hospital setting. Instead, the parents explained that their perspective was often systematically disregarded by professional health care providers. How often do nurses hear parents say "I know my child best" and how often is this put aside? As one mother explained:

I live with the child for twenty-four hours of the day, and I know the child, and I know what he's capable of doing, and what he does and doesn't do when he's sick. I mean I've been around him for five years when he's in and out of hospitals all the time.

### **Adversarial Situations**

Parents reported a sense of being under-valued within the professional medical system. This led to dissatisfaction with the health care received, and promoted an adversarial relationship with professional health care providers. This is the essence of the double bind situation. Parents say they get a subtle message in



the professional care setting: They are no longer competent health care providers. Instead, they are to leave the care of their child in the hands of the "experts". "Doctor knows best." "Nurse knows best." The parents' fear is that non-compliance with the hidden message to leave illness management to the professionals may result in suffering for the child. From the parents' perspective, there are long-term risks associated with this approach as the illness is not self-limiting. One mother expressed her fears this way: "You hate to really say anything because if you're not here you don't know what they could be doing to your kid, you know." Thus, all the elements of a full double bind are present. The first injunction, "You must be competent," is contradicted by the second more subtle injunction, "You must not be competent," and both are qualified by punishments. Furthermore, most parents feel caught in the situation because their child's long-term prognosis depends to some measure on professional intervention.

The parents' accounts emphasized the important role their evolving long-term relationships with professional health care providers plays in the experience with illness. Initial uncertainty about how the hospitalization would progress prompted an extensive search for information by the parents while they patiently waited for opportunities to actively participate in managing the child's illness experience in hospital. At this point, the parents described themselves as seeking involvement, but having difficulty sorting out their role because information was hard to get, hard to understand, and often incomplete. Beck, Rawlins, and Williams (1984) state that "communication patterns in which only one person has access to the truth rely on trust as the basis for action" (p.606). Apart from their experience, many parents had become exceedingly well informed about the disease process. However, despite feeling under valued in the hospital setting, their trust in the "good intentions" of the professional health care providers usually promoted compliance and patience, and they continued to wait for information and recognition.

Experience teaches the parents that the medical focus on disease often does not take into account the child's experience with illness. Trust is then shaken and the "no win" situation becomes operational. Parents are faced with the dilemma of either complying with the unspoken professional medical injunction to relinquish responsibility, or of assuming a non-compliant position by actively advocating a more positive involvement with the illness. Either action carries the inherent threat of causing suffering for their ill child.

Beck and colleagues (1984) state that "double bind interactions occur rather commonly in normal human interactions both within and outside the family. When caught in a double bind, a healthy individual usually responds defensively or literally. The individual experiences discomfort, but corrective interactions . . . prevent a pathological state" (p.606). In their allegiance to the sick children, the parents uniformly responded defensively. As a group, they

were united in their sense of being responsible for insuring a positive experience in hospital. One mother explained it this way:

Maybe I'm more protective than I should be when he's in the hospital, because I do have to make sure that he never has a bad experience - because of the time he does spend in hospital.

The ill children are viewed as vulnerable and in need of protection. The adversarial relationships with professional health care providers are associated with parental feelings of anger, uncertainty, helplessness, hopelessness, and confusion. One mother vividly described the relationship this way:

We, parents, were talking the other day in the parents' room and we were saying, "We think the nurses have a conspiracy

phone the doctors and say "Okay, they're gone, you can come up and do it without the mum in the way."

The predominant emotional response was one of anger.

Sometimes when we're sitting there we'll be really calm and stuff - then it starts to build up to where you get so mad at these people because they treat you like a nobody it seems.

Much of the defensive behaviour that the parents described is traditionally viewed by health care professionals as "interfering". The parents became extremely vigilant in their role as advocate: questioning, observing, spending long periods of time in hospital, and "interfering" in decisions about care. As one mother explained, "I realize now that you really have to fight if you want something." All of the parents expressed concern about the routine occurrences that health care professionals consider simply "part of being in hospital."

Well I think we're trying to avoid anything that isn't really necessary. I guess it bugs him a bit, you know, to be poked around and that kind of stuff - and if it isn't really necessary. In the beginning we didn't mind because they can learn from it. So we can appreciate the fact that they need somebody to be a guinea pig but it comes to, after so much of it, it's just go and find somebody else to poke around now.

It is the parents' view that if they are not with the child, he or she will have to go through the experience alone.

### **Implications for Nursing**

Clearly, this double bind situation has a negative impact on relationships in the health care setting. This has significant implications for nurses who are committed to the provision of high

quality, family-centered care. The cycle of conflicting expectations must be broken through the negotiation of mutually satisfying care. Traditional ways of dealing with "interfering" families, which are focused on re-establishing compliance and trust by simply reducing or eliminating the "interfering" behaviours, do not promote understanding of the parents' perspectives.

The first step in the negotiation process involves gaining an understanding of the parents' views. This attention reinforces the importance of the parents' position in the health care team, and the value of their unique perspective of the ill child. It requires on-going, active listening on the part of the nurse. Pediatric nurses must recognize that parents of chronically ill children are different, and that their needs are different from those of parents of children with acute, episodic illnesses.

Parents must also be given the information about their child's experience that will permit informed decision making. In other words, what are the benefits and risks to the daily problems of living that arise from being chronically ill? As one set of parents stated: "You don't know what to do when you don't know."

The study also revealed that discussion between the nurse and the parents is an essential element in the care of the chronically ill. Nurses should ask parents questions that indicate a desire to understand their perspective and which may provide information that sheds light on the implications of medical management for the child's experience. It is also a nursing responsibility to promote parental understanding of the professional medical perspective, which includes acknowledging the limitations of medical management. However, again, mutual understanding is not enough. Parents must also feel that their concerns are attended to, and thus viewed as valid. This may be as simple as maintaining the child's usual diet to reduce the likelihood of vomiting.

You walk in here and you tell them the answers to all the questions they ask. They put it on the chart but nobody reads the chart. I say I've told them three times, "Don't give him homogenized milk, it makes him too phlegmy," but it's still coming up on his tray.

Nurses are in a position to increase parental competence by assisting them in planning for management concerns that are likely to arise after hospitalization. This is part of recognizing the on-going nature of the chronic illness experience and of acknowledging the parents' health care responsibilities. Unfortunately, the opportunity is often missed. One father explained his experience this way:

The hospital is concerned with any immediate illness that is going on with him. Then they'll do something about it. But as far as trying to set out a diet or a lifestyle for him, to pattern him after - they're more concerned when things are

already wrong, like his asthma. That's an immediate thing. But as far as seeing what they can do to develop him like a normal kid they don't seem to do much in that aspect. Somewhere along the line they've got to start preparing him for his future, and giving us some kind of idea of what we can do to develop his future as normally as possible.

When chronic illness is involved the children do not get well but they do go home to the care of their parents.

### Summary

When a foundation of mutual respect and understanding is established it is possible for parents and professional health care providers to negotiate care that is mutually satisfying. Under these circumstances the double bind is eliminated. Parental competency would be recognized as a valuable adjunct to illness management in the professional setting.

Given that high quality, family-centered care is a priority for pediatric practitioners, it is imperative that good working relationships be promoted with families of sick children. In the opinion of parents in this study of hospitalized chronically ill children, health care professionals must recognize the long-term nature of the family's experience with illness and the implications in terms of sharing illness management. When these parents feel that their competence as health care providers is in question, and that their role on the health care team is under valued, a complex double bind situation results. The cycle of dissatisfaction that arises for parents and nurses under these circumstances can be broken, and in the process family "interference" in professional health care can become productive. The key is negotiation.

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## RÉSUMÉ

### Parents d'enfants hospitalisés a la suite d'une maladie chronique: remise en question de la compétence

Le présent article fait état des résultats d'une étude qualitative conçue pour explorer les expériences des parents alors que leur enfant atteint de maladie chronique était hospitalisé. Aujourd'hui, un nombre croissant d'enfants atteints d'une maladie chronique sont soignés à la maison. Dans ces cas, les parents jouent un rôle primordial dans la presentation des soins quotidiens. Ces parents deviennent rapidement des experts sur les effets de la maladie, le traitement et les réactions de l'enfant aux soins. L'hospitalisation, un aspect souvent répété de la maladie au long cours, exige des parents qu'ils cèdent leur rôle de premier plan dans la presentation de soins. Il s'ensuit que les parents éprouvent des sentiments ambivalents complexes, car ils se sentent dévalués et ignorés au sein de l'équipe de soins. Ce sentiment entraîne une insatisfaction qui influe de manière négative sur les rapports qui lient les membres de l'équipe de soins. La compréhension du point de vue de la famille permettra aux infirmiers d'entretenir des rapports plus satisfaisants et plus efficaces avec ces parents.

### CALL FOR ABSTRACTS

The Council on Nursing and Anthropology and the Transcultural Nursing Society are sponsoring a one-day conference, "International Nursing: The Cross-Cultural Context" on May 6, 1986 at the Convention Center, Edmonton, Alberta, CANADA. This conference precedes the Second International Nursing Research Conference. Abstracts of one page or less should be received by February 1, 1986. Send abstracts to:

Dr. Janice Morse  
Faculty of Nursing  
Clinical Sciences Building  
University of Alberta  
Edmonton, Alberta  
Canada T6G 2G3