

CULTURE AND ILLNESS: PARENTS' PRECEPTIONS OF THEIR CHILD'S LONG TERM ILLNESS

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The family is often the primary decision-maker in matters related to health and illness. Litman (1974) states that, "the family constitutes perhaps the most important social context within which illness occurs and is resolved" (p. 495).

Spiralling health care costs have resulted in shorter hospital stays and a shift to home care services (Davis, 1980). Families are increasingly being called upon to take on the role of health teacher and caretaker. In those instances when a child has a long term health problem and is cared for in the home, parents must assume a major decision-making role in the child's treatment. Cultural meanings applied to sickness are therefore of considerable importance to health professionals and consumers (Kleinman, Eisenberg, & Good, 1978).

PURPOSE

This paper is based on a study which was conducted to examine how Chinese and white families dealt with the long term illness of a child in the home. More specifically, the study sought to explain how families perceived their child's health problem, and how family members managed their interactions with the child on a day-to-day basis in the home.

LITERATURE REVIEW

Much has been written about the chronically ill child and his or her family (for example, Adams, M., 1978; Adams, D. W., 1979; Anthony & Koupernik, 1973; Holaday, 1978; Mailick, 1979; Mann, Kmetz, Patel, & Weber, 1980; Mattsson, 1972). While this literature deals with parenting, the dynamics of family interaction, and adaptive tasks in relation to illness, little is known about how different cultural

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groups within the context of North American society experience and manage their child's long term illness in the home. This is not to say that there is not a wealth of information on how culture shapes illness experience (see, for example, Eisenberg, 1977; Fabrega, 1972; Good & Good, 1981; Kleinman et al., 1978; Leininger, 1978; Lewis, 1981; Zola, 1966). This literature argues that illness experience is strongly influenced by culture.

Kleinman et al. (1978) make a conceptual distinction between disease and illness. They state that:

Illness is shaped by cultural factors governing perception, labeling, explanation, and valuation of the discomforting experience . . . , processes embedded in a complex family, social and cultural nexus. Because illness experience is an intimate part of social systems of meaning and rules for behavior it is strongly influenced by culture: it is . . . culturally constructed . . . Both concepts (disease and illness) are explanatory models mirroring multilevel relations between separate aspects of a complex, fluid, total phenomenon: sickness. (p. 252).

Illness can be perceived as the human experience of disease. This experience does not stand in a direct relationship to the disease as defined by Western biomedical science. "Similar degrees of organ pathology may generate quite different reports of pain and distress" (Kleinman et al., 1978, p. 251).

While the literature informs us that cultural categories confer specific meanings on sickness, what is missing are actual descriptions of how, for example, Chinese families in North American society manage a child's health problem in the setting of their homes. This study was therefore designed to find out families' perception of a child's health problem, and how they managed a child in the home.

METHODOLOGICAL AND THEORETICAL PERSPECTIVE OF THE STUDY

A qualitative approach was used in this study to obtain families' perception of a child's health problem. In recent years the qualitative approach has gained increased recognition among nurse researchers as one of the appropriate methods for the study of phenomena which are nursing's prerogative (for example, Anderson, 1981, a,b; Anderson & Chung, 1982; Davis, 1978, 1980; Degner, Beaton, & Glass, 1982; Field, 1981; Lindermann, 1974; Munhall, 1982; Oiler, 1982).

Many researchers who use a qualitative approach see their work as having its theoretical underpinnings in phenomenology. The phenomenological approach has its genesis in the writings of some European social theorists, most prominently, Edmund Husserl (1952), and Alfred Schutz (1964, 1967, 1973). The aim of this perspective is to formulate a model for the study of human behavior at the level of everyday social organization, which focuses on the subjective experiences of persons in everyday life. The relevance of this approach to nursing research has been addressed by some nurse researchers (Davis, 1978; Oiler, 1982).

The phenomenological approach assumes that there is value to an analysis of both the inner experience and outer behavior of a subject as viewed by both the researcher and the participants (Rist, 1979). Oiler (1982) points out that "the aim of the phenomenological approach is to *describe* experience as it is lived" (p. 178).

The phenomenological approach emphasizes indepth qualitative analysis of data to gain an understanding of how people interpret and give meaning to their situation. This often necessitates the presentation of verbatim accounts to show the reader how the researcher arrived at interpretations of the data.

The phenomenological perspective is of particular value in clinical nursing research when there is a wish to understand how people perceive their situation. It was for this reason that this methodology was selected to address the research question presented in this paper.

METHOD

Data were obtained over a one year period from seven white families and six Chinese families having a child with a long term health problem. Families were contacted with the assistance of health care personnel who agreed to present a letter describing the study to the families. Those families who wished to participate so informed the health care workers and gave permission for the researchers to contact them.

The families

The white families were all English Canadian, born and raised in Canada. They were of English (from British Isles) descent, with the exception of one family of Italian descent many generations back. They could all be categorized as belonging to the middle class. In the Chinese families, the parents had all emigrated to Canada from China, Hong Kong, and Taiwan. The parents in one family moved to Canada as children; the other parents emigrated in adulthood, and have lived

in Canada for varying lengths of time. The men all spoke English but some of the women were limited in their use of this language. Communication was facilitated by their husbands' presence during the visits to the families. Also, the research assistant spoke some Cantonese. The Chinese families could be categorized as belonging to the working and middle classes.

The children

The children were all born in Canada. They ranged in age from six months to ten years, and had a variety of long term health problems. The health problems varied in outcomes for the child. Four of the fourteen children had life threatening health problems (one family had two children with health problems). The other health problems could be categorized as non-life threatening. This category included two children with hearing impairments and one child with visual impairment. The children were looked after at home by their families. Only two children, one Chinese and the other white, were briefly hospitalized over the course of the study. The Chinese child was hospitalized for elective surgery related to her health problem, and the white child for fractures. This child had osteogenesis imperfecta, and fractured easily. The hospitalization was therefore related to his health problem.

Data Collection Procedures

Indepth interviews were conducted with the families in their homes. Each family was visited on three or four occasions, and from two to five hours were spent with each family at each visit, depending upon the time of day, and other family commitments. All family members living in the home usually participated in the interviews, except in those instances when other commitments took priority over the researchers' visits. As well, the researchers observed parent-child-sibling-playmate interactions under a variety of circumstances in the home, and participated in activities with families. These activities included play with the children, mealtimes, and recreational activities such as watching television.

In only one family did a grandparent live in the home. This was in one of the Chinese families. He participated in the interviews, and his interactions with the child were observed and tape recorded.

The interviews and family interactions were tape recorded. In addition, fieldnotes were made of each visit to permit the documentation of those activities that could not be captured on tape.

Data Analysis

Audiotapes were transcribed after each interview, and coded so that participants' names would not appear on the transcripts. Repetitive

patterns were identified in the data and fieldnotes, and these were used to develop conceptual categories.

The joint collection and analysis of data over the course of the study reflect the strategies for carrying out qualitative research described by Glaser & Strauss (1965). The conceptual categories were worked out in a systematic way by the principal investigator and the research assistant in relation to the data gathered.

The analysis of the data from each interview generated questions that were followed up in the later interviews. This permitted clarification of the families' accounts of their experiences. This total process facilitated the tightening up of the conceptual categories, and the elucidation of their conceptual properties.

THE FINDINGS

This paper will focus on two of the five major conceptual categories developed from the data that reflect differing perceptions of illness in white and Chinese parents. These categories show how illness experiences can be located within cultural contexts.

Whereas the white families emphasized the "normalization" of their child, a repetitive theme in the interviews with the Chinese families was maintaining the "contentment" and "happiness" of their child. These conceptual categories were *independent of a child's actual health problem*. That is, regardless of the health problem of the child, the notion of treating the child as "normal" was a constant theme in the interviews with the white families, and the notions of "contentment" and "happiness" of the child constant themes in the interviews with Chinese families. These could be regarded as *invariant properties of illness experience located in the data from each cultural group*. It is for this reason therefore, that these categories are highlighted in this paper. The one grandparent who participated in the study subscribed to this notion of having a happy and contented child. These dimensions of illness experience will be discussed, and parents' accounts presented.

The White Families: Normalization as a dimension of illness experience

One of the underlying themes in the accounts of the white families was that they treated their child as a "normal" child. They viewed their child's health problem, as defined by Western biomedical science, as distinct from their perceptions of the child as a "normal child," and some parents changed their lifestyles so that the child would not stand out as being different (Anderson, 1981 (b); Anderson & Chung, 1982).

The usage of the term "normal" needs to be clarified. By this is meant the commonsense notion of normality, that is, the "ordinary," "average" child who does not stand out as being different from his or her peers. This is what the parents meant when they said their child was normal, as borne out in their accounts to the researchers.

This feature of minimizing the difference of the sick child from other children was evident among all parents, regardless of the child's health problems. Family members in the families with diabetic children, for example, altered their eating habits so that the child would not have a different diet. This is borne out in this parent's account:

Father: He eats the same food exactly as we eat . . . We are not having sugar except when we are having coffee, that's about it . . . I wouldn't want to bring up a kid on a strict diet.

Parents curtailed the use of "sweets" in the home. One parent described, for example, how she substituted dream whip for icing when she made a cake, which was about once a month. She stated that they all liked dream whip, and used it so that the child would not feel different. Similarly, according to the mother, treat consisted of potato chips or cheesies. In her words, "it is not really a sweet, it doesn't make him feel any different."

The siblings in these families also altered their eating habits so that the children with diabetes would not have a different diet from their own. One of the researchers spent some time watching television with the children in one family. They all ate "cheesies", and the "well" sibling told her that he never ate candies when his brother was around. Similarly at dinner time, the child with diabetes was not required to have different dessert from other family members.

This feature of minimizing the difference of the child from other family members, and emphasizing the child's normality was also evident among parents who had children with life-threatening diseases. Here is one mother's account:

Really, he is to us now a normal child and it is a day-to-day basis but the pressure is off. Really we just treat him normally. This is the best way to look at it and do because if you are going to worry about it, I think you can cause harm to the child and that is not good for the child.

It is of interest that this particular family would not allow the researchers to interview their 10-year-old son, out of concern that such an interview might upset him. The discussion of certain topics was not allowed with the child.

Parents of a child born with a cleft palate and hydrocephalus also emphasized that they treated the child as normal. They were quick to point out that the child now looked normal since her operation, even though the child's physiological abnormality was still quite obvious to the observers.

In the situations where a child was required to do exercises, parents ensured that these were done, and in fact a child would sometimes demonstrate the exercises to the researchers. What was stressed by parents in the interviews was that such treatments had to be carried out to facilitate the child's rehabilitation. So, although in the interviews the parents focused on how they treated the child as normal, in actual practice the child still had to cope with the limitations of the health problem, follow treatment schedules, and keep medical appointments for diagnostic tests and treatments (Anderson, 1981 a, b).

The Chinese Families: "Contentment" and "happiness" as a dimension of the illness experience

It is of interest that the patterns of interaction in Chinese families observed by the researchers were different from those in the white families; they had a different way of dealing with the child's illness. One of the main themes observed in the Chinese families was that they placed emphasis on the child's "contentment" and "happiness." The achievement of normality in so far as this involved rigorous rehabilitative exercises and other treatments was not constructed as an important dimension of illness experience in the Chinese families. Rather, they tended to treat the child in terms of what they could do to help cope with the limitations placed on everyday life activities. This was particularly evident among the parents with a handicapped child. As one parent with two deaf children put it:

I think K. and I are very practical people, and it took us, I don't think as long, as most people to accept . . . So therefore, I feel that, . . . because of that we just said "okay, fine, we don't have . . . a normal child." We channeled our energies towards what can we do to help with this handicap, instead of trying to not acknowledge that he has a handicap. Because we know he won't be normal and that's all there is to it. We'll have to be able to teach him to cope with situations.

What was evident in this particular family was a "clash" with the requirements of health professionals. In fact, on the first visit to this family the mother expressed her concern that health professionals tended to "push" the child and wanted him to measure up to some

norm. According to her, health professionals (researchers included) did not recognize the child's difference, nor did they recognize milestones that the child accomplished, which may be great achievements for him although they may not measure up to the professionals' views of normalcy.

Families, when describing their children to the researchers, focused on the features that made the child "stand out" as being different. Here is one mother's account of her two-year-old son with Down's Syndrome as compared to her four-year-old son:

When he was born, he was really quiet. He just lie down on the bed and did nothing . . . He is different, he is a quiet baby and the other is a noisy baby.

This feature of perceiving the child as being different from other family members was also evident among the responses of the families' significant others. Here are two parents' accounts:

Parent 1: My parents, my mother rather, and my sisters, have trouble coping with them . . . Now they've more or less accepted that they are different and they will make allowances.

Parent 2: I told my parents, my side, and didn't tell my husband's side. Because my mother-in-law doesn't like him at all.

According to these parents, their response to the attitudes of their significant others in relation to their child was to limit their contact with these significant others or to avoid bringing their child to the homes of their significant others when they visited.

Quite clearly, the parents' perception of the child as being different was also consistent with their actual management of the child's everyday life. Further indication of this was borne out in one mother's description of how she managed her two deaf children when they had colds. This mother said that she tended to administer a fair bit of decongestants to her two children. Her reason for doing so was to prevent her children from getting ear infections to which, unlike other children, they were susceptible.

Underlying the management of the child's health problem was their emphasis on maintaining and promoting the comfort of the child. Treatments prescribed by health professionals were organized within the context of this significant aspect of family life. This was particularly evident among the parents with either a physically handicapped or developmentally delayed child who were required to perform exercises with the child as part of the treatment regimen. For example, one

father with a developmentally delayed child as a result of prematurity indicated that he and his wife seldom did the exercises to assist the child in gross motor development because the child disliked the exercises and cried when they were being done. Another father with a child born with hydrocephalus remarked that he would stop doing exercises with his child when she cried, and to comfort the child he would give her food or drink.

Some of the families attempted to do the exercises during the researchers' visits — they demonstrated that they knew what should be done. It was significant, however, that these demonstrations were promptly discontinued at any show of discomfort by the child. Thus, among the Chinese families maintaining the comfort of the child took precedence over strictly following treatment that might disrupt the harmonious state of the child even if following treatment might ultimately result in some improvement in the child's condition. Rather, the families subscribed to the notion of "looking after" the child in the best possible way. That is, they wished to fulfill the needs of the child. The notion of normalization was not highly stressed.

DISCUSSION

The data from the Chinese and white families revealed some striking contrasts in terms of how they viewed a child with a health problem, how they viewed the phenomenon of normalization, and how they interacted with the child. It would appear from this study that "normalization" is a culturally located phenomenon. It was noted that the white families emphasized the normality of their child. In contrast to the white families the Chinese families tended to help the child cope with limitations, and emphasized the comfort and contentment of the child.

What is at issue here is that the Chinese families had a different world view from the white families, and most often from the health professionals who worked with them. This was borne out in informal discussions with health professionals during the course of the study. They said that the emphasis of their programs with these families was to help the child to live as normal life as possible.

The normalization process is often considered as a way of improving the quality of life of the person with a health problem. Wolfensberger (1972) is one of the leading proponents of normalization. His work is accepted by many health professionals as one model which provides direction for the provision of care to persons with physical or mental handicaps. What seems to be the case is that health

professionals and white lay persons subscribe to a similar viewpoint. That is, a person with a health problem ought to be treated as normal so that he or she will not stand out deviant.

This was definitely not the case in the Chinese families. In fact, when a child had a health problem the child was protected from the discomforts of treatment. Let us note that Chinese families put a high priority on having a normal child; as one mother put it, "everyone wants a normal child." However, if the child had a health problem, then the main thrust was to help the child cope and to have as contented a child as possible.

It became clear during the course of the study that raising a child with a health problem and assuming the role of health teacher were new experiences for Chinese families. When asked what would have happened if their child had been born in Hong Kong or China, they said that there were no services for such children, and quite likely the child might not have survived. If the child survived the family would have "looked after" the child. Families that could afford it usually employed someone to look after the child.

This raises an important point. When health professionals request that these families carry out the treatments of the child they are asking that the families do what may be unfamiliar to them. It stands to reason, therefore, that families may find it difficult to comply with health professionals' requests. There is a need to question if some of the models currently used which place an expectation on parents to manage a child's health problem are appropriate within the context of Chinese families. From this study it could be argued that the opportunities for the child's rehabilitation may have been minimized, as families were unfamiliar with the roles they were supposed to assume. An important question that arises is whether, in the long run, this will have negative consequences on the child's rehabilitation. Further study is needed to focus on the outcomes of treatment of these children.

IMPLICATIONS FOR PRACTICE

The findings from this study have implications for professional nursing practice, particularly with Chinese families. It was noted earlier that for Chinese families normalization was not the issue, nor did the treatments prescribed by health professionals take top priority. Protecting the child and keeping the child contented were important to them. It was also noted that assuming the role of health teacher was a new experience. In fact, some of the families said they would have liked more frequent visits from health professionals to help them look

after the child, and to teach the child. In a sense, their expectations conflicted directly with those of the professionals who expected families to teach their child, and to promote their child's health.

This study emphasizes how cultural factors influence the ways in which families manage treatments in the context of everyday life, and points to the need for practitioners to take into account a family's priorities and understanding of the situation if culturally acceptable care is to be provided. Kleinman et al. (1978, p. 254) have argued that patients and practitioners operate from within different explanatory models which are often discrepant in cognitive content, therapeutic values, expectations and goals.

Where there are major differences in social class and cultural beliefs, these comparisons should systematically search for tacit conflicts in expectations and goals . . . Here the clinician mediates between different cognitive and value orientations. He actively negotiates with the patient, as a *therapeutic ally*, about treatment and expected outcomes. (p. 257)

The process of negotiation, critical to providing effective care, can only take place if the nurse understands the patient's perspective. This will demand getting information from families about their priorities and expectations, and organizing care for the family based upon their particular situation. Kleinman et al. (1978) point out that "no simple outline (for negotiation) suffices at this stage, because negotiation between explanatory models depends on where discrepancies lie and whether they affect care" (p. 257). What is important is the ability to identify discrepancies between explanatory models and to seek out ways of working with the family that will result in efficacious care.

There were differences between the priorities of health professionals and the priorities of the Chinese families who participated in the study. For professionals, helping a child to develop motor skills was critical, but for families the comfort of the child took precedence over the development of motor skills. In this light, failure to follow the professionals' recommendations for the child may be an expression of the conflict in priorities that exists between the professional and client, and not an expression of negligence on the client's part. This being the case, professionals need to negotiate with their clients so that the care provided can be culturally acceptable.

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RÉSUMÉ

Culture et maladie: les parents face à une maladie chronique chez leur enfant

Le présent article traite de la façon dont les familles chinoises et les familles blanches font face à la maladie chronique de leur enfant, dans le milieu familial. Les renseignements recueillis des familles révèlent qu'il existe des contrastes frappants entre les deux groupes de familles, tant dans leur façon de considérer l'enfant affligé d'un problème de santé que dans leur façon d'envisager le "phénomène de normalisation." On y examine les implications que les conclusions de l'étude représentent pour les professionnels des soins infirmiers.