CLINIC MOTHERS' PERCEPTIONS OF THEIR CHILDREN'S HEALTH CARE

by

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A Thesis Submitted to the Faculty of the

COLLEGE OF NURSING

In Partial Fulfillment of the Requirements
For the Degree of

MASTER OF SCIENCE

In the Graduate College

THE UNIVERSITY OF ARIZONA

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November 14, 1980
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To my wonderful family,

whose love, support,

and encouragement

sustain me.

ACKNOWLEDGMENTS

The researcher would like to express her appreciation to the following individuals for their assistance:

The members of my thesis committee Dr. Agnes Aamodt, Chairperson; Ms. Patricia Barton and Dr. Margarita Kay.

The staff at the Crippled Children's Clinic for their suggestions and interest.

The mothers who willingly gave of their time and themselves to make this study possible.

My classmates for their support, friendship and encouragement.

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ABSTRACT

"Clinic Mothers' Perceptions of Their Children's Health Care" was an exploratory study designed to answer the following research question: What knowledge informs (cognitively directs) the health behavior of mothers who bring their children to a multispecialty ambulatory clinic setting? What do these mothers say about what they do?

Ethnographic techniques were used to collect and analyze the data. Four informants were each interviewed four times. Five domains were analyzed and presented; they include: "things that tell me my child is feeling well," "things that let me know my child isn't feeling well," "things that I take care of," "things to consult a doctor about," and "kinds of feelings mothers have about the health care of their children."

Five cultural themes emerged from the data. They include: (1) Let me participate in my child's health care, (2) Know how your children act when they feel well, (3) Parents should feel responsible for their children's health care, (4) Mothers should want their children to be comfortable, healthy, and respected by health care givers, and (5) I have a way I take care of my child.

Finally, recommendations were made for nursing practice, as well as for further research study.

CHAPTER 1

INTRODUCTION

Quality health care for all children is a goal which most everyone desires. For years, barriers to children's health care have been investigated, pondered over, and studied. The literature is replete with researcher's attempts to ferret out variables which negatively influence mothers' use of today's health care delivery system. In order to understand why mothers behave as they do, we must seek an understanding of the cognitive processes they put into play as they make decisions about their child/ren's health and illness care. This study attempts to look at how clinic mothers define health and illness and the information they use in planning for the health care of their children.

It is difficult to analyze just which elements trigger the care-seeking behaviors which a mother demonstrates. However, it is well established that the behaviors she demonstrates affect her family and therefore affect the child. In fact, maternal and child health care-seeking behavior tends to form a consistent and somewhat predictable pattern (Morris,Hatch and Chipman 1966). In other words, the mother's health care behavior becomes the child's health care.

Before the recent bacteriological era (Suchman 1970) most health care was based on what we call psychosocial factors. Primitive medical men relied heavily on the power of suggestion derived from the social

authority vested in them and the psychological readiness of their patients to believe in their cures.

In the past, the appearance of illness was likely to mean that the individual had fallen out of equilibrium with himself and his surroundings. It wasn't until approximately the 17th century (Bennett 1979) that the ideas about health and illness in Europe emphasized that disease was a natural phenomenon with a process of its own. It was the philosophical splitting of the mind and body which lead to the accumulation of information about the structure and function of the body and the process of disease.

Today, as in the past, man's state of health is often determined by what he does to himself (Suchman 1970) rather than by germ causation. Man's psychosocial environment, as well as his physical environment, is again being implicated as the prime determinant of his state of health.

As one can see, man's beliefs about health and illness have come full circle. We have gone from theories of illness linked to psychosocial variables, to theories of germ causation, and back to psychosocial causes. It is important to recognize that illness has a meaning and significance beyond the descriptions of pathology; it goes beyond the considerations of pathological processes, signs, symptoms, and diagnostic categories. It is part of an individual's relationship with society.

How does this relationship affect the behavior of mothers and ultimately the care of their child/ren? Since mothers are the prime determinants of their children's health care one must look at what affects them. Some of the facets which the literature identifies as significant include: cultural group, social group, reward systems,

psychological processes, etc. In other words, there are many variables which affect the health behavior of mothers regarding their children's health care.

Mothers are influenced in their health decisions to accept or reject the new, to abandon or cling to the old, by their cultural background which gives them a value system justifying their likes and dislikes, beliefs and attitudes, customs and habits (Clark 1970). Comprehending the mother's culture is imperative, for it is through this knowledge that she determines what is medically relevant (Adair 1970).

The mother's perceptions of social factors within her environment affect not only the occurrence of illness, but also play a part in determining the content, course, chronicity and outcome of disease (Meyer and Sainsbury 1975). Furthermore, it is likely that the degree to which a mother sees herself as able to control these aspects of her world, bears some relationship (Gochman 1971) to her beliefs about health and illness.

King (1962) stresses the importance of social factors and their relationship to mothers' health behaviors. He states that any beliefs and attitudes regarding health and disease are integrated with all other important belief and practice systems such as: kinship relations, religious beliefs, methods of political and social control, esthetic interests, etc.

Previously, it was stated that quality health care for all children was desired by everyone. In reality, attainment of this goal may not be possible as there may be no simple solution to the provision of quality health care for all children. For as has been found in the

quest for answers to other perplexing societal problems such as poverty, the determinants of utilization and motivation are highly complex. However, if we can identify and define variables which influence a mother's perceptions of her child/ren's health care, perhaps we can assist her to utilize the professional health care system to her childrens' best advantage and to make that experience a positive and meaningful one for all.

Statement of the Problem

The research question to be investigated in this study is: What knowledge informs (cognitively directs) the health behavior of mothers who bring their child/ren to a multispecialty ambulatory clinic setting? What do they say about what they do?

Many of the studies done on the health behaviors of mothers have dealt with superficial demographic and background variables rather than with fundamental, theoretically derived attitudes and subjective perceptions. There is no doubt that the joint effects of a mother's health beliefs and personal characteristics are much greater than the effects of either alone. These variables, then, play a part in determining the care she seeks for her child/ren.

Many children receive little or no care from the professional health care delivery system. This sometimes means that certain states become chronic, that correctable situations remain unchanged, and that treatable conditions go untreated. Without evaluation and appropriate intervention some children may not have the opportunity to reach their fullest health potential.

Information on the way mothers perceive and plan for their children's health care was sought, as well as the definitions they ascribe to health and illness. This study was designed to ascertain what mothers know about health care, what kinds of needs mothers and children identify, what means they use to solve their problems and meet their needs, and what barriers they perceive to the use of today's modern health care delivery system.

Definitions of Terms

Culture -- "the acquired knowledge that people use to interpret experience and generate social behavior" (Spradley 1979, p. 5).

Health behavior -- the actions and attitudes displayed by a mother when her child is ill or while she is trying to maintain her/his wellness.

Informs -- an internal process which directs or tells; provides the cultural context for the behavior and prescribes a cognitive map.

Clinic mother -- a mother of a child under six years old who utilizes clinic services for her child/ren's health care.

Ambulatory clinic setting -- a multi-specialty outpatient pediatric health care facility.

Statement of the Purpose

Mothers define health and illness differently. They also act and react to these states in a variety of ways. At certain times and for certain reasons mothers decide to take action to either maintain their child/ren's health or to try to restore or improve it. The

purpose of this research was to try to identify the way clinic mothers perceive and define health and illness and how they plan for the care of their children. Perhaps by understanding mothers' cultural definitions as one of the factors which influence their behaviors, the professional health care system can determine how best to assist them to meet their needs.

Mothers that use a state funded Crippled Children's Clinic for their children's health care were interviewed for this study. Eligibility requirements for utilization of this clinic include such factors as: the child must have a good prognosis and the family must be unable to afford private care (most are indigent).

Assumptions

Prior to entering into the research process the following assumptions were made:

1. Mothers do distinguish between health and illness in their children.
2. Mothers make decisions concerning the health care received by their children.

Limitations

The following restrictions of this study need to be acknowledged:

1. Eliciting information can introduce artifact in the information given (Tyler 1969).
2. Chronic conditions, however minor, may affect health behavior.

3. What mothers actually do and what they say they do may not be the same.

Conceptual Framework

Health care of children is usually directed by their parents, more specifically by their mothers. The perceptions and actions of mothers are determined, to a large extent, by the society in which they were raised. Variables such as ethnicity, education, religion, etc. affect mothers and ultimately the health care of their children. The variables which affect the health behaviors of mothers have an important effect on the future health behaviors displayed by their offspring. It has been speculated that many of the health related attitudes and behaviors that the child will exhibit later in life are acquired largely from those family members responsible for early definitions of the child's illnesses.

The pictorial model conjectured for this research (Table 1) was hierarchically erected with the most general conceptualizations at the top and the most specific conceptualizations on the bottom. Each lower level is a smaller component of the level above it. For instance, definitions of health and illness are thought to be part of one's health care beliefs. Health care beliefs are part of one's belief and value system which, in turn, may be part of one's culture. Performance may be a component of health behavior cues. Health behavior cues may be a part of general cues, which, in turn, are thought to be part of one's health care behavior.

Table 1. Conceptual Framework -- Model of Relationship of Culture Conceptualized as a Cognitive System and Health Care Behavior

(Level I)	Culture (Cognitive)	Health Care Behavior
(Level II)	Belief and Value System	General Cues
(Level III)	Health Care Beliefs	Health Behavior Cues
(Level IV)	Definitions of Health and Illness	Performance

The model should also be viewed horizontally at all levels. This horizontal view is intended to convey speculated relationships. For instance, culture may be related to health care behavior; the belief and value system may be related to cues, etc. These relationships are indicated with broken lines in the model which describe a speculated relationship without indicating causality or direction.

Level I, the most general, is the construct level. It incorporates the constructs of culture or that which informs one's knowledge, and health care behavior or what one does (how one behaves) as a result of this cultural knowledge.

Level II is the first conceptual level. It incorporates the concepts of belief and value system (the qualities and convictions considered significant and desirable) and general cues (anything internal or external that incites some action).

Level III is the second conceptual level. It incorporates the concepts of health care beliefs (convictions which determine what is done to prevent the occurrence of health problems, to maintain good health, or to treat health deficits) and health behavior cues (anything internal or external that incites health behavior).

Level IV, the most specific, is the empirical level. It incorporates the referents definitions of health and illness, as well as performance (behavior in accordance with some requirement or obligation).

This research study addresses primarily the empirical level. It is at this level that a mother's definitions of health and illness are viewed as being related to her "performance" in taking care of the health of her child.

CHAPTER 2

REVIEW OF LITERATURE

In the past, health and illness have been explored both socially and culturally. Folk care systems have been researched and the role of poverty has been assessed. This chapter looks at the variables which influence the health care received by children. To understand what influences children's health care, one must be especially aware of what influences a mother's decision making processes. For the purposes of organization, this review will be divided into four sections: definitions of health and the health behavior of mothers, factors which influence a mother's perceptions of illness and sick role behavior, mother's perceptions and utilization of care, and the influence of the role of the family on mothers' perceptions of health care.

Definitions of Health and the Health Behavior of Mothers

Generally, good health is a universal value; a state prized by everyone. The World Health Organization defines health (Kosa, Antonovsky and Zola 1969, p. 36) as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."

Mothers' definitions of health and their health behaviors are somewhat complex and influenced by a variety of variables. Not only do definitions of health vary, but health is at differing priority levels for different people and/or groups of people. The way in which a mother

defines health, influences many areas of her life, as well as the lives of her children.

Kasl and Cobb (1966, p. 531) define health behavior as "any activity undertaken by a person who believes himself to be healthy for the purpose of preventing disease or detecting disease in an asymptomatic stage." The health behavior of mothers is what determines the care received by their children. Desirable health behavior is prescribed by culture.

Although a mother may espouse concern about the health of her children, her behavior may indicate that health is really of little consequence. Little research has been done on this gap because it is hard to measure. It is likely that the degree to which a mother sees herself as able to control various aspects of her world has an influence on the relationship to her beliefs about health and illness (Gochman 1971). One's perceptions of control reflect the level of a person's behavioral organization. For instance, persons with high levels of perceived internal control see themselves as able to determine outcomes of their encounters with the world.

According to Suchman (1965) a mother's needs strongly color her perceptions and interpretations and motivate her behavior in regard to health. Her individual personality needs are her motivations and result from her life experiences. Antonovsky and Kats (1970) equate motivation with goal oriented behavior and identify the health relevant goal as health maintenance. A health goal must be one with salience or value for the individual.

Most of the variance in regard to health behavior is accounted for by the interaction of the perceived threat of disease and the perceived value of preventive action (Kasl and Cobb 1966). It is assumed that a mother's perceptions of her children's vulnerability to health problems (Gochman 1971) operates as an anxiety state with arousal properties.

Poor health care habits, undue risk-taking, delay in seeking medical care, disregard of medical advice and other areas of direct relevance to disease causation and prevention reflect positive or negative social attitudes (Suchman 1965). Green (1970) found that variations in normal health behavior were more highly correlated with income, education and occupation than with other variables. However, one must be cautioned that explanations of variables affecting the perception of symptoms can not always be used to explain variables affecting preventive health behavior.

Culture (Paul 1969, p. 27) involves "a group's design for living, a shared set of socially transmitted assumptions about the nature of the physical and social world, and the goals of life as well as the appropriate means of achieving them." A mother's culture, then, defines health and illness for her. The culture influences the prevailing ecology of health and disease (Paul 1969). A mother's culture creates its own definition of and reaction toward disease and it influences the effectiveness of any health programs because a community's response is based on its cultural values.

Meyer and Sainsbury (1975) stress the importance of studying the ways in which social and cultural factors influence health for a variety of reasons. First, it is essential to identify and preserve the system of relationships, cultural patterns, and customs within the community which favor health. Second, it is important to see if it is possible to restore or reintroduce beneficial social behavior that some societies have lost as a result of social changes. Finally, those social, economic and cultural factors that are harmful must be identified.

Religion also plays an important role in health and its meaning. The focus of many religions (Adair and Deuschle 1970) is the maintenance of the balance between the individual and his total physical and social environment, as well as the maintenance of the balance between the supernatural and man. When maintained, this equilibrium constitutes health while an alteration in the equilibrium causes disease. For example, Mexican Americans (Rose 1978) believe that health is a gift from God.

Borsky and Sagen (1959) have identified certain health related beliefs which may be necessary for taking advantage of preventive or screening tests as well as acute health care. First, is a mother's underlying health attitudes and beliefs. This includes her perception of her children's susceptibility to illness, belief in the need for professional diagnosis and care for illness, and the belief in the ability of modern medicine to help. Next, is the belief in the potential benefits to be derived from the health examination. This includes the mother's dissatisfaction with her personal efforts to care for the health of her children. Finally, is the mother's feeling regarding the appropriateness of the examination procedures.

It is evident that poverty represents a specific social environment which affects most, if not all, aspects of life including health, illness, and related behavior. Differences in socioeconomic levels include (Mechanic 1969) differences in health values, differences in understanding and information concerning disease, differing views of the future and preventive planning, certain cultural expectations concerning health services, feelings of social distance between oneself and the health practitioners, etc.

People in the lower socioeconomic groups tend to give greater priority to immediate rewards rather than to achievement of long range goals. However, the current professional health care delivery system requires an orientation toward the future (Roth 1969), toward planning, and toward deferment of immediate gratification in the interest of long range goals.

Morris et al. (1966) found that poor mothers are often less impressed with the purposes and potentialities of well child care than are more affluent mothers. The lower classes, in general, have been found to have higher prevalency rates for many diseases (Brinton 1972) as well as more serious illnesses; however, the impoverished tend to accept discomfort more routinely (Lindstrom 1974).

The most important characteristics of the mother-child dyad related to poverty are the psychological characteristics (Bullough and Bullough 1972). These characteristics include feelings of despair and resignation, fatalism, violence, unstable family structure, a feeling of abandonment, a total sense of the present (Spector 1979), dependence, and feelings of inferiority. The feelings of alienation, previously

mentioned, may be a product of a general negative outlook. Poverty itself creates the negative feelings that deter planning and preventive behavior. Any type of segregation or discrimination (Bullough and Bullough 1972) magnifies the effects of poverty. Unfortunately, poverty does not foster the personality characteristics which would be useful in breaking away from the poverty status (Shostak 1969).

Poverty may reinforce medical deprivation by emphasizing the informal social group's definition of health and illness (Saunders and Hewes 1969). Where concepts of disease causation include transgression of social taboos, people are likely to think that such diseases occur among themselves and therefore cannot be understood or treated by outsiders.

Factors Which Influence a Mother's Perceptions of Illness and Sick Role Behavior

There are many factors which seem to influence a mother's perceptions of illness and sick role behavior. Things such as her value system, her culture, her definition of illness, the nature of the symptoms she sees in her child, etc. all play a significant role in the mother's care-seeking behavior.

MacLeod (1978) describes illness as a state involving increased awareness of the body and feelings of invasion by unseen forces. Bennett (1979) feels that poor health can be associated with any kind of loss. The nature of the symptoms the mother perceives in her child/children is the most powerful factor influencing her definition of illness and her care seeking behavior. Brinton (1972) reports that

symptoms of illness are defined by the individual's value system. Thus, the illnesses of children are defined by their mother's value system. Disease may be viewed as a maladjustment resulting from misperception, misinterpretation, and misbehavior.

Rosenstock (1969, p. 169) defines illness behavior as "behavior undertaken by persons who feel ill for the purpose of defining the state of their health." Illness behavior is important because the diagnostic process can be biased by different respondent tendencies and because it can influence a mother's responses to treatment for her children.

A number of variables which relate to illness behavior (Mechanic 1969) have been identified. First, is the mother's estimate of the present and future probabilities of danger. Second, is the extent to which the child's symptoms disrupt the family and other social activities. Also important is the frequency of the appearance of symptoms, their persistence, and their reoccurrence. Another variable is the tolerance threshold of the mother who is evaluating the deviant signs and symptoms. The available information, knowledge, and cultural assumptions and understanding of the mother-evaluator also impact on illness behavior.

The appearance of clear symptoms in the child (Becker, Drachman and Kirscht 1974) is the most frequent instigator to health action taken by mothers. Little research has dealt with the identification of cues mothers use to determine when their children are not well. The cues (Mechanic 1969) may be internal perceptions of the body's state as

expressed in some fashion by the child or they may be external. Some cues are fleeting and are of little intrinsic significance; however, others serve as triggers to appropriate action. The mother's readiness to act provides the energy to take action and the perception of the resulting benefits provides the preferred path of action. However, without certain cues (Rosenstock 1974) to set the process in motion, inaction might still result.

Becker et al. (1974) studied mothers' attitudes and perceptions of their children's care. They found that mothers who are not likely to adhere to the medical regimen have little concern about health matters. They see their child/children as relatively healthy and likely to remain so. Generally, they do not feel much need for medical advice. They neither take the child to the doctor as symptoms appear, nor do they do anything special to maintain the child's health. Most are little threatened by illness in their child. They are often skeptical of the diagnoses and have little confidence in the physician or in medicine in general. Lindstrom (1974) found that most mothers recognized illness in their children by changes in the child's behavior rather than by the symptoms of the malady.

Suchman (1970) identified three fundamental ways psychosocial factors effect illness: (1) they may be the basis of disease, (2) they determine how an individual or group defines and reacts to illness, and (3) they determine the form which the delivery of care takes. In other words, culture plays a role in the interpretation of causation of illness (Spector 1979). The environment strongly influences the

kinds of problems considered legitimate, the acceptableness of solutions, and the rejection or acceptance of new ideas, etc. For instance, some cultural groups believe (Clark 1970) that illness is the result of real or imaginary parts of the body falling out of normal position. Sometimes illness is thought to reflect moral weakness. For others (Jelliffe and Bennett 1969) illness may indicate that a taboo has been broken or a ghost of the dead has been contacted.

A mother's social level involves the roles, relationships, attitudes, and techniques that enable members of her cultural group to identify various types of illness and disease and to behave appropriately. The stronger the ingroup identification is, the more likely the mother will lack objective knowledge about disease, will be skeptical of professional medical care, and will be dependent on the group for support during illness. One's culture (Leininger 1970) can provide reassurance and ready-made solutions to life's problems.

From the psychosocial point (Suchman 1970) disease is viewed as the result of failure to perceive and interpret a health danger combined with the failure to react appropriately and effectively. The attitudes and customs (Meyer and Sainsbury 1975) that prevail in a culture are important not only in defining who is to be labelled as ill but also in deciding who needs treatment, the form the treatment will take, and the type of service one uses. Saunders and Hewes (1969) found that local disease taxonomies, though seldom explicit and usually varying greatly from culture to culture, are often as orderly and systematic as they are complex.

It is well known that personality determinants affect one's predisposition to illness. These determinants are important intervening variables because they determine how one copes with life's stresses.

Mothers' Perceptions and Utilization of Health Care

Getting mothers to utilize health care services for their children can sometimes be a formidable task. The highly personalized world view of many low class mothers makes it difficult for them to understand or cope with the bureaucracies involved in the delivery of health care. Mothers who feel powerless and socially isolated are caught in a cycle (Morris et al. 1966) in which feelings of unworthiness are reinforced by each dissatisfying contact with the outside world. When these mothers must accept loss of dignity or disrespect for their time and convenience, they may choose to omit or postpone health care. Clients hope to receive kindness, a willingness to listen, a feeling of caring and concern and continuity of care.

Social isolation interferes with health care behavior (Triplett 1970) in the following ways: it limits the knowledge of existing services, it lowers one's expectations for good health care, it makes one less aware of other's beliefs, and it increases one's feelings of powerlessness. Interaction may pose a threat to an individual's self-esteem. Triplett (1970) states this perceived threat may involve a person fearing his ignorance may be exposed, disrespect, or fears of losing control of the situation.

When scientific preventive health measures and treatment are not compatible with folk medical beliefs, the mother will often reject what is foreign and contrary to tradition. Varying definitions, objectives and methods of health care create a conflict or incongruity between the professional and the mother.

Freidson (1961) found that good medical care requires taking an interest in the patient and his culture so that he obtains technical competence as well as emotional satisfaction. Unfortunately, in most public clinics there is little or no chance to establish personal relationships between the patient and the physician, so often the emotional needs of the clients are not adequately met.

Most mothers base their judgments about physician competence on the socio-emotional dimension of the child-mother-physician relationship (DiMatteo, Prince and Taranta 1979). Mothers often complain (Belkin et al. 1964) that their children's physician lacks in warmth, sympathy and friendliness. A. U.S. study reported by DiMatteo et al. (1979) found that physician shopping was related to disliking the physician as a person, dissatisfaction with the amount of time spent in delivering care, and feelings that their current doctor is not interested in them or their child as a person. A physician's effectiveness in treatment, therefore, often varies with her/his understanding of how the patient perceives the situation (King 1962). According to Creson, McKinley and Evans (1969), a moderate amount of acculturation is associated with the acceptance of the professional health care system.

Spector (1979) has listed the following barriers to health care: language/communication difficulties, the poverty cycle, rural clients facing an urban institution, seasonal migration patterns, sexism, institutional prejudice and depersonalization. Lindstrom (1974) includes unfamiliar procedures, passivity of family members, high costs, and control by the professionals. Additionally, many people simply do not like to ask for help. A mother's conceptualizations about the nature of disease, her previous experience, her state of mind, and the social environment in its broadest sense all feed into the problem of health care utilization (Bennett 1979).

Influence of the Role of the Family on Mothers' Perceptions of Health Care

Maternal health behaviors occur within the context of the family. The values a mother ascribes to health care and her rationale for acting are those she has learned from the group and socioeconomic level to which she belongs. Her ethnic traditions serve as a source of knowledge about health behavior as well as appropriate treatment. The family in general, serves as a source of support and protection for its members in addition to serving as a source of care and as a resource for decision making. Group life is dependent upon the formation of values which are shared and passed from generation to generation largely through the family.

The family remains (Meyer and Sainsbury 1975) the principle means of caring for the sick in every society even today. The family is usually involved in the decision making and therapeutic processes at

every stage of a member's illness. Family ties serve supportive and protective functions against the risks of failure, economic loss, embarrassment, and vulnerability to criticism encountered in the broader society. In short, the kin group is a reliable place of refuge from a hostile world.

The family unit plays an essential role in where health care should be sought. One may run into difficulty if the goals of the family and those of medicine differ. Most health and illness behavior, definitions of signs and symptoms, patterns of utilization, health practices, etc. are acquired in the family setting.

A family's use of health care services is related to the parental educational level, concern about health issues, feelings of powerlessness and alienation, as well as the existence of a closely-knit nonscientific ethnic tradition (Moody and Gray 1972). When a member is ill, the family may be in a state of disequilibrium. The extent to which a member's illness affects the family's role relations seems to be a function of the nature of the illness itself.

The family acts as a buffer between the folk care system and the professional or scientific care system. Familism works indirectly (Hoppe and Heller 1975) to decrease the feelings of alienation. Kinship obligations and the strength of emotional ties inhibit the acceptance of medical practices involving separation of family members. Then too, a large number of folk illnesses and etiologies (Rose 1978) are related to problems between family members or neighbors.

Parental attitudes toward the child (Moody and Gray 1972) and their relationship to him have been found to have a direct effect on the family's ability to manage and treat health problems. Generally, the social conditions which disrupt family life (Meyer and Sainsbury 1975) decrease a child's social contacts or isolate the family from the larger community which decreases the child's chances of becoming a healthy and contented citizen. Lindstrom's study (1974) found that mothers frequently consult other family members about health problems and health decisions regarding their children. A mother's health behavior must be understood not only in terms of the belief system (Adair and Deuschle 1970) in which she functions, but also in terms of her relations to other members of her family and community.

Summary

Through the preceding literature review one can see that there are a number of variables which affect a clinic mother's perceptions of her children's health care. The next chapter will describe and explain the research methodology used in this study to get at the question of what cues mothers use to define health and illness in their children and to take action. Much information is needed on which cues (anything internal or external that incites action) are relevant to health behavior. For instance, when does a mother consider her child ill? At what point does a mother feel her child needs to see a doctor? and so forth.

CHAPTER 3

METHODOLOGY

This study explored clinic mothers' perceptions of their children's health care. Definitions of health and illness of these mothers were elicited as well as the ways clinic mothers plan for their children's care. In this chapter the following aspects will be addressed: design, sample population, protection of human subjects, data collection, data analysis, reliability, and validity.

Design

An exploratory design was chosen for this research in order to give the subjects the maximum opportunity to express their feelings and thoughts regarding the planning for the health care of their child/ren and to obtain the widest range of information. It was believed that this type of design would allow the flexibility needed to accomplish this goal, and to allow the researcher to recognize some commonalities among clinic mothers.

An ethnographic study is a method used to discover how a group organizes, codes, and defines experiences. Spradley's (1979) techniques for an ethnographic interview were used to identify elements in the cognitive culture. Through interviews one attempts to get at an informant's way of talking in various social situations. Spradley (1979) refers to

this talking as speech events. In order to learn about a culture it is necessary to try to define the cultural rules surrounding these speech events.

The investigator asks questions of individuals (see Appendix D) in the cultural group. These questions are framed in the language of the group and responses are recorded exactly as the informant gives them. This insures that the categories and themes later identified are, indeed, particular to the cultural group being investigated.

Ethnographic interviews are more than a series of friendly conversations. Both the informant and the ethnographer are aware that the interviews are goal directed and have an explicit purpose. Making this purpose clear is the responsibility of the ethnographer. Likewise, it is the researcher's responsibility to direct the conversation into pathways that will lead to discovering the cultural knowledge of the informant. In order to accomplish this goal, it is important for informants to use their everyday language (Spradley 1979), to speak to the researcher in the same way they would speak to others in their own culture.

Ethnography is an inductive mode of theory construction whose purpose is to generate concepts. In ethnography the informants are the experts; they teach the ethnographer. It involves more than finding out what people know; it also involves discovering how people know. Moreover, it involves discovering how people have organized that knowledge (Spradley 1979).

Most informants lack assurance that they know enough and that the researcher is really interested in what they have to say and in

their culture. Therefore, another important role of the ethnographer is repeated expressions of ignorance and interest. A verbatim record of the interviews must be kept as the words of the informants are the key to their culture. The language record is then analyzed following each interview.

Sample Population

The target population consists of clinic mothers of pre-school children (under six years old). This age group was chosen because of (1) the high incidence of illnesses among pre-schoolers, (2) the frequent numbers of preventive health care visits which are recommended, and (3) mothers of children in this age group are likely to be the determinants of their children's care.

The criteria used to select the informants were: (1) the child must live with the mother, (2) the mother and child must live within the Tucson metropolitan vicinity, (3) the mother must speak English, (4) the mother must not work during the day, and (5) the child's handicapping condition must be minimal.

Protection of Human Subjects

Permission for this study was obtained from the Human Subjects Committee (see Appendix A). Every attempt to safeguard the rights, interests, sensitivities, and privacy of the informants was made. Procedures for assurance of the protection of the rights of human subjects were in accordance with the Department of Health and Human Services. The subject's consent form is presented in Appendix C.

Data Collection

Permission to conduct the study was obtained from the clinic manager at a state funded multi-specialty clinic for children. A list of families meeting the study criteria was provided by the clinic staff and through chart review.

A letter was then sent to prospective subjects (see Appendix B) briefly describing the purpose and nature of the study. This letter was then followed by a telephone call to the mother. If the mother agreed to participate, the researcher made an appointment at the informant's convenience to begin the interviews. If for some reason the mother could not be reached by phone or if she chose not to participate in the study, the next person on the list was contacted. The first four mothers who agreed to participate were chosen for the study.

Data collection for an ethnography begins with descriptive questions. These questions aim to elicit a large sample of utterances in the informant's native tongue and to encourage informants to talk about a certain cultural scene (Spradley 1979). The interviewing process begins with "grand tour" questions. Spradley (1979) explains that this type of question elicits a description of the informants' situations. For instance, typical "grand tour" questions such as, "What is your child like when s/he's well?" are asked in order to get a description of how things are usually. Specific "grand tour" questions such as, "Can you describe your child during her/his last illness?" results in a description of the most recent events.

Example questions take some single act or event identified by the informant and ask for an example. Native-language questions ask informants to use the phrases and terms most commonly used in their everyday language; they serve to remind informants that the researcher wants to learn their language.

Alternately with descriptive questions, structural questions are utilized. Structural questions facilitate the discovery of how informants organize their knowledge. An example of a structural question is "What are all the different kinds of illnesses?" Structural questions often require an explanation and are of most use when they repeat some included terms (Spradley 1979) used by the informant. Verification questions (a type of structural question) are used to confirm or disconfirm hypothesis about a domain. "Is witchcraft a kind of illness?" is an example of a verification question. This method of randomly mixing the types of questions utilized helps to keep an informant from becoming bored and helps to decrease the test-like or interrogative type effect of the interview. This alternation of types of questions also serves as a method for assisting informants to be better teachers.

Card sorting is a quick way to find the boundaries of a folk domain. It involves writing a number of included terms on cards and asking informants to sort into piles the ones which are the same kind of thing. Next the informants are asked what they call each pile. These names then become the cover terms or names for a category of cultural knowledge (Spradley 1979).

Contrast questions are questions which ask how one thing is different from another and serve to confirm differences and similarities among a large group of folk terms. An example of a contrast question is: "What is the difference in the care you get from your child's pediatrician and the care you get from your child's osteopath?" Triadic contrast questions require that an informant, when presented with three folk terms, indicate which two of the terms are most alike and which is different. For instance, "Which of these terms is different and which two are most alike: (a) curandera/o, (b) doctor, (c) friend?" The card and triadic sorts are a means of getting at tacit knowledge and identifying how informants organize their knowledge.

Tacit culture, as opposed to explicit culture, is arrived at through inference by the ethnographer. The ethnographer makes these generalizations about people's knowledge by listening carefully to the informants and by observing their behavior (Spradley 1979). Tacit knowledge, because it is outside of the awareness of the individual, is difficult to explore; it can not be verbalized specifically or observed. However, techniques such as the triadic sort and componential analysis are designed to get at tacit culture.

Data Analysis

The information from the interviews was collected and analyzed simultaneously in order to find the reoccurring ideas expressed by clinic mothers regarding their children's health care. The ethnographic data were organized and a taxonomy was eventually constructed. Taxonomies represent an approximation of the way the informants organize their

cultural information. The structure of the taxonomy includes domains which are "the basic units in an informant's cultural knowledge" (Spradley 1979, p. 60). Domains were identified by the informants by requesting them to categorize the information they had given. This information was hierarchically organized into classes of progressively less abstraction and served as an outline for ethnographic statements.

A componential analysis is a systematic search for the components of contrast (Spradley 1979) or an analysis of linguistic symbols which form the core of the differences in the meaning system of each culture. It involves searching for all the relationships among the folk terms used by the informants. Paradigms are a pictorial representation of these components of contrast. Using a chart-type format, terms in a domain are compared with the dimensions of contrast.

A final analytical technique is the identification of cultural themes or (Spradley 1979, p. 186) "the cognitive principles, tacit or explicit, recurrent in a number of domains and serving as a relationship among subsystems of cultural meaning." These themes are the means by which the informants connect and make use of the domains. A theme may be something repeatedly stated by or implied by the informants.

Reliability and Validity

Reliability and validity are important to consider because the adequacy of the research design depends on the quality of the measurement procedures. The answer to the research question is based on the data collected by these procedures; therefore the answer is only as good as

the procedures. The information produced must not only be relevant to the research question, it must be accurate.

Reliability refers to the repeatability, the ability to get the same client responses on repeated trials. Further, definitions of key terms must be specified and the interviewing format and the behavioral scenes for observation must be identified. The ethnographer must be careful when translating interviews into generalizations about a specific population. Much of this analysis is often intuitive and non-quantitative. Research methods need to protect the researcher from her/his own assumptions and value judgments. It is important to try to use a mixture of relatively unstructured observations (which are said to have high validity) and structured interviews (which are reported to have high reliability and replicability) (Pelto 1970).

Reliability in this study is assumed to be high because questions were repeated several times, often on different days. In addition, the informants were shown and read the information they had given and were asked whether it was accurate.

Since every informant was subjected to more than one interview over time in which the same questions were repeated, the answers can be treated as a test-retest (Brink and Wood 1978). Thus changes or discrepancies can be noted and in this way a measure of the reliability of an individual informant can be estimated.

Validity is "the extent to which the measurement reflects the subjects true relation to the characteristic being measured" (Brink and Wood 1978, p. 117). In anthropoligical research, it is not uncommon to

do long-term work in one area which utilizes a variety of participant observation and interviewing techniques. This practice is generally thought to produce data with a high degree of validity (Pelto 1970). In addition, Pelto (1970) asserts that detailed descriptions of behavior given in ethnographic interviews generally have a high level of both face validity and construct validity.

Face validity refers to measures which focus directly on behavior in which the investigator is interested. On the assumption that all members of a culture are carriers of that culture, any person who belongs to the group has face validity (Brink and Wood 1978). In this investigation, there was no measurement tool; however, I have no reason to doubt the accuracy of the information given by the informants. Therefore, face validity appears adequate.

Construct validity refers to the accuracy of a measure whose scores separate groups in order to predict differences on the basis of some theory (Selltiz, Wrightsman and Cook 1976). The degree to which members of a group possess a particular cultural trait or status is established by the informant's statements in conjunction with the statements of others (Brink and Wood 1978). At this point, a statement regarding construct validity would be premature. Through replication with other informants, in other cultures, etc. it would be feasible to determine (inductively) if the relationship between the hypothesized constructs is valid.

In terms of content validity, informants must be qualified to discuss their cultural knowledge. Therefore, the investigator must

learn the position of the informant prior to accepting the interview as valid. More than one informant is used for any single element in order to cross-check the collected data. Each informant is considered to be an expert on a particular content area and at least two expert informants are used with each content area to establish validity. Content validity is established (Brink and Wood 1978) by the informants who certify that the situation or behavior is representative of the culture. Cross-checking informant's statements within and across groups will establish norms for one group and for the population as a whole. Content validity in this study appears adequate.

The major method of establishing concurrent validity is the use of observations in conjunction with interviews. This enables the researcher to compare what informants say with what is actually done. Another method might be for the investigator to have along another observer to validate observations and impressions. Concurrent validity can not be established in this research study, although the use of a tape recorder does lend some credence.

In the course of an interview, the informant explains, describes, and predicts what will happen in any given situation. The informant may be describing her/his own behavior, the behavior of others, or the behavior of the group as a whole. The researcher then validates that prediction with her/his own observations; thus, predictive validity is established. Due to the small sample size and limited time factor involved, predictive validity can not be established. However, through replication this would be an important goal.

Summary

This chapter has dealt with various aspects of the research methodology including the design, the sample population, protection of human subjects, data collection, data analysis, as well as reliability and validity. In subsequent chapters the research data will be presented and further analyzed.

CHAPTER 4

PRESENTATION AND ANALYSIS OF DATA

In this chapter, the characteristics of the sample including the selection of informants, data collection, and the interviews are described. The researcher-informant experience is discussed. The research findings and data analysis are presented. Finally, cultural themes are identified and explained.

Characteristics of the Sample

The informants for this study were selected from suggestions made by the staff at the Crippled Children's Clinic, as well as by contacts the researcher made while attending various sessions at the same clinic. All the informants met the selection criteria specified by the researcher regardless of the source of the recommendation. The nursing staff were queried regarding the suitability of the clients for this particular project before making contact with a prospective informant.

Ultimately, a list of four prospective informants was formulated. All four were sent a letter (see Appendix B) asking them to volunteer for the study. A week after the letters were sent, all prospective informants were contacted by telephone in order to further explain the project, to answer their questions, and, if they agreed to participate, to make an appointment to begin the interviews.

Two of the original volunteers were eliminated. One was a young mother who I felt was overwhelmed by her daily responsibilities. The other prospective volunteer was dropped after the third time she failed to keep an appointment to discuss the project further. Consequently, two more volunteers were recruited.

After receiving Human Subjects Committee approval (see Appendix A), all the informants signed consent forms (see Appendix C) and the interviewing began. The data were collected over a two-week period in September 1980. A total of sixteen interviews were conducted, four with each informant. All of the interviews were conducted at the homes of the informants, at their request.

Interviewing Procedures

In all but one instance, the child whose health care was being discussed was at home at the time of the interviews. One interview was cancelled due to the illness of the informant; it was subsequently re-scheduled. One informant developed what appeared to be an allergic reaction during the course of the discussion session and was ultimately transported to the county hospital for treatment.

Each interview took place in the informant's living room. All sessions were tape recorded and lasted from forty-five to seventy-five minutes. On three occasions the spouses of the informants were at home and expressed a desire to participate in the discussion. The spouses were allowed to contribute; however, all questions were directed to the mother. Information from the spouses was not included in the research findings or data analysis.

The initial interview sessions necessitated the establishment of rapport as well as the beginning of the collection of the language sample. The purpose of the study was reiterated, questions about the project were invited, and confidentiality was assured. Informants were reminded that they could refuse to answer any questions and/or withdraw from the study at any time without reprisal.

After the first interviews, the tapes were transcribed and the domains were explored and identified. In this study, domains such as the following were generated: "things to keep my kid from getting sick," "when to call the doctor," "kinds of advice to accept from friends," "things I get advice and help from," "things that influence a child's everyday life," "things that show lack of concern from doctors," "health problems handled at home," etc.

During the second interviews, the domains were shared with the informants. They were asked to make additions, deletions or changes. Structural questions (Spradley 1979) which enable the discovery of information about the domains such as, "What are the different kinds of illness?", were interspersed with descriptive questions. The third interviews consisted of card sorts and triadic sorts as well as additional structural and descriptive questions.

In the fourth interviews, paradigms, that is componential analyses representing meaning of contrast, were filled in by the informants. These paradigms are further attempts to get at the tacit culture. They were also asked to review the taxonomies for completeness and accuracy.

Researcher-Informant Experience

In order to lend more meaning to the findings and data analysis, each informant will be subjectively and objectively described. Then the researcher-informant interactions will be discussed.

Informants

The informants were between twenty-one and thirty-one years old. One mother had just one child while the other three mothers each had two children. Three of the informants were married; one was not.

Ann*. Ann is a thirty-one year old Anglo who lives with her two-year old son and husband in a modest, well-kept home owned by her parents. She is an only child who has been involved in conflicts with her own parents since her early teenage years. Her relationship with her parents remains strained to date.

Since her marriage seven years ago, Ann has encountered numerous problems. There has been marital discord on and off, her son has experienced health problems, and most recently there have been mounting financial problems as a result of her husband being laid off from his job.

Ann spends most of her time at home with her child. She has little time for socializing with friends, as her son, who is making a slow recovery from a debilitating illness, requires a great deal of her time and attention. Though socially isolated, Ann has no desire to participate in group activities outside of her home. She has a warm

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*To preserve anonymity, fictitious names will be used throughout this study.

relationship with her in-laws and describes her mother-in-law as "fantastic".

Ann is very concerned with her son's health care. She actively seeks answers to her questions regarding his health status. In fact, she has utilized a wide variety of health care givers in search of those answers.

Skip, Ann's son, is a bright, alert child who is moderately restricted by his motor limitations. He often asserts his independence, yet can be quite demanding when frustrated by his limitations.

Maria. Maria is a twenty-five year old Mexican American mother of two children. She, her children, and her husband live in a small low-income apartment. She and her husband "resent" the "lack of sanitation" of their apartment specifically and the condition of most low-income housing in general. Together they have approached the landlord about improving conditions and have done many things on their own to improve their environment. Finances are a continuous problem.

Maria is a verbal young woman who seems to give a great deal of thought to a philosophy of life, parenthood, and health care matters. She, too, seeks answers to her health related questions. She puts quite a bit of emphasis on the emotional and mental health of her children.

Maria left home at an early age. She apparently was never close to her parents, although she sees them occasionally and talks with them on the phone weekly. She has several brothers and sisters with whom she visits frequently. Her socialization involves family more often than friends. She cares for a nine year old child both before and after school on a daily basis.

Manuel, age six months, and Lucy, age four years, Maria's children, are kept up-to-date on their routine physicals and immunizations. They are playful, active children who look to their mother for comfort and support. Manuel recently had neurosurgery which has completely corrected his craniostosis.

Sonia. Sonia, twenty-eight years old, is a single parent. Her heritage is Mexican American. She lives alone with her two children, Jesus, seven years old and Nancy, four years old. She does not work outside of her home.

Sonia is the second oldest in a sibship of ten. As a child she was left with the responsibility of caring for her younger brothers and sisters while her mother worked. She continues to have a close relationship with her family and stepfather even though she now has a family of her own. In addition, she has a number of friends who are her age and in a similar social situation (single, unemployed, etc.).

Sonia's children are both epileptics. They are a constant source of worry for her. Their well-child care is obtained at the county hospital and is kept current. The family's health care system involves the folk care system and kinship system, as well as the professional care system.

Sonia is a tense person with multiple concerns. She was most eager to verbalize; however, it was often difficult to keep her focused on health care issues. She would often get off on a tangent and want to discuss other matters.

Betty. Betty is a twenty-one year old Anglo mother of two children. She and her husband, along with their two children, live in a small trailer. Betty was only sixteen years old when her first child was born. She came from a large family with nine brothers and sisters. Her mother lives in the midwest; her father died three years ago.

During the day, Betty cares for a variety of small children. Some days she can have as many as nine children to care for. She is a calm, good-natured young woman with a real interest in children. She and her husband have applied to become foster parents and are currently taking courses for that purpose.

For such a young woman, Betty has some interesting insights into the behaviors of her children and herself. She often expressed that she felt the interviews were "fun, really enjoyable." Her oldest daughter, Patty, who is now five years old experienced degeneration of the head of the right femur about one and a half years ago. The child remains in a brace, but is ambulatory.

Even though Betty's husband is employed, they have multiple financial worries. They were not covered by health insurance when Patty's problem was diagnosed and she was hospitalized for an extended period of time. Due to the child's growth, the brace has had to be replaced on a number of occasions which has further increased their debts.

Interviews

Rapport was rather easily established with all of the informants. It seemed as though health care was a topic they enjoyed discussing. At first, several of the young mothers expressed fear that they would not

be able to teach me anything. Sonia remarked, "I don't know anything good enough to teach you." It was necessary to offer continuous reassurance that what they had to say was very important.

Most all of the informants were initially uncomfortable with the tape recorder, though none refused to be taped. However, once the discussions were under way, they seemed to forget that the recorder was on. One informant enjoyed hearing herself on tape for the first time.

I tried to remain as flexible as possible with respect to the time of the interviews, as well as the meeting place. This was an effort to allow the informants to choose the setting and time most convenient for them. If there were several days between interviews, I called to remind the mothers of the date and time of the upcoming session.

As the interviews progressed, the informants seemed to be more anxious to share their thoughts and feelings. They gave evidence of having pondered over previous discussions. At times they would ask, "Is that what you want?" I would then reiterate that what was important to them was what I wanted to learn. The ethnographic methodology was explained as we went along to avoid overwhelming the informants with lengthy and confusing details.

By the final session, most of the informants seemed to be enjoying the research process. In fact, two of the informants wondered if the sessions couldn't be continued. During the course of the sessions, several of the informants asked health related questions, and at the end asked if I would permit them to contact me with further questions. One informant commented, "This is the first time someone's ever taken the

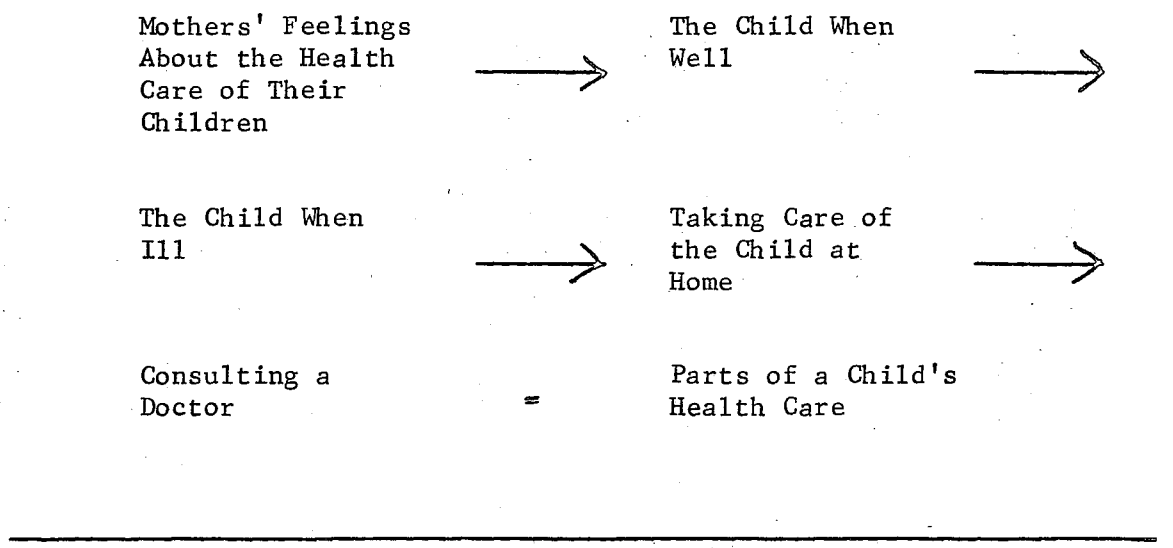
time to go out and ask us and find out what really is happening. Maybe there's going to be more people who will be concerned. People are never given the choice."

Ethnographic Data Regarding Mothers' Views of Their Children's Health Care

The purpose of this research was to try to identify the way clinic mothers perceive and define health and illness and how they plan for the care of their children. It is hoped that by understanding mothers' cultural definitions as one of the factors which influence their behaviors, the professional health care system can determine how best to assist them to meet their needs. The research question was, "What knowledge informs (cognitively directs) the health behavior of mothers who bring their children to a multi-specialty ambulatory clinic setting?" In order to make the data more comprehensible, this section has been divided into the following parts: the child when well, the child when ill, taking care of the child, consulting a doctor, and how mothers feel about the health care of their children. Within each part, related domains are presented.

Of approximately twenty-five domains identified and analyzed, five have been selected for presentation. The domains presented were chosen because they were included by most or all of the informants in their original taxonomies. What emerged from the data was a sequential pattern mothers use in making health care decisions. Table 2 is a pictorial representation of that identified pattern. In some instances, parts of the individual domains have been meshed into one. In other instances, the domains of one individual are discussed. The five domains

Table 2. Stages in Utilization of Cues in a Mother's Decision Making About Her Child's Health Care



presented include: "things that tell me my child is feeling well," "things that let me know my child isn't feeling well," "things to consult a doctor about," "kinds of feelings mothers have about the health care of their children," and "things I take care of." Occasionally, additional domains may be discussed in order to add dimension to the data or to demonstrate a point.

The Child When Well

All four informants were able to describe what their child was like when feeling well. Most of the descriptions of wellness related to the mothers' observations about behavior. Some of the informants such as Betty were able to give a detailed description of her child, while others like Sonia were able to elaborate very little. Table 3 represents a meshing of parts of the taxonomies from each individual mother that represent the domain, "things that tell me my child is feeling well." Terms in this domain include: talking all the time, asking for things constantly, clowning around, insisting on things, telling certain things, his attitude, coming out with things, breathing when asleep, being very active, being very curious, having a hearty appetite, having their attention as high as it can be, being playful, being giggly, liking to know and do things, being very observant, fighting a lot, can't sit still, smiling, being happy, going outside and playing, loving to be on the move, being alert, and being all-in-all a good child.

By looking at many of the terms in this domain, it becomes evident that the chief measure of a child's wellness, according to the

Table 3. Things That Tell Me My Child Is Feeling Well

Things That Tell Me My Child Is Feeling Well	Talking all the time
	Asking for things constantly
	Clowning around
	Insisting on things
	Telling certain things
	His attitude
	Coming out with things
	Breathing when asleep
	Being very active
	Being very curious
	Having a hardy appetite
	Having their attention as high as it can be
	Being playful
	Being giggly
	Liking to know and do things
	Being very observant
	Fighting a lot
	Can't sit still
	Smiling
	Being happy
	Going outside and playing
	Loving to be on the move
	Being alert
	Being all-in-all a good child

mothers in this study, is the maintenance of a typical activity level. All the mothers related wellness to a high rate of physical activity. For example Betty says, "For her not to constantly move is very abnormal." Ann explains "tells you certain things" by saying, "When he's feeling well and I ask him to pick up his toys he'll tell me to come back later or go and take a hike." She explained "his attitude and the things he comes out with" by saying, "When he's well he likes to be independent and he'll say cute things, but when he isn't well he wants me to do everything for him and he won't talk much." When Betty's child is well she reportedly "can concentrate and stick with things. In other words, their attention for them is as high as it can be." To Maria "all-in-all a good child" is one that "isn't fussy all the time; is happy."

It is interesting to note that none of the mothers mentioned the absence of symptoms when asked what their child was like when they were feeling well. However, a lack of symptoms were expressed in their definitions of wellness. For instance, when one mother was asked what wellness meant to her she responded, "Healthy I guess." When pressed further to define healthy she said, "You know, nothing's wrong with them." Another mother said, "I think health is part of wanting to stay alive. If you take care of yourself you stay alive longer." A third mother said, "For a child to be healthy, in my opinion, there's nothing wrong. It has a hearty appetite, they're playful, and they're always moving something."

Maria carried the discussion of wellness further. She began to elaborate on things which she felt influenced the wellness or health of a child. Table 4 illustrates the domain which she titled "things that influence a child's everyday life." She had been doing a great deal of thinking about the emotional and mental aspects of health. Terms Maria included in this domain are: frustrations, (family) lifestyle, family problems, the way they act (parents), being in a strange place, mind replays tapes, society makes people, whatever they do is all right, everyone needs to be a person, giving in to satisfy other people, and comfortable with themselves.

I was intrigued with Maria's phrase "the mind replays tapes" as something which influenced the child's everyday life. She explained,

> Sometimes a child can just sit and cry for no reason. A person's mind is so great that people are just unaware of what it does. I think what it does is that it replays tapes. That's the way it feels to me; that the brain holds all of these tapes and all of a sudden you'll just get one tape pulled out. You know, like years ago something that you felt, something that you experienced is played back for no reason.

She viewed this process as a variation of wellness and described it as a temporary state. This concept of variations of wellness is a unique way of describing subtle daily differences in a person's health status.

A final comment involving this domain is that if mothers do judge a child's state of health by his activity level, it might be very difficult for them to accept that the child is ill if he is still active and without symptoms.

Table 4. Things That Influence a Child's Everyday Life

Things That Influence a Child's Everyday Life	Frustrations
	(Family) Lifestyle
	Family problems
	The way they act (parents)
	Being in a strange place
	Mind replays tapes
	Society makes people
	Whatever they do is all right
	Everyone needs to be a person
	Giving in to satisfy other people
	Comfortable with themselves

The Child When Ill

Illness was a topic that seemed easier for most informants to discuss than wellness. Once again the domains of all four informants were meshed into one which they entitled "things that let me know my child isn't feeling well." Table 5 represents that domain. Terms in this domain include: (child) tells me, just doesn't want to do anything, when he's not really peppy, doesn't want to talk, just wants to sleep, wants you to hold him, mostly wants me (mother), if he feels hot, cries, whines, acts uncomfortable, face looks like he just doesn't feel good, eyes look red, gets down, sleeping, quieter than usual, eats different--not so much, being jumpy, constipation, a blackbird limping on one leg only, loss of weight, won't giggle as easily, doesn't like to cause trouble, not being strong, just sitting, just lying there, and not very interested in doing things.

On close inspection, one can see that many of the folk terms are related to a decrease in the child's normal activity level. It is interesting to note that when old enough to communicate, the child himself is permitted to identify when he is not feeling well. The notion that if one doesn't know their child, one may not recognize the signs that the child is not well comes across. Betty illustrates by saying, "I've always had a very good idea of how my kids act when they're well. I've seen mothers that leave their kids so much that it's kind of hard for them to tell (when the kids don't feel well) because they leave them so much."

Table 5. Things That Let Me Know My Child Isn't Feeling Well

Things That Let Me Know My Child Isn't Feeling Well	(Child) Tells me
	Just doesn't want to do anything
	When he's not really peppy
	Doesn't want to talk
	Just wants to sleep
	Wants you to hold him
	Mostly wants me (mother)
	If he feels hot
	Cries
	Whines
	Acts uncomfortable
	Face looks like he just doesn't feel good
	Eyes look red
	Gets down
	Sleeping
	Quieter than usual
	Eats different -- not so much
	Being jumpy
	Constipation
	A blackbird limping on one leg only
	Loss of weight
	Won't giggle as easily
	Doesn't like to cause trouble
	Not being strong
	Just sitting
	Just lying there
	Not very interested in doing things

Some of the terms included by the mothers are things which might demand more of the mothers' attention or might be irritating to them. "Wants you to hold him" would indicate a situation which demands the mother's time, as would "wants mostly me." Behaviors which might be annoying to the mother are things such as "cries" and "whines." These behaviors almost force a mother to take notice of a child.

By reading through this domain it also becomes evident that more than one system of health and illness is in operation. Folk terms such as "being jumpy" and "a blackbird limping on one leg only" are not signs of illness which are recognized by the professional Western health care system. To illustrate "being jumpy" one informant said, "Like when my little brother for anything he was just jumping. Like I had one sister that would yell and he (brother) would jump up just for nothing and my Mom said he has susto." Susto is an illness state believed by many Mexican-Americans to be caused by a fright. "A blackbird limping on one leg only" is a sign of witchcraft. An informant said, "On his window flew a blackbird limping with one leg only. I saw it. It was awful. See that means the lady (witch) who did this to him had him real real bad."

Folk terms such as those illustrated are signs of illness which, while not recognized by the professional health care system, can not be ignored because they have great significance to the client whose health care system is at variance with the Western system. Unfortunately, most clients will not share these concerns and most Western health practitioners know nothing of other health care systems. When one informant was asked if she would ever share signs of illness such as "being jumpy"

or "a blackbird limping on one leg only" with a doctor or nurse she replied, "No! I believe that very strong, but they'd think I'm crazy."

In order to attempt to uncover the tacit aspects of a mother's health care decision making processes, such as her classification and use of care givers, one informant was asked to complete a paradigm. In this paradigm I attempted to discover contrasts amongst the members of her domain entitled "things that tell me my child doesn't feel good" (see Table 6). Vertically listed are the folk terms included in her domain and across the top are listed the dimensions of contrast.

This informant indicates through this paradigm that she uses certain resource persons in specific instances to assist her with health care plans. It is worth mentioning that she implies she would consult a nurse more often than she would consult a physician.

The mother's role in the health and illness care of the child is interesting to consider. All the informants in this study are reportedly active participants in health care decision making. One informant stated she and her husband made health care decisions involving the children jointly. She said, "When it comes down to a major decision like they need a certain medicine or like Patty with the decision about surgery, neither one of us could have made that decision alone."

Another informant expressed the notion that making decisions about a child's health care involves much more than merely being the child's mother. She explained, "It's just the whole point of being responsible. You have to be responsible for yourself. You have to make sure you can do things for yourself before you give life to these children." She felt it was only at this point of commitment to the

Table 6. Dimensions of Contrast in the Domain, "Things That Tell Me My Child Doesn't Feel Good," According to Care Giver Consulted

y = yes n = no s = sometimes na = not applic.	I take care of	Ask somebody older	Ask grandpa	Ask curandera/o	Ask doctor	Ask nurse	Ask social worker
Gets down	y	y	n	n	n	s	s
(Child) Tells me	y	s	s	n	s	y	n
Sits down	y	y	n	n	y	y	n
Quieter sometimes	y	y	n	n	y	y	n
Eats different -- not so much	y	y	y	n	s	y	s
Crying	y	s	n	n	y	y	y
Sometimes they stay put	s	s	n	n	y	y	y
Sleeps	s	n	n	n	y	y	n
Being jumpy	y	n	n	y	s	n	n
Constipation	y	y	y	s	s	y	n
A blackbird limping on one leg only	n	n	n	y	n	n	n
Fever	y	s	y	n	s	y	n

responsibilities of care for self and child, that one was capable of making decisions about health. On further questioning, she related the ability to take responsibility for the care of a child to the acceptance of the child. Table 7 illustrates dimensions of contrast in the domain, "things that influence acceptance of a child (by adult caregivers)."

In this paradigm, this mother illustrates that a woman who merely bears a child is not necessarily concerned about her child, nor does she have to feel for others, or know what it feels like to hurt (have experienced deprivation or the insensitivity of others). Only "sometimes" does she expect a woman who has a baby to not want the child to "feel uncomfortable," expect the child to "become part of her," and expect her to be "honest." One can logically speculate from this informant's discussion that quality of parental care, compliance, etc. might be influenced by the acceptance of the child and the responsibility the mother feels toward her/him.

It is interesting to note that the qualities this mother expects in a "true parent" are the same qualities she expects in the child's doctor and nurse. She describes a "true parent" this way,

> Being a true parent is something that you feel. You have to really like your kid. You have to be part of them (children). I don't like to classify everyone who has a baby as a mother. I think 'mother' is very superior. I think you have to put yourself aside. There's no time for glamour and dining. You have to show them (children) the basics. Never lie to them. I tell them (children) I'm not right just because I'm your mother. I can just guide them because I'm older and I've been through it.

Table 7. Dimensions of Contrast in the Domain, "Things That Influence Acceptance of a Child," According to the Type of Care Giver

y = yes n = no s = sometimes na = not applicable	A woman who has a baby	A family	A true parent	Kids' doctor	Nurse
Concerned	n	y	y	y	y
Common sense	y	y	y	y	y
Liking your kid	n	y	y	y	y
Don't want them to feel uncomfortable	s	y	y	y	y
You have to feel	n	y	y	y	y
Child has to become part of you	s	y	y	y	y
You have to know what it feels like to hurt	n	y	y	y	y
Being responsible	y	y	y	y	y
Honesty	s	y	y	y	y

Taking Care of the Child

In the domain "things I take care of" conditions mothers handle without consulting a physician are presented. Even though this domain lists things mothers take care of it does not mean that they do not seek advice for these problems from others or that they may not ultimately consult a doctor. The terms in this domain(see Table 8) are quite specific in many instances. For example "fever up to 101°" or "throwing up if not more than two days or too frequent" illustrate that many times mothers have recognized and delineated their limitations. Other terms in this domain include: colds or flu that doesn't persist longer than three to four days, diarrhea, stomach cramps if not more than two days, the beginning of everything, first-aid things, bee sting, ticks, constipation, diaper rash, teething, and cuts.

All four informants had a number of persons from whom they took health care advice (see Table 9). This advice might be taken before, during, or after consultation with the doctor. Interestingly, one informant's domain entitled "things to ask mother-in-law about" exactly matched her domain called "things to consult doctor about." Further investigation revealed that this mother did not call or take her child to a physician without being instructed to do so by her mother-in-law. In another instance, a mother said if she didn't like or agree with the advice she was given in one place, she would go on to another care giver or institution. This type of behavior leads one to suspect that mothers know what they want out of a visit to the physician, clinic or hospital. When their expectations are not met they might seek professional help elsewhere, consult with others, or try things on their own.

Table 8. Things I (Mother) Take Care Of

Fever up to 101^{o}
Colds or flu that doesn't persist longer than 3-4 days
Diarrhea
Stomach cramps if not more than two days
Throwing up if not more than two days or too frequent
The beginning of everything
First-aid things
Bee sting
Ticks
Constipation
Diaper rash
Teething
Cuts

Table 9. "Where I (Mother) Get Health Care Information and Advice"

Friends	Somebody older
	A lady with kids if she's good
Social worker	
Hospital	
Curandera/o	
Stepfather	
Mother	
Father	
Grandpa	
In-laws	
Nurse	
Medical books	
Common sense	
Husband	
Magazines and books	
Doctor's office	Doctor's receptionist
	Doctor

In the domain "where I get health care information and advice" the following terms were included: friend (including somebody older, and a lady with kids if she's good), social worker, hospital, curandera/o, stepfather, mother, father, grandpa, in-laws, nurse, medical books, common sense, husband, magazines and books, and doctor's office (including doctor's receptionist and the doctor).

Each mother classified things that she does to prevent her child from getting sick. All mentioned some type of diet regulation. Some common folk terms related to nutrition were: "keep away from junk food," "don't put sugar in anything," "try to feed him the right foods," "don't give mustard, chocolate, eggs, milk," "don't let them drink ice cold water," etc. Here too, there was evidence of more than one health belief system at work. Evidence of non-traditional health care practices to prevent illness include such folk phrases as: "don't let them sit in direct air (wind)," "don't let them swallow gum," and "rub child with an egg and pray."

In two of the mothers' taxonomies there were domains such as "useful things to treat illness" and "things to do if child isn't feeling well." In these domains the mothers shared some of their home remedies. These remedies spanned the gamut from the common, to the practical, to the unusual. For example, tea was used for diarrhea, a cold cloth and the radio were used for headache, and sliced tomatoes were put on the throat for sorethroat. Some of these remedies were things these mothers had discovered on their own, some were passed throughout the kinship system, and others originated in other health care belief systems.

Consulting a Doctor

All of the informants in this study were able to identify specific times they felt their child needed to see a physician. This was true even of those informants who utilized more than one health belief and care system. At times the mothers were able to be very specific about the things which could no longer be handled at home. For instance, one mother said she would take the child to the doctor "after the second time he throws up." Another mother said she would consult the doctor for "a fever over 101°." Only one mother felt that a phone consultation with the doctor regarding the condition of her child was acceptable.

Table 10 represents the domain "things to consult a doctor about." Terms included in this domain are the following: severe cold, constipation, diarrhea that doesn't go away, real bad coughing, when she has trouble getting her breath, doesn't act right, starts running down, acting just blah, when there's nothing else I can think of to do for them, anything that doesn't go away, when just relaxing doesn't make them feel better totally, if symptoms persist for two days, acting different (seem weaker and/or sleeping more), anything that looks too bad from the start, walking funny, acting slow in some ways (including not doing what they should and can't see well), breaking out with something after contact with a skin disease, continues tugging on his ear and is fussy, anything worse than a cold, when it (illness) goes into another stage, fever if I can't get it down, when there's blood, and when they're hurt.

Table 10. Things to Consult a Doctor About

Things to Consult a Doctor About	Severe cold Constipation Diarrhea that doesn't go away Real bad coughing When she has trouble getting her breath Doesn't act right Starts running down Acting just blah When there's nothing else I can think of to do for them Fever over 101° Anything that doesn't go away When just relaxing doesn't make them feel better totally If symptoms persist for two days
	Acting different: Seem weaker; Sleeping more
	Anything that looks too bad from the start Walking funny
	Acting slow in some ways: Not doing what they should; Can't see well
	Breaking out with something after contact with skin disease Continues tugging on his ear and is fussy Anything worse than a cold When it (illness) goes into another stage Fever if I can't get it down When there's blood When they're hurt

Most of these folk terms relate to specific symptoms. In most instances, the mothers stated that the things they listed necessitated a visit to a physician. Fever seemed to be a unanimously alarming symptom. All the mothers indicated they were uncomfortable handling a high fever even after the child had seen a physician. Bleeding is another thing that seemed to be a source of anxiety for these informants. For instance, one informant said, "When there's blood there's no waiting and no question -- we go in (to the doctor)." Another mother said, "When there's bleeding I can't handle it. I just freak out; I get so scared."

The informant who listed "anything that looks too bad from the start" as something to consult a doctor about explains it this way,

> If they're (child) just throwing up that's something that could just be from too much to eat or the wrong thing to eat, but if they're throwing it across the room (projectile vomiting) that's so far abnormal that there's a definite reason for it. Or if they're playing outside and they hurt their leg and they can't walk on it, it might just be a sprain, but I don't like to take chances. If they've fallen and hit their head and they're very unstable or they're throwing up, then I'll take 'em (to the doctor)."

Another mother explained "acting different" the following way, "When she was three years old just standing there staring. You could talk to her and move around her and her eyes wouldn't move. That's different; that's something she couldn't play a game around me with." To further illustrate "acting different" she said, "If they seem to get weaker, like one day they can pick up something and a month later they can't pick that item up, for some reason the body's not as strong as it was. To me that's different." "When it goes into another stage" was illustrated by, "He just gets worse and worse; there's no improvement."

One mother's taxonomy included a domain called "things that tell you a doctor cares." Table 11 represents those things she deemed important. The following are the terms she included: gives more medicine if the first doesn't work, tries something just to see, asks another doctor for another opinion, and tries to find out what is really going on. Feeling that a doctor cares was an important aspect of health care not only to this mother but to all the informants.

Table 11. Things That Tell You a Doctor Cares

Gives more medicine if the first doesn't work
Tries something just to see
Asks another doctor for another opinion
Tries to find out what's really going on

How Mothers Feel About the Health Care of Their Children

This domain (see Table 12) includes feelings which mothers have about what happens to them in the course of trying to fulfill their children's health care needs, as well as feelings which mothers have regarding their attempts to care for their children themselves. "Feeling I have to try to figure out what is important and what isn't" is a dilemma faced by all mothers, not only in regard to health care but also to everyday happenings. One informant stated, "You play a lot of guessing games when they're babies -- is she wet? is she cold? is she

Table 12. Kinds of Feelings Mothers Have About the Health Care of Their Children

Feeling I have to try to figure out what's important and what isn't
Feeling it's important to learn when crying means they're sick and when it doesn't
Feeling like I'm being pushed off (by the doctor)
Feeling stubborn
Feeling a mother isn't so stupid she doesn't know something
Feeling helpless when told nothing is wrong and I know there is
Feeling maybe she'll think I don't love her
Wondering if I'm doing my best or taking the easy way out
Feeling frustrated when not told what might have caused this
Guilty
Nervous and indecisive
Feeling an honest doctor is one who says he hasn't found anything yet
Hysterical
Feeling I prefer they (doctor) say they don't know
Feeling like killing somebody
Frustrated because virus is a very incomplete word
Feeling I should go for how I would feel if that was me
Feeling their (Dr.'s) books don't know when my child is sick
Feeling if it wasn't right for me, it wasn't right for them
Feeling he's (Dr.) just a person with a little more knowledge than me
Feeling no one else can tell someone how their child is -- not even Dr.
Tired of people looking at me as if I was some kind of fool
Feeling a need to keep a close eye on things
Refusing to be laughed at
Feeling the doctor was wrong
Feeling if a Dr. makes a mistake once he can make it twice

hungry? does she need to burp? is she uncomfortable? is she lonely? At first I took her (to the doctor) all the time. The doctors got tired of seeing me." She further explained "don't feel a mother is so stupid she doesn't know something" by saying, "The doctor may know something about my kid's insides that I don't know, but that's not about just my kid, it's about every human being."

The domain "kinds of feelings mothers have about the health care of their children" includes the following terms: feeling I have to try to figure out what's important and what isn't, feeling it's important to learn when crying means they're sick and when it doesn't, feeling like I'm being pushed off (by the doctor), feeling stubborn, feeling a mother isn't so stupid she doesn't know something, feeling helpless when told nothing is wrong and I know there is, feeling maybe she'll think I don't love her, wondering if I'm doing my best or taking the easy way out, feeling frustrated when not told what might have caused this, guilty, nervous and indecisive, feeling an honest doctor is one who ways he hasn't found anything yet, hysterical, feeling I prefer they (doctor) say they don't know, feeling like killing somebody, frustrated because virus is a very incomplete word, feeling I should go for how I would feel if that was me, feeling their (doctor's) books don't know when my child is sick, feeling if it wasn't right for me, it wasn't right for them, feeling he's (doctor) just a person with a little more knowledge than me, feeling no one else can tell someone how their child is -- not even the doctor, tired of people looking at me as if I was some kind of fool, feeling a need to keep a close eye on things, refusing to be laughed at,

feeling the doctor was wrong, and feeling if a doctor makes a mistake once he can make it twice.

One mother illustrated "guilty" by saying,

> There were a lot of times I was wrong and she didn't go (to the doctor) when she should have. One time she had a temperature of 104°. She was so tired and pale looking. I took her (to the doctor) two days later and she had pneumonia. I feel so guilty about that. If I'd taken her earlier they could have started her on penicillin and gotten her feeling better.

Guilt, or concern that she (mother) had erred, was a commonly expressed feeling. "Felt like killing somebody" was how one informant described her feelings when she entered the room after her eighteen month old child had a spinal tap and she found the child screaming and blood on the table.

"Virus is a very incomplete word" was described this way,

> You go in there (doctor's office) with a cough and sneezes, he (doctor) tells you you've got a virus. You go in there with stomach cramps and diarrhea and he says you've got a virus. You go in there with a headache and scratchy throat and he says you've got a virus. You go in there with a thousand different things and you've got a virus. That's just the easy way out of saying, 'I don't know what's wrong with you; get out of here.' I don't like that word (virus) at all. I'd prefer he tell me he just doesn't know, because to me they don't know.

Several informants elaborated on those things they felt were important to look for in those who give health care to their children (see Table 13). Most of the folk terms mentioned involve some type of feeling the mother and child perceive from the care giver. The most frequently mentioned desirable feelings are: caring, interest, concern, respect, and the opportunity to participate in the child's care. Other terms which the informant included are: having some answers, trying to find out the sources of things, let me know they're at least trying

Table 13. Qualities Important to Mothers in Those Who Give Health Care

Having some answers
Trying to find out the sources of things
Let me know they're at least trying (to find cause of illness)
Ask me questions
Don't make me feel useless
Don't make me feel they know more about my child than I do
Interested in the child
Seem to like kids
Have a good attitude toward kids
Caring
Talk to the child
Be nice (to the child)
Be polite
Make me (mother) feel involved
Care about my opinion
Give respect to kids
Protect and look out for child's rights and feelings
Spend a little time
Explain how they come to that conclusion
Give time to ask questions
Be concerned
Be honest
Tell what the kid has

(to find cause of illness), ask me questions, don't make me feel useless, don't make me feel they know more about my child than I do, interested in the child, seem to like kids, have a good attitude toward kids, caring, talk to the child, be nice (to the child), be polite, make me (mother) feel involved, care about my opinion, give respect to kids, protect and look out for child's rights and feelings, spend a little time, explain how they come to that conclusion, give time to ask questions, be concerned, be honest, and tell what the kid has.

One of the informants listed things which she said bothered her about physicians. Some of the things she listed include: "I stay hours waiting only to be told they can't do anything," "I try what he says and it doesn't work," and "Being told to come then being told the child doesn't need anything." These statements lead one to conclude that when mothers feel the child's condition warrants seeing a physician she expects something tangible to be done for the child. This is an important point to consider especially in those instances when there is no indication for medication or specific treatment.

Another informant listed the ways she was able to tell that the physician was wrong. She included such things as: "a feeling," "a little child can't fake hurting," "after awhile it wasn't right," "told me she was faking it and I knew she wasn't," and "mothers pay close attention and know what her kids are going to do." These feelings had a definite impact on the health care of this mother's children for when she felt the physician was wrong she would search for care elsewhere. In other words, her inability to believe in the physician's diagnosis and treatment lead to health care shopping.

In summary, these ethnographic data have described mothers' views of their children's health care. The domains discussed and analyzed focused on when a child is well, when a child is ill, what things the mother takes care of, when to consult a doctor, and how mothers feel about their children's care.

Cultural Themes

According to Spradley (1979, p. 186) a cultural theme is "any cognitive principle, tacit or explicit, recurrent in a number of domains and serving as a relationship among subsystems of cultural meaning." Through theme identification, the general patterns of a culture become more comprehensible. Every culture is more than bits and pieces of convention and habit, it is an intricate complexity of pattern unique unto itself. Culture involves a system of meaning which is organized into a general pattern. Themes represent rules or principles that inform (or give direction) to the behavior of clinic mothers. Five cultural themes were identified from the taxonomies of the informants in this study. The themes include the following:

1. Let me participate in my child's health care.
2. Know how your children act when they feel well.
3. Parents should feel responsible for their children's health care.
4. Mothers should want their children to be comfortable, healthy, and respected by health care givers.
5. I have a way I take care of my child.

The first theme "Let me participate in my child's health care" was perhaps the most striking theme to emerge from this study. Mothers want to feel that they are being listened to and that they will be allowed to make choices regarding their children's care. One mother gave a rather vivid description,

> If they (doctor) come in (to the room) and don't ask me any questions, then that to me means they think they know everything without my help at all. That makes me feel useless and makes me feel like they're not really interested to begin with. They (doctors) should at least ask you questions. I want to be involved and feel like they care about my opinion.

Another mother said, "I had a feeling there was something wrong, but when I'd tell the doctor he'd never say anything to me. One even said there was nothing wrong. I don't think they even listened to what I said; that would have made me feel like I belonged." A third informant said, "The doctor said it was nothing. He didn't do x-rays or nothing, and he did have something in there. I knew he had something." Another mother said, "He's (child's doctor) a nice guy. He doesn't pass judgment on you. I guess it's being more than non-judgmental, it's permitting freedom of choice." These feelings are further born-out in the domains "kinds of feelings mothers have about the health care of their children" (Table 12, p. 65) and "qualities important in those who give health care" (Table 13, p. 68).

The theme "Know how your children act when they feel well" was one that was expressed by all four informants. As can be illustrated by looking at Table 3 (p. 46), all of the mothers were able to list some characteristics of their child when well. As was previously pointed out, all of these informants seemed to assure themselves that

their child was well by the child's activity level. The implication here is that only by knowing her child when well, would a mother be able to identify when her child was ill. One informant expressed this sentiment when she discussed mothers she knew who didn't spend much time with their child and who therefore, she felt, might not be able to pick up signs of illness.

The third theme is "Parents should feel responsible for their children's health care." This means that parents need to play an active part in keeping their children well, as well as a part in providing them with the care they need when they're not well. Taking this responsibility is part of what one mother described as being a "true parent."

Table 5 (p. 51) illustrates things that indicate to a mother that her child isn't well. One informant identified two types of illness -- mental and physical. A second informant identified four types of illness -- physical, physical witchcraft, mental, and mental witchcraft. This indicates that in order for a mother to adequately monitor her child's health status she would need to know what behaviors, signs, and symptoms indicate each type of illness she identifies. It might also be necessary for her to know how and when to utilize more than one type of health care delivery system.

Table 6 (p. 54) illustrates the contrasts the mother views in those things which tell her that her child isn't feeling well. This type of analysis is an attempt to elicit tacit ways a mother monitors the health status of her child. One informant expressed the thought that in order for adult care givers to be responsible for a child, they must accept the child. Her analysis is presented in Table 7 (p. 56). One of

the thoughts she expresses is that a woman who has given birth isn't necessarily a responsible care giver. All the informants included examples of things they do to prevent their child from getting sick. Due to the lack of time and space, those domains are not presented; however, mothers do do specific things to maintain the wellness of their children.

"Mothers should want their children to be comfortable, healthy, and respected by health care givers" is another theme. This is closely related to the third theme, but includes a certain relationship and feeling necessary between the mother and child. In regard to keeping the child comfortable and healthy, Table 10 (p. 62) represents times when the mother feels she needs help from the doctor to attain that goal. One informant said she sought a physician for her children "when there's nothing else I can think of to do for them." In other words, her children see a physician when she is no longer able to keep them comfortable or when she has been unsuccessful at keeping them healthy.

One informant said, "If you respect your kids you see how they react to different things. You'll know their daily routines and what makes them feel good and when your child is sick. You've got to learn how they feel; you have to respect their feelings. You have to respect your kids." In other words, a mother should consider the worth and feelings of her children. Another informant described what she felt was lack of respect shown toward her child by the physician. This infuriated her and she commented, "My kids deserve respect just as much as anybody else does. Their rights and their feelings deserve to be protected and looked out for just as much as anybody else's."

The final theme is "I have a way I take care of my child." All the informants did seem to have a specific plan for the care of their children. They were able to specify what things they felt comfortable handling by themselves (see Table 8, p. 58). Some of the mothers also included domains specifying measures they take when their child isn't feeling well. All the informants also included domains which identified ways the mothers tried to prevent illness in their children.

Summary

This chapter has included a description of the sample, as well as a description of the data collection and the interviews. In addition, the researcher-informant experience was discussed and finally mothers' views on their child's health were presented. The domains included in the ethnographic data are as follows: "things that let me know my child isn't feeling well," "things to consult a doctor about," "kinds of feelings mothers have about the health care of their children," and "things I take care of."

Cultural themes were identified and discussed. The themes identified are: (1) Let me participate in my child's health care, (2) Know how your children act when they feel well, (3) Parents need to be responsible for their children's health care, (4) Mothers should want their children to be comfortable, healthy and respected by health care givers, and (5) I have a way I take care of my child.

CHAPTER 5

CONCLUSIONS

In this chapter the research conclusions will be presented. The sections which will be included are: an analysis of the cultural themes from the view of the conceptual framework, a comparison of the literature review and the ethnographic data, a discussion of how the health care system relates to clinic mothers, how nursing practice relates to clinic mothers, and finally recommendations for research.

The purpose of this research was to identify a way clinic mothers perceive and define health and illness and how they plan for the care of their children. The procedures of the ethnographic interview according to Spradley (1979) were used to discover culturally relevant domains in order to learn how mothers organize their health relevant information. The ethnographic data attempts to describe the culture of clinic mothers as they view it.

Cultural Themes and the Conceptual Framework

The concepts included in the conceptual framework for this study are: at level I (the most abstract level) culture and health care behavior, at levels II and III (less abstract levels) belief and value system, general cues and health care beliefs and health behavior cues, at level IV (the least abstract level) definitions of health and illness

and performance. This exploratory study did not attempt to address the most abstract levels of the framework.

It was speculated that the culture of clinic mothers is in some way related to the health care behavior of clinic mothers, that their belief and value system is related to the general cues they use, that their health care beliefs are related to health behavior cues, and that their definitions of health and illness are related to their performance.

The first cultural theme "let me participate in my child's health care" links with the mother's belief and value system. Such domains as "kinds of feelings mothers have about the health care of their children" (Table 12, p. 65) further reflect the culture of clinic mothers; how they interpret experience and generate behavior.

The cultural theme "know how your children act when they feel well" relates to the framework concept of definitions of health and illness. The theme implies that a mother feels she must know her children when they're well in order to determine when they're ill. In other words, the definitions of health and illness are derived, in part, from knowing your children.

In addition, the informants reported domains such as "things that tell me my child is feeling well" (Table 3, p. 46) and "things that let me know my child isn't feeling well" (Table 5, p. 51). Such domains further illustrate how mothers define health and illness and how they organize their health related knowledge.

"Parents need to be responsible for their children's health care" a third cultural theme, involves not only the parents' definitions of

health and illness, but it involves their health performance as well. It is important for mothers to be able to detect deviations from normal and once having done so they must elect either to do nothing or to take action.

The fourth cultural theme, "mothers should want their children to be comfortable, healthy, and respected by health care givers" also relates to the cognitive and behavioral parts of the conceptual framework. The notion of respecting your kids is derived from the mother's belief and value system. These beliefs will then influence her motivation to take action or not.

The fifth and final theme is "I have a way I take care of my child." This theme is part of the empirical concept of performance in the conceptual framework. Domains such as "things I take care of" (Table 8, p. 58) and "things I do to prevent my child from getting sick" further define clinic mothers' behaviors.

Review of the Literature and the Ethnographic Data

There were a number of questions raised by the review of the literature. These questions include: What variables influence the health behaviors of clinic mothers? How do clinic mothers define health and illness? What qualities do clinic mothers desire in those who give health care to their children? These questions were not the sole basis of this study; however, the ethnographic data collected does provide some insights into the answers.

The question of "what variables influence the health behaviors of clinic mothers" is a complex one. In this research, the variables

of ethnicity and culture, feelings of depersonalization and alienation, kinship systems, and socioeconomic level seemed to play a part in the health behaviors of these mothers. The two informants whose ethnic background was Mexican utilized the folk care system as well as the professional health care delivery system. Another informant whose ethnic background was Anglo American utilized a variety of alternative care givers in addition to the professional care givers.

Most all of the informants expressed feelings of depersonalization and alienation when discussing their views of the professional health care delivery system. This is illustrated in the domain "kinds of feelings mothers have about the health care of their children" (Table 12, p. 65). Phrases such as "feeling like I'm being pushed off," "don't feel a mother is so stupid she doesn't know something," "tired of people looking at me as if I was some kind of fool," etc. illustrate their feelings of depersonalization and alienation.

The kinship system proved to be another important variable in relation to the informants' health behaviors. Much advice and health information was passed along the kinship lines. One informant utilized the professional health care system as directed by her mother-in-law. The socioeconomic level of the informants, to a large extent, determined where health care was obtained. All the informants were from the lower socioeconomic level; all were having financial difficulties.

The question of "how do clinic mothers define health and illness" was partially answered. The informants offered their definitions and further illustrated their definitions through such domains as "things

that tell me my child is feeling well" (Table 3, p. 46) and "things that let me know my child isn't feeling well" (Table 5, p. 51).

Another question "what qualities do clinic mothers desire in those who give health care to their children" was touched upon. All the informants discussed what qualities were important to them and included such domains as "qualities important in those who give health care," "things important for those who give health care," "things I want in my kid's doctor," etc. in their individual taxonomies.

Clinic Mothers and the Health Care System

Mothers often feel intimidated by and helpless within the professional health care system. The informants in this study all expressed not only the desire, but the significance of being allowed to participate in the health care of their children. Their exclusion from the decision making processes which affect their offspring produces feelings of impotence, incompetence, and worthlessness. These feelings of unworthiness are in part responsible for lack of compliance, health care shopping, dissatisfaction, and avoidance of the professional care system.

It should be noted, that for many mothers, in fact for many persons, the physician is equated with the health care system in general. In many cases, probably not unrealistically, mothers do not feel they have access to other health care providers such as nurses, nutritionists, etc. except through the physician. Bearing this in mind, it is not surprising that at times mothers' dissatisfactions and negative feelings toward the health care system are expressed as dissatisfaction and

negative feelings toward the physician. It therefore behooves all health care professionals to reassess their views of the parent's and/or client's role as a member of the health care team.

Clinic Mothers and the Nurse: Recommendations for Practice

The cultural themes identified in this research may have clinical significance for nursing practice. The ethnographic data provide insights into clinic mothers' views of their children's health care. The ethnographic interview provides the informants the maximum opportunity to communicate in their own words.

The five cultural themes discovered which include: (1) Let me participate in my child's health care, (2) Know how your children act when they feel well, (3) Parents need to be responsible for their children's health care, (4) Mothers should want their children to be comfortable, healthy and respected by health care givers, and (5) I have a way I take care of my child, all suggest some considerations for nursing practice.

First, I feel it is essential for nurses to take the time to allow mothers to participate in planning for their child's health care, as well as sharing in the decision making processes. This may involve the nurse researching a topic for a mother or a mother researching a topic for the nurse. The procedure may also involve the nurse acting as an advocate for the mother and child, especially in situations involving other professionals. Often the mere inclusion of the mother in the planning process and giving her time for questions communicates a feeling of caring and concern.

Second, it is important for nurses to observe how mothers (parents) interact with their children. This interaction must be assessed in light of the mother's cultural context. In other words, nurses need to be aware of their own cultural biases in order to avoid imposing their values and judgments on their clients.

Third, it would seem important for parents to know how to get acquainted with their child. Therefore, I would recommend that nurses learn how to teach parents to interact with their offspring. Parents need to know how to handle and fondle their children, how to play with them, how to talk with them, how to communicate with them, how to provide age adequate stimulation, etc. This teaching can begin at birth and can be revised and expanded through adolescence.

A fourth recommendation is to provide parents with parenting classes. If mothers feel responsible for monitoring their children's health and health care then they should be provided with the basic skills they feel they need to achieve that goal. This teaching might involve temperature taking, adequate nutrition or it might necessitate teaching more involved monitoring such as how to watch a child after a head injury or what steps to follow if their child ingests a toxic substance. This parent education might be at the program and/or individual level. I would also recommend exploring information resource persons with the mother in order to decrease her feelings of isolation and to provide her with a means of avoiding guilt in the event that her attempts to monitor her child's care should fail.

Fifth, I would recommend that nurses elicit the mother's view of her child's health status as well as those remedial measures which

are used in the home (in the case of illness). The mother's view is likely to provide valuable insights into disease causation, the use of other health care delivery systems, etc. In addition to the mother's view of her child's health status, the mother's expectations of the health visit need to be elicited. For the most part, the mother's home remedies should be supported and encouraged. This encouragement not only helps build rapport between the nurse and the mother, it also allows the mother to develop a sense of self-confidence.

Recommendations for Research

The following recommendations for further research are suggested:

1. Investigate father's perceptions of their children's health care.
2. Replicate this study at a well child clinic.
3. Replicate this study on a variety of ethnic groups.
4. Replicate this study on mothers of children over six years old.
5. Investigate the child's perceptions of health and illness.
6. Investigate how the child under six years old views her/his participation in her/his own health care.
7. Investigate how the child over six years old views her/his participation in her/his own health care.
8. Explore how children view their role in the health care of their siblings.
9. Explore how extended family members view their role in the health care of young family members.

10. Investigate mothers' views on how they might participate in their childrens' health care.

Hypotheses generated during the course of this research include:

1. The views of clinic mothers, whose children attend a crippled children's clinic, regarding their children's health care differ from the views of clinic mothers whose children do not attend a crippled children's clinic.
2. Mothers from low socioeconomic levels view the health care of their children differently from mothers from high socioeconomic levels.
3. Clinic mothers with a child under six years old view their children's health care differently than do clinic mothers with a child over six years old.
4. Children from low socioeconomic families receive less health care than children from high socioeconomic families.
5. Clinic mothers treat more illness at home than non-clinic mothers.

APPENDIX A

PERMISSION TO CONDUCT STUDY

THE UNIVERSITY OF ARIZONA
TUCSON, ARIZONA 85724
HUMAN SUBJECTS COMMITTEE
ARIZONA HEALTH SCIENCES CENTER 2305
TELEPHONE: 626-6721 OR 626-7575

17 September 1980

Ms. Jayne F. Linley
4641 East Burns Street
Tucson, Arizona 85711

Dear Ms. Linley:

We are in receipt of your project entitled, "Clinic Mothers' Perceptions of Their Children's Health Care", which was submitted to the Human Subjects Committee for review. We concur with the opinion of your College Review Committee that this is a minimal risk project. Therefore, approval is granted effective 17 September 1980.

Approval is granted with the understanding that no changes will be made in either the procedures followed or in the consent form used (copies of which we have on file) without the knowledge and approval of the Human Subjects Committee and your College Review Committee. Any physical or psychological harm to any subject must also be reported to each committee.

A university policy requires that all signed subject consent forms be kept in a permanent file in an area designated for that purpose by the Department Head or comparable authority. This will assure their accessibility in the event that university officials require the information and the principal investigator is unavailable for some reason.

Sincerely yours,

Milan Novak

Milan Novak, M.D., Ph.D.
Chairman

MN/jm

cc: Ada Sue Hinshaw, R.N., Ph.D.
College Review Committee

APPENDIX B

LETTER TO PROSPECTIVE SUBJECTS

4641 E. Burns
Tucson, Arizona
June , 1980

Dear

I am a graduate student in pediatric nursing at The University of Arizona. I am conducting a study to explore how mothers view their children's health care. The information obtained in this study will help nurses understand what things related to health care are most important to mothers and their children.

Mothers and children who utilize the Crippled Children's Clinic are being asked to participate in this study. The study involves interviews only. I will contact you by phone within the next couple of weeks to explain this project further.

Your cooperation will be greatly appreciated.

Sincerely,

Jayne F. Linley

APPENDIX C

SUBJECT'S CONSENT FORM

Project Title: Clinic Mothers' Perceptions of Their Children's Health Care

You are being asked to participate in a study exploring clinic mother's perceptions of their children's health care. The information obtained in this study will help nurses learn how mothers plan for their children's health care so that they might better assist you to attain high quality care for your child/ren.

Participation in this study requires several interview sessions lasting no longer than one hour each. The interviews will be conducted at a place of your choosing, and will be at a time at your convenience. The interviews will involve questions about you and your child/ren both when your child is well and during illness. This is a study of mothers with children six years and under enrolled at the Crippled Children's Clinic.

Your identity and the identity of your child will remain anonymous. All information will be kept confidential. The interviews will be tape recorded. Transcriptions of the tapes will be used for education, research, and publication. The tapes will be destroyed. No names will be presented to the clinic staff or used in the final research report.

There are no known risks or discomforts involved by your participation in this study. Neither is there any cost or payment involved. Your participation is strictly voluntary. You may ask questions or withdraw from the study at any time without reprisal. You are also free to refuse to answer certain questions as you desire. There will be no direct benefits received by you or your child during this study.

I have read the above. The purpose of the study, the risks, and the benefits have been explained to me. I understand that this research may be published, but that my name and my child's name will not be used. I know that I may ask questions and that I am free to withdraw from the project at any time. I also understand that this consent form will be filed in an area designated by the Human Subjects Committee with access restricted to the principle investigator or authorized representatives. A copy of this consent form is available to me on request.

Subject's Signature_____Date_____

Researcher's Signature_____Date_____

Witness' Signature_____Date_____

APPENDIX D

"GRAND TOUR" (BEGINNING) QUESTIONS

(1) Tell me what your child is like when s/he is ill.

(2) What is your child like when s/he is well?

(3) When do you feel your child needs to see a doctor?

(4) How do you plan for your child's health care?

(5) What kinds of health problems do you handle at home?

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