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THE "TAKING CARE OF MYSELF" PHENOMENON IN MEXICAN-AMERICAN
CHILDREN WITH LEUKEMIA

The University of Arizona

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THE "TAKING CARE OF MYSELF" PHENOMENON IN
MEXICAN-AMERICAN CHILDREN WITH LEUKEMIA

by

Maria Isela Luna Solorzano

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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STATEMENT BY AUTHOR

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This thesis has been approved on the date shown below:

Agnes M. Aamodt

AGNES M. AAMODT
Professor of Nursing

October 24, 1986

Date

DEDICATION

This is a story about six children who have cancer. I have tried to capture a part of what it is like to have cancer. In the following pages, I have also tried to write about their fears and joys, their smiles and their tears.

I dedicate this thesis to these and other children who have taught me so much through their struggles with their tragic illness, and through their love for life. I thank them for teaching me to see as they see, and feel as they feel.

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ABSTRACT

The purpose of this research was to identify the self-care behavior of Mexican-American children with leukemia. The ethnographic methodology was used using six informants 5 to 11 years of age. The recordings were transcribed and analyzed between sessions. Children's drawings were also used to gain additional information about children's perceptions of their world.

Nine domains of meaning were identified. Examples of domains include; "The meaning of being healthy"; "Things kids think about before the clinic visit"; and "Taking care of myself". These were then placed into either of three categories;

- 1) Pain and illness as correlaries to wellness,
- 2) Encounters in the oncology clinic, and
- 3) Dimensions in caring.

Six cultural themes emerged from further analysis of the data.

- 1) take care of me and allow me to take care of myself,
- 2) being happy is being healthy,
- 3) sometimes I really need to cry,
- 4) in the world where I live, one learns to take things as they come,
- 5) being sick makes you different, and
- 6) first, I ask my family to help me.

A model representing the world of the Mexican-American child with leukemia emerged from the conceptual orientation and data analysis.

Recommendations for care and further research in this population were suggested.

CHAPTER 1

INTRODUCTION

Why should I, or anyone for that matter, study the concept of self-care in Mexican-American children with cancer? In a world of continuous change and increased modern technology, how important is it for human beings to take care of themselves? Should nurses and other health practitioners be concerned with these concepts? Does self-care behavior really vary from culture to culture? Furthermore, can children with cancer really take care of themselves?

According to Fry (1978), approximately 75 percent of all health care is self-care. In fact, health care systems would be overcrowded without self-care. Indeed, self-care is one of many human responses that is practiced by all age groups and all cultures. According to Orem (1971), older children and youth are eager and want to assume responsibility for issues related to their health. Furthermore, the nurses' sustained support for the child who initiates his/her own care can make a significant contribution towards the development of his/her role as an effective self-care agent.

Nurses must be knowledgeable about health values, concerns and behaviors of various cultural groups since they too interact and are part of our present health care system. In fact, cultural factors

are the major forces that influence the quality of nursing care (Leininger, 1979).

My interest in the self-care behavior of Mexican-American children with cancer is rooted in my past experiences. My interest in the cultural patterns or behaviors of care that Mexican-American children practice stem from my practice as a pediatric nurse. In addition, my continuous search for an identity as one who was born and raised in Mexico and who migrated to the United States as a young adult has motivated me to do research in this area.

Another point of interest is the importance that culture plays in the phenomena of health care. Because the family plays such an important role, they must be included when doing patient education. Before children can initiate their own care they must be allowed to do it. Because of the family's ties and the increased dependency that Mexican-American children have on their family, self-care may never be initiated. In my experience, families of another culture require perhaps more time and teaching than the middle class American family. While at times it may be discouraging to know that some of these children and their families respond slowly, and insist in practicing their own folk beliefs, working with these families can be rather challenging. The answer very simply lies in achieving a happy medium between modern medicine and the Mexican-American folk beliefs. Having worked with the Mexican-American population for a number of years, I have identified a peculiar distinction in communicating effectively with families of Mexican-American descent. The

point that needs to be made is that families as well as children who are Mexican-American, require a particular level of hermandad that is needed in order to build rapport and therefore make an impact on their health behavior. This hermandad requires just enough involvement on the part of the nurse or health professional that conveys to the family and the child that one is interested in them as more than just another patient. This concept of hermandad can be translated into "brotherhood". This level of involvement in my experience is with more depth and breadth than one has with American families. It is also this hermandad that makes the line between being personal and objective for the nurse slightly more vague than with Anglo American families. However, it is this degree of hermandad that has challenged me to work with this type of clientele.

My interest in children with cancer stems back to the time I took care of a young Mexican girl who had been diagnosed with rhabdomyosarcoma, and who later died peacefully in the solitude of a hospital room in Texas. I will never forget how her parents tried to take care of her. Etched in my memory is an emaciated, fatigued and almost breathless young girl who wanted to do things for herself. Two days later, her parents stopped by the hospital to thank me for not being afraid of their situation and for being able to communicate with them.

It was not until I conducted my graduate clinical practicum at the oncology clinic, that I realized the impact that this experience had in my life. Working and talking to parents and children who

have cancer has brought new and exciting challenges for me as a clinician. Furthermore, as I began to explore the literature in pediatric oncology, I realized and began to appreciate the need for research in this area.

Statement of the Problem

The problem explored in this research is: what cultural knowledge informs the self-care behavior of Mexican-American children with cancer?

Statement of the Purpose

The purpose of this research was to identify the self-care behavior of Mexican-American children with cancer. The objective was to identify the self-care behavior that Mexican-American school-age children practice as a skill in dealing with cancer.

Data were collected as specified through the ethnographic interview approach (Spradley, 1979) and culturally relevant domains concerning self-care behavior of Mexican-American children with cancer were developed. Children's drawings also validated the child's eye view of experience.

Significance of the Problem

Why is self-care important to nursing? According to Orem (1980), "nursing has as its special concern the individual's need for self-care action and the provision and management of it on a continuous basis in order to sustain life and health, recover from disease

or injury, and cope with their effects". Self-care is a universal requirement for sustaining and enhancing life and health. Health education and identification of needs are some of the ways through which nurses can assist clients in achieving competence in self-care. Care of the self includes actions directed toward minimizing threats to personal health, self-nurturance, self-improvement, and personal growth.

According to the American Nurses' Association (1980, p. 9), nursing is "the diagnosis and treatment of human responses to actual or potential health problems". Self-care is therefore important to nursing because it is an ongoing activity and a competence to be developed, and because these human responses are of primary concern to nurses. Furthermore, nurses' unique role within the health care system may play an important role in influencing the client towards a self-care orientation to health care.

Much attention has been given to the adult Mexican-American folk health care system and beliefs, however the concept of self-care of children with cancer has stimulated little if any research. As a result of cultural differences, Mexican-American children may act differently from other children and nurses may wonder why these children do not act like the others. Therefore, the knowledge elicited from this study will contribute to better communication between nurses and the child resulting in the possibility of delivering a higher quality of care.

According to Zenty (1985), the price tag for medical services rendered during 1984 was almost \$400 billion, and annual spending levels were expected to increase at double-digit rates. As a result, the Tax Equity and Fiscal Responsibility Act was passed, and the Diagnostic Related Groups (DRGs) were implemented. Due to the implementation of the Diagnostic Related Groups (DRGs) in the health care system, home care has come to assume an important role as an alternate to the inflating costs of hospital care. Although the total health care spending in the United States during 1984 rose 9.1%, and the consumer price index increased 6.2% (Zenty, 1985), this represented an improvement over previous year's statistics.

A study by the National Center for Health Statistics (NCHS) puts overall medical costs for cancer at \$10.8 billion for 1980 (American Cancer Society, 1983). The American Cancer Society estimates that since medical care costs have been inflating at 20% or more a year, the figure of \$10.8 billion could easily double (1983, p. 24). No statistics are available as to the amount of dollars that are spent in the health or cancer care of the children.

In spite of the dramatic change or reshaping of the payment mechanism in the hospital industry, Zenty (1985), the American Cancer Society (1983, 1984), and others believe that hospital costs can be maintained in greater amounts by restructuring the health care environment. According to Koocher (1985), the focus of care of the child with cancer has shifted from hospital inpatient setting to the community where the child is treated on an outpatient basis unless or

until the illness reaches a critical stage. This shift indicates that more and more the responsibility for care rests mainly with the child and the child's significant others. The information elicited by this study will enable nurses in hospitals and outpatient settings to deliver care which is of high quality and with a decrease in cost. In this manner, nurses will form a viable partnership with Mexican-American children with cancer in order to maintain their optimum level of functioning.

Definition of Terms

For the purpose of the study, the following definitions of terms were utilized.

1. Cultural Knowledge: "Obtained knowledge that people use to interpret, experience, and generate social behavior" (Spradley, 1979, p. 5).
2. Self-Care Behavior: Practice of activities that individuals personally initiate and perform on their own behalf in maintaining life, health, and well-being (Orem, 1980).
3. Mexican-American Child: A child who speaks either the Spanish or English language in the home, may be born in Mexico or the United States, and must reside in Tucson, Arizona. At least one of the child's parents must be of Mexican descent.

Conceptual Orientation

A structural model (see Figure 1) has been designed to illustrate the concepts and hypothetical relationships underlying this investigation. The constructs included in this research are Mexican-American health care system, culture of childhood, and care. A description and the relationships of these constructs follows.

Mexican-American Health Care System

The fastest growing minority group in the United States is the Spanish speaking people from various parts of the Western Hemisphere. Mexican-Americans possess a great variety of culturally differentiated subgroups. They may differ from each other in the length of residence in the United States, racial composition, use of Spanish or English as the language of the home, and degree of acculturation, integration, and participation in the Anglo American society to name a few. For purposes of this research, the Mexican-American child may speak English or Spanish in the home, and no differentiation will be made with respect to the order of the generation of the child.

According to Goodenough (1957, p. 167), "a society's culture consists of whatever it is one has to know or believe in order to operate in a manner acceptable to its members". The Mexican-American culture of the child with cancer is then a cognitive appraisal of the child's surroundings.

Extensive research related to the Mexican-American health care system has been done. Some of this research is written from the

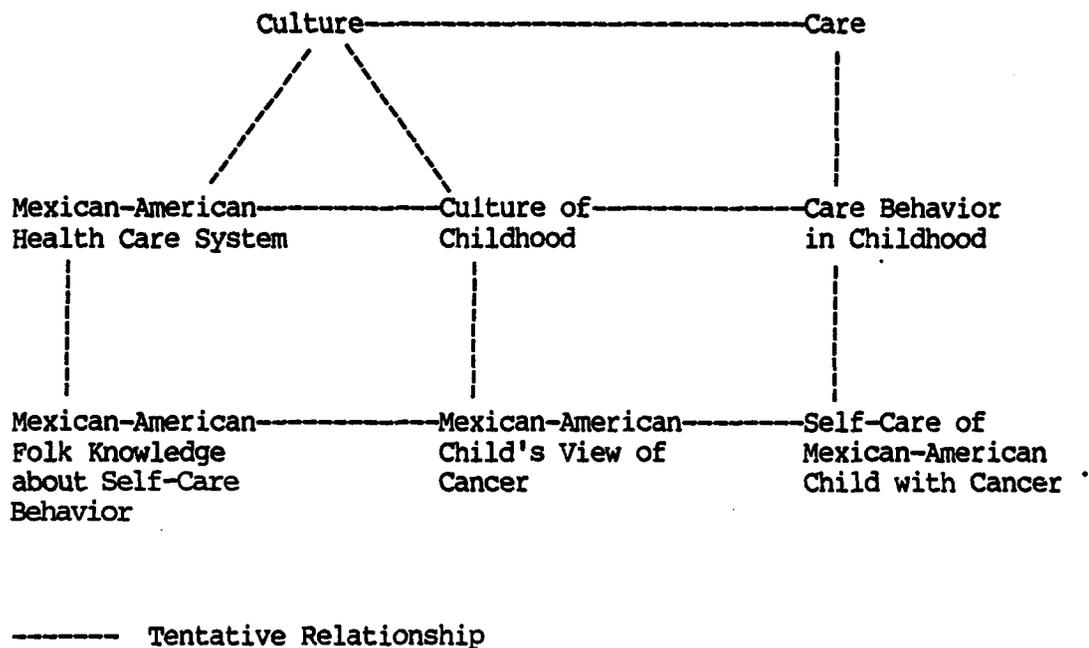


Figure 1. Conceptual Orientation of an Exploratory Study of the "Taking Care of Myself" Phenomenon in Mexican-American Children with Leukemia

adult's point of view. A literature search reveals that there is no literature related to the Mexican-American child that deals with health care from the child's point of view.

The Mexican-American health care system is significantly different from the American medical system. The major folk practitioner in the Mexican-American community is the curandero or curandera. The curandero's roles in treating illnesses are many and his functions are as diverse as the disagreements referred to in the literature regarding the validity and treatments of the curandero.

When the Mexican-American individual is faced with an illness, the individual searches and exhausts family resources first. Knowledge of herbs and how these are used in treating illness is passed on from generation to generation. After the individual has exhausted the resources of the family, he may seek a sobadora (massager) who is the lowest in status of folk curers and whose role is one of providing therapies rather than medicine. Next in the referral system falls the curandero who is not only more knowledgeable about herbs than the typical housewife, but also possesses charismatic qualities of value for the treatment of the spiritual aspects of the illness. The partera or midwife is also an important practitioner. It is believed that the partera may play a role of greater importance in Mexico than in the United States where hospital deliveries are more common.

Several sources have documented the fact that when faced with a health problem, Mexican-Americans tend to use a combination of the

folk and the American scientific method (Knowlton, 1975; Bullough & Bullough, 1972). Martinez and Martin (1966) however, found in a study of Mexican-American women living in a housing project, that the overwhelming majority knew about and used the folk system of diagnosis as a part of their care. Kay stated that while Mexican-American women may believe deeply in the supernatural causation of illness, "women believe that much illness is due to life habits ... and illness is a major daily concern" (1972, p. 6). This may in turn be interpreted as self-care behaviors. If Mexican-American women are constantly concerned with self-care behaviors when ill, and if their patterns of behavior influence the culture of the child, how does the child organize this information cognitively and how are his self-care behaviors expressed?

Culture of Childhood

Cultural knowledge is defined as the "knowledge that people use to interpret experience, and generate social behavior" (Spradley, 1979, p. 5), and is largely dependent upon the environment in which the child grows. A child's world is uniquely distinct from that of an adult. Therefore, much of how the child sees and interprets and responds to his/her surroundings is influenced by listening and observing others. The manner in which a child responds to a life-threatening illness such as cancer is therefore dependent upon various factors, one of which is the child's surroundings.

It is this unique response to phenomena surrounding children that Mary Ellen Goodman (1970) refers to as the culture of childhood. The concept of the culture of childhood is composed by a series of behaviors, attitudes and knowledge that children perceive. This unique culture that children have is evidence and recent research in the area of pediatric oncology has been approached from the child's point of view. In "The Child's View of Chemically Induced Alopecia", Aamodt, Grassl-Herwehe, Farrell and Hunter (1984, p. 217) state that, "a crucial need in clinical nursing research is descriptive accounts of health and illness experiences ... from the point of view of human beings".

Care

Why study the construct of care? Care or self-care, as is conceptualized in this study, is only one of the many human responses which nurses tend to. According to the ANA Policy Statement (1980), it is nurses' concern with caring which differentiates nursing from curing health professions. Furthermore, since the focus of care of a pediatric oncology client has shifted from the inpatient into the outpatient ambulatory setting, the need for health professionals to understand the self-care system is maximized.

The care concept has been studied by Leininger (1972, 1979), Hyde (1975), and Aamodt (1978). Leininger (1972) analyzes care as a process or type of behavior in order to gain insight into the transcultural perspective of care. She believes that care behavior

varies from culture to culture (Leininger, 1979), depending on the importance of care within the rest of the cultural system. For Hyde (Aamodt, 1972), care is a human characteristic which is not fully understood. Aamodt (1978) states that "care as a concern for others, ...is a culturally relevant domain that organizes human experiences and is necessary for a viable society". Aamodt (1981) has identified three categories within the care domain. These include: care eliciting, care giving, and care receiving behavior.

In "The Child's View of Chemically Induced Alopecia" (Aamodt, et al., 1984), the authors identified several self-care rituals regarding alopecia. No other literature was found that deals specifically with the self-care behavior of the child with cancer. This study attempts to identify different aspects within the concept of self-care as perceived by the Mexican-American child.

Summary

This chapter presented an introduction to the study and its significance to nursing, the statement of the problem, and the statement of the purpose. In addition, the conceptual orientation of the "taking care of myself" phenomenon in Mexican-American children with cancer was depicted.

CHAPTER 2

REVIEW OF THE LITERATURE

There is very little if any literature related to the patterns of self-care of children with cancer. However, the major focus of literature review is in the linkages between the constructs of culture and care discussed in the conceptual orientation. The culture construct includes the traditional Mexican-American health care system, the culture of childhood, and the child's view of cancer and childhood cancer in the Mexican-American culture. Self-care behavior in childhood is addressed by defining self-care in childhood and self-care of the Mexican-American child with cancer. Childhood leukemia, both physical and psychological aspects, is the focus of cancer for the review of literature.

Traditional Mexican-American Health Care System

In order to find out the needs of people, we need to know the particular practices and beliefs regarding wellness and illness. A considerable amount of research has been written on the Mexican-American health care practices (Saunders, 1954; Clark, 1959; Rubel, 1960; Madsen, 1964; Kay, 1972). While most studies have focused on the Mexican-American health care system in general, Kay (1972) has focused explicitly on the women's point of view.

Mexican-American folk medicine refers to the series of beliefs and patterns of practices which comprise the pre-Columbian and sixteenth to seventeenth century Spanish medicoreligious ideologies (Macklin, 1980).

Several health care practices are exercised by Mexican-Americans in order to maintain health and/or prevent illness. These include the use of (Clark, 1959; Rubel, 1969; Madsen, 1964):

1. One's knowledge of how the environment can affect one's health and using the environment to one's advantage.
2. Several healing networks within the community who assist in maintaining one's balance. The illness referral system is as follows:
 - a. family resources
 - b. curanderos (faith healers)
 - c. sobadora (massager)
 - d. partera (midwife)
 - e. scientific doctors
3. Healing practices involve remedios caseros (home remedies), including hierbas (herbs).

There are certain common beliefs within the traditional Mexican-American health system. These are (Clark, 1959; Rubel, 1969; Madsen, 1964; Kay, 1977):

1. The empirical knowledge for healing is passed through an oral tradition from one generation to the next.

2. The ultimate source of power is God. The curer is the instrument of God.
3. An important ingredient in the healing process is faith on the part of the client.
4. There is an underlying correlation between illness and offenses against others as well as against God.
5. Religion influences every aspect of life in the Mexican-American culture.
6. Curanderos/curanderas (folk healers) are distinguished individuals who have been given a unique and divine gift called el don.
7. All levels of curers help individuals achieve balance.

The Child's View of Cancer

Some literature regarding the child and leukemia has been taken from subjective observations made by parents of leukemic children. Binger (1923) conducted a study where 23 pairs of parents evaluated subjectively their leukemic children. In this study, younger children demonstrated anxiety related to disfigurement, separation or hurt; and while most of the children were not told of the diagnosis, most were aware of the seriousness of their diagnosis and anticipated their death. Travis (1976) reported areas of concern to children with leukemia as perceived by their mothers. Mothers reported children had difficulty in sleeping and "abnormal concern" over persons or pets under threat (p 360).

Richmond and Weisman (1955) documented observations during medical management of 48 children with leukemia and other diseases. In this study, children were noted to express greater passivity to diagnostic and therapeutic procedures than normal children. Passivity in these children tended to increase as the disease worsened.

Spinetta and Maloney (1975) compared 16 children with leukemia, and 16 children with non-fatal illnesses. The study had as its purpose to study the child's awareness of his condition even when not in the hospital. Like Binger (1969), Spinetta and Maloney (1975) found children preoccupied with body integrity, and abnormal degrees of anxiety. Spinetta and Maloney also found that leukemic children exhibit a lack of adaptability and increased anxiety related to clinic visits; anxiety increased as the illness prolonged.

Aamodt, et al. (1984) in "The Child's View of Chemically-Induced Alopecia" identified cultural themes which guide the behavior of children with chemically induced alopecia. This research is in many aspects the beginning of what self-care behavior of children with cancer can teach professionals regarding the care of children.

Strosnider (1986) identified in her work several self-care responses to pain from the leukemic child's point of view. "Things that make the hurt worse," "things others do for me," "things that keep it from hurting so much," and "it hurts worse if you don't hold still," are some of the domains of meaning that Strosnider identified. Some of the things that "keep it from hurting so much" were: "pain-

killers, thinking, bandaids, getting used to it, holding still, staying calm and relaxed, listening, and squeezing dad's fingers" (p. 42).

Dunscumb (1982) studied ethnographically "The lumbar puncture: perceptions of leukemic children". Cultural themes which can be identified as self-care responses are: "get a good doctor," "we don't like surprises," "eight year old boys need their parents," "getting my mind on other things," "I need to 'hold on'" and "you can't see behind your back" (p. 83, 84).

Childhood Cancer in the Mexican-American Culture

Several studies have been done on cultural differences in coping strategies and the successful outcome of attempt at mastery have been conducted. Based on the work of Diaz-Guerrero and Holtzman, Spinetta and Spinetta (1981) compared coping styles of Mexican and American children with cancer. They found that families from Mexico when compared to American families, tend to 1) be less open with and understanding of the needs of children regarding knowledge of illness and treatment effects, 2) rely less on spouse's mutual support and more on family and friends, 3) have a much deeper belief in the meaning of life and its events (this upholds them through the experience), and 4) as a result, tend to be passive and pessimistic regarding efforts at treatments and cure of the child. The degree to which these differences affect how the child takes care of himself is not known at this time, but can be speculated that they indeed affect

how the child adjusts and learns to master cancer and its associated treatments.

Self-Care Behavior in Childhood

Definition of Self-Care

Widespread interest in the concept of self-care has been stimulated partly by the increased cost of health care and partly by the individual's need for internal locus of control related to his/her health (McCorkle, 1983). Self-care according to Orem (1980), involves the patterns of activities expressed by an individual in response to a self-care demand. Orem (1971) states that a change in health status may bring about a change in the way people conduct themselves. She goes on to state that the person moves "from the position of self-care agent to that of patient or receiver of care" (Orem, 1980, p. 29). Orem believes that parents experience a similar phenomenon when the demands of child care exceed their capabilities.

Levin (1978) defines self-care as the process which lay persons initiate in an attempt to promote health, prevent and detect illness. Individuals wish to assume responsibility for all aspects of self-care. This includes decision making related to the amount of self-care knowledge needed, and the means used to deliver it (Bennett, 1980). For Levin (1978), self-care is initiated by the patient's perceived needs regardless of the needs identified by health professionals.

Fry (1973) identified the following four roles for self-care: 1) health maintenance; 2) disease prevention; 3) self-diagnosis, self-medication and self-treatment; and 4) patient participation in health services. In addition, Levin, Katz, and Holtz (1976) identified common characteristics of self-care. Among these are the premises that self-care is: universal, self-limited, non-organized, and varies depending on the complexity of the need, socialization and cognitive experience.

For children, a self-care orientation to care is expressed in terms of what health is. Self-care in children as well as in adults includes preventive self-care, self-treatment, and initiating health care assistance. The following two examples are definitions of health given by children. "Health is the things you do, like staying clean, eating good, getting good enough exercise (eight year old)," "health is being well and being able to do what you want to do (eleven year old)" (Koster, 1983, p. 29).

Types of Self-Care Behavior

Self-care behavior is composed of a series of patterns or a sequence of actions which result in a goal: illness prevention or health maintenance. For Orem (1980), there are three types of self-care: universal, developmental, and health deviation.

The category of universal self-care is a type of therapeutic self-care demand required by all. These universal self-care demands include: air, food, water, elimination, a balance between activity and rest and social interaction and solitude, hazard protection, and

normalcy. Meeting these universal needs is seen by Orem (1980) as activities of daily living of people within their cultural system.

Developmental self-care demands are universal self-care patterns of behavior which are unique to an individual. These types of self-care demands result from particular developmental processes or novel activities derived from conditions such as pregnancy or loss of significant others. Orem (1980) describes two types of developmental self-care demands: the maintenance of living conditions which promote developmental processes and prevention of harmful effects which may affect negatively human development.

Health deviation as a self-care demand is a need required only in the event of illness, injury, or disease. Health deviation self-care demands include change in human structure, physical functioning, and activities of daily living. The characteristics of health deviations extending over time determine the kind of self-care demand individuals need. Orem (1980, p. 90) lists six kinds of health-deviation self-care demands:

1. Seeking medical assistance,
2. Knowing, identifying, and responding to effects resulting from the health deviation,
3. Practicing the prescribed, therapeutic, and rehabilitative measures,
4. Regulating the discomforting medical care measures performed by, or prescribed by physicians,

5. Modifying the self concept in accordance with the particular health status with unique health care needs,
6. Learning to live with the health deviation and its associated effects in a life style which promotes continued personal development.

Self-care behavior in children with cancer has stimulated little research in the past. Children's abilities to care for themselves may be questioned by many; however studies to date on self-care of children support the view that indeed children are capable of self-care. Orem (1971, p. 130), believes that "guiding and supporting the child in self-care action, are appropriate methods of nursing children to the degree permitted by the health state". Nursing care of children will be influenced by the child's chronological and developmental age, heritage, physical and social environment, health status and health needs (Orem, 1971). For Orem (1971), the most important factor in being able to positively influence a child in taking on an active self-care role, is to be able to communicate effectively with the child.

In 1974, Lewis conducted a study in which children in an elementary school were encouraged to decide on their own care, when they needed care, and to participate in decisions on managing their health problems. Lewis asked herself whether the existing style of pediatric care was related to the failure of adults to develop optimal patterns of behavior when ill, and whether the active participation of children in decision making related to health care affected their

behavior as adults. In the cited project, health and illness beliefs of 5 to 12 year old children were determined, and a child-initiated health care system was established. The child was seen as an active participant of decision-making related to health care. A post-test was used in order to measure the effects related to the use of the experimental nursing services. During the year this child-initiated care system was in practice, the services were made available to 400 black, white and hispanic children and almost 70 percent of the children initiated care themselves. Lewis saw the nurse as the most influential unit in the transmission of care, and the client as his/her own best advocate. She went on to say that the extension of this type of intervention to other health care areas was dependent upon the methods of transmitting information during the processes of providing care.

Pierce and Giovinco (1983) conducted a four year project to provide community based health care support services to chronically ill children and their families. During the course of this project, services were provided to approximately 1000 severely ill children and their families who live in 16 county areas in Florida. Their study was based on Orem's conceptualization of self-care. In addition, several assumptions within the project were made based on the fact that self-care enhances self-image. These assumptions include the following (Pierce & Giovinco, 1983, p. 38):

1. Most children are able to initiate self-care from birth (i.e., cry by infants can represent an attempt to meet their own needs).
2. Children strive for independence which is positively related to a high self-concept.
3. Because self-care leads to an increase in independence, it improves self-concept.
4. A high self-concept and independence during childhood may lead to a more effective functioning adult.

The goal of this project was to minimize self-care deficits and limitations in chronically ill children and their families. The authors concluded that as children and their families learn to be their own self-care agents, compliance with treatment plans improves, overuse of medical services decreases, and recurrent episodes of illness diminish (Pierce & Giovinco, 1983).

Hussey, Hirsh and Laster (1983), in their article on health education, mention several factors required to effectively motivate a self-care orientation to health care in children. One of the factors mentioned included the use of a developmental approach in meeting the health related educational needs of children. Because of their developmental and cognitive achievements, school-age children seem to be at a prime time for learning. According to Piaget (1977), the school-age child is in the concrete operational stage of thought. This stage is characterized by the child's ability to use logical thinking and problem solving abilities provided that concrete or visible

evidence is given to help identify the cause and effect relationships (Pontious, 1982; Piaget, 1977). Because the school-age child is able to conceptualize reversibility, he/she is able to create new solutions to problems. Research projects up to date which deal with self-care have studied school-age children and have found this particular stage of development optimal for learning (Brown, 1985; Kubly & McClellan, 1984; Lawson, 1977; Green & Kolff, 1980). Furthermore, Koster (1980), Hussey and Hirsh (1983), and Natapoff (1978) believe that if children learn to actively participate in their care early in life, they will as future adults demand a self care approach to health care. In addition to developmentally related needs, using the child's world, specific teaching-learning strategies, and providing an atmosphere optimal for learning are other important considerations in motivating the child to achieve a self-care orientation to health care (Hussey & Hirsh, 1983; Koster, 1983; Natapoff, 1978).

Because children have a natural curiosity and desire to learn about themselves and their world, they are eager to learn how to take care of themselves and to maintain their health. Furthermore, the child's significant others such as parents and sibling should be included in teaching. Koster (1983, p. 40) states that "cultural influences and family health practices may have a stronger effect on the child than health education in the schools."

Teaching strategies which motivate school-age children to learn should be used. These may include: drama, different types of therapeutic play, stories, audio-visuals and dialogues. Regarding the

effective teaching strategies, trust between the nurse and the child seems to play a role of primary importance for learning to take place (Hussey & Hirsh, 1983; Whaley & Wong, 1983; Pontious, 1982).

A teaching strategy which fosters mutual trust and open communication is also important. In addition, determining the "point of time which the learner is most responsive to learning" is a skill necessary for learning to occur (Havighurst, 1976). An environment conducive to learning includes one which is non-threatening and familiar to the child.

A vast amount of literature was found on a variety of self-care aspects of school-age children with diabetes or asthma. Like Hussey and Hirsh (1982) and Koster (1983), Brown (1985), Kubly and McClellan (1984) and others have found through their research on asthmatic and diabetic children that a child's health internal locus of control and level of responsibility increases when a child is introduced or encouraged to follow a self-care orientation to his/her health condition. Furthermore, similarly to Hussey and Hirsh (1982), Koster (1983) and Brown (1985), who studied school-age children's knowledge and management of the disease and measurement of self-concept, concluded that their self-concept was significantly higher in self-care.

In general, studies to date on self-care patterns of chronically ill children have focused on several factors. These include: cognitive levels and developmental experiences of the child, coping and psychological responses to the chronic illness, impact of

the illness on self-esteem, self-concept, and family unit (Delbridge, 1975; Rubin, 1968; Bruch & Hewlett, 1947; Mattson, 1972; Yancy, 1972).

Childhood Leukemia

Cancer is the leading cause of death from childhood disease beyond infancy in the United States (Kellerman, 1980; Christ & Flomenhaft, 1984). According to the American Cancer Society (1983) between 6000 and 7000 children under the age of sixteen were diagnosed with cancer in 1985. In spite of this, it is estimated that 60 percent of the children who are diagnosed with lymphoblastic leukemia, the most common form of childhood cancer, will be free of disease five years after the diagnosis, and less than 5 percent of these survivors will ever have a recurrence of leukemia (Kellerman, 1980; Pratt, 1985). It is expected that by the year 2000, one of each 100 individuals under the age of 20 will be a survivor of cancer (Pratt, 1985).

Pratt (1985) reports in the Surveillance Epidemiology and Results that the annual incidence of childhood cancer is 12.1 per 10,000 white children and 9.3 per 100,000 blacks. Israel has the highest incidence of cancer, with 30.6 per 10,000 individuals both of European and American born fathers. The lowest incidence is in India with 6.8 per 100,000 males. No statistics are provided for Mexican-American children.

Leukemia accounts for approximately one-third of all childhood malignancies (Pratt, 1985). Acute lymphoblastic leukemia is the most common type of childhood leukemia. Brain tumors are the second most

common cancer in children with an incidence approximating half that of leukemia. Hodgkin's disease, non-Hodgkin's lymphoma, neuroblastoma, Wilm's tumor, and rhabdomyosarcoma make up most of the remainder of the childhood cancers.

Despite statistical inconsistencies, most investigators believe that the incidence in cancer in children has been increasing over the past half century (Sutow, et al., 1973; Whaley & Wong, 1979; Kellerman, 1980; Christ & Flomenhaft, 1984). This can be attributed partly to better diagnostic procedures for detecting cancer and partly to a decreased mortality rate caused by infectious diseases. The cause of many types of cancer is not known, and even less is known about the etiology of childhood forms of the disease.

A variety of environmental exposure has been described that are oncogenic in man, however only ionizing radiation has induced cancer in children (Miller, 1964). Low doses of radiation have been known to cause thyroid cancer and leukemia. There is also some evidence that exposing pregnant women to diagnostic x-ray procedures increases the occurrence of leukemia and other forms of cancer among their children. Intrauterine exposure to diethylestibesterol resulted in increased incidence of clear cell carcinoma of the cervix and vagina. Also, environmental exposure to asbestos, nickel, chromium, and arsenic could predispose the child to the development of lung cancer in late life, as these agents have been associated with lung cancer in adults with occupational exposures (Pratt, 1985).

Present observations do not exclude the possibility of a viral role in the genesis of leukemia. According to Sutow, et al. (1973), it is likely that the type of cellular reaction produced by the virus depends on the degree to which the host can resist the invasion. It is also probable that the virus may be triggered by various carcinogens.

Specific genetic predispositions to some cancers are known to occur in children, but are not common. The incidence of leukemia in identical twins is 25 percentage when it occurs early in life. In addition, children with certain genetically determined conditions such as Down's syndrome, Fanconi's anemia, Bloom's syndrome are at greater risk of developing leukemia and lymphoma than the general population. Retinoblastoma has long been known to be transmitted as an autosomal dominant trait.

During the last five or ten years, there has been much interest in regard to two speculations: first, that certain personality features and/or stress predispose people to cancer; and second, that among those who have cancer, personality or stress can affect its progress and/or survival rate (Christ & Flomenhaft, 1984). At this time however, the efforts to directly link personality characteristics to cancer predispositions have been unsuccessful. This failure has been attributed mainly to lack of enough research and poorly designed methodologies of present studies.

With the advent of chemotherapeutic agents, improvement in the survival rate of children with cancer has been apparent. Today, the overall survival rate of cancer in children is greater than 50 percent

(Waskerwitz & Ruccione, 1985). With this fact in mind, oncology professionals have shifted their concern from what was an inevitable death in the 1950s and 1960s, to helping the child with cancer to cope with an increased chance of long-term survival in the 1980s. Furthermore, the shift of the care of the child with cancer from a hospital inpatient setting to the community indicates that the care rests mainly with the child and his/her significant others. Therefore, it is important for health practitioners to learn about the patterns of self-care of these clients.

Physiological and Psychological Aspects of Leukemia and Care

Leukemia of an acute nature was first described by Friedriek in 1857 and in 1889 Ebstein described the disease clinically (Lobell, 1985). However, Hippocrates (c. 460-370 BC) first used the term karkinos (crab) to describe cancer (Foley & Yeske, 1982). Hippocrates presented one of the first theories of cancer etiology. He believed cancer was caused by an excess of black bile or melanchole, a theory which was later refuted by Galen (133-201 AD) (Foley & Yeske, 1982), who was the medical authority for the western world for the next 13 centuries. Galen and Hippocrates believed advanced cancer was to be left alone but proposed that superficial lesions could be managed by excision or cautery. These ideas were virtually unchallenged until the era of the Renaissance. Inventions such as William Harvey's description of the circulation of blood, van Leeuwenhoek's invention of the microscope and Robert Hooke's observation of plant cell contributed to

general advances in medicine. Specific contributions to oncology during the 19th Century include Racamier's formulation of the concept of metastasis in 1829. Roentgens' discovery of x-rays in 1845 and the isolation of radium by the Curies in 1898 are also specific contributions to the field of oncology.

The United States' Death Registration System was initiated in 1900, and played a major role in identifying incidence, mortality rates and end results of cancer treatments. The post World War II era marked the emergence of chemicals as a treatment modality. As the options for treatment increased, so did the concept of total care, especially in relation to children. Today, the treatment modalities are many. A brief description of management of the leukemic child follows.

Leukemias have been traditionally classified according to the type of cell involved. These may include: lymphocytes, myelocytes, monocytes, or undifferentiated cells. Thus acute lymphoblastic leukemia involves the lymphoid cells. The cells affected by leukemia are usually white blood cells, although red cell leukemia (erythroleukemia) has been known to occur.

Another factor used in the classification of the leukemias relates to the acuity or chronicity of the disease. Prior to modern treatment, if the cells involved were mostly primitive blast cells the leukemias were likely to be of an acute nature (Ruccione, 1983; Fochtmann, et al., 1982). Now with new treatment modalities, distinctions have become blurred, but the terminology remains. Acute leukemia today

is characterized by immature blasts which accumulate and inhibit production of normal white cells, red cells and platelets.

Another method used to classify leukemias is the French-American-British (FAB) Classification. Multi-institutional studies have reported a correlation between FAB morphology and acute lymphocytic leukemia (ALL) prognosis (Ruccione, 1983). Cell surface markers which define B and T lymphocytes and monoclonal antibodies that can distinguish specific antigens on the surface of the cell are also used for classifying leukemias. Lobell (1985, p. 359) concluded that patients with the poorest prognosis had a propensity for early relapse and involvement of one or more of the following:

1. Extreme leukocytosis (greater than $100,000 \times 10^9/l$) is predictive of a shorter response to treatment.
2. CNS disease at diagnosis indicates poorest prognosis.
3. Black patients in all studies have been noted to have a significantly poorer prognosis than non-blacks.
4. Best prognosis for children with B-ALL or T-ALL for those diagnosed at 3 to 5 years of age.

There are four phases of cancer therapy: 1) induction, 2) consolidation or intensification, 3) maintenance, and 4) observation (Pinkel, 1976; Fochtman, 1982; Lobell, 1985; Ruccione, 1983). After the diagnosis is confirmed by the various classification modes, the induction phase begins. The goal is to remove the bulk of the tumor through chemotherapy, radiation or surgery. As a result of this phase, complete remission will be demonstrated by the normal appearance of

bone marrow aspirates. According to Fochtman, et al (1982) and others, this is the most intensive phase of therapy with the side effects posing the highest threat to the child. The consolidation period is one where the client is believed to still have some clinical disease, and its therapy is geared toward eliminating the malignant cells. The maintenance phase is aimed at maintaining the client free of leukemia, usually with chemotherapy. This phase may last several years. The observation phase continues indefinitely and starts when the patient has been disease-free for a period of about two years.

The psychological care of the child with cancer is one which has attracted several researchers. Most research done in this area is geared towards the minimization of chemotherapy related side effects. Self-hypnosis as antiemetic therapy in children receiving chemotherapy has proved to have some therapeutic effects in dealing with nausea and vomiting (Hochenbery & Cotanch, 1985; Cotanch, et al., 1985; Hartman, 1981). Stress reduction techniques such as thought-stopping (Ross, 1984), recreational play (Gibbons & Boren, 1985), attention diversion, substitution of meaning and incompatible imagery (Ross & Ross, 1984) have proven to be therapeutic for the child living with cancer. Other aspects of psychosocial and cultural care of the child with cancer include the involvement of the family and significant others as well as cultural considerations (Fochtman & Foley, 1982; Ruccione, 1983; Spinetta & Spinetta, 1981; Aamodt, et al., 1984).

Although many of the articles previously mentioned, in particular those dealing with the psychosocial and cultural aspects of care,

can be interpreted as ways in which children attempt to achieve or maintain wellness; an effort must be made to identify patterns which guide the behavior of the child with cancer. As it can be seen, if the child is perceived as an active participant of his/her care, he/she can contribute to his/her wellness or health maintenance during any one of the phases of therapies.

There are not reports found in the literature that deal specifically with self-care responses of leukemic Mexican-American children.

Summary

Theories and research on the concepts of the Mexican-American health care system, the culture of childhood and childhood cancer, and the self-care behavior in childhood have been discussed. The scarcity of the literature on Mexican-American children and self-care suggests the need for exploratory research in this area. This research therefore, proposes a linkage between the constructs of culture and care.

CHAPTER 3

METHODOLOGY

This chapter will present a discussion of the design of the study, the informants, methods of data collection and data analysis.

Research Design

Since little systematic attention has been given to the self-care of Mexican-American children with cancer, an exploratory design was used. The purpose of this study was to identify the self-care behavior of Mexican-American children with cancer. Specifically, six school-age Mexican-American children with leukemia were interviewed about their experience with childhood cancer and its treatment effects. This study explored several questions. What are some of the self-care demands unique to Mexican-American children with cancer? What are some of the children's self-care responses to the physiological psychosocial and cultural demands posed by their condition? How much do these children know about their condition, and is that knowledge enhancing or inhibiting their potential for self-care?

Ethnography

Spradley (1980) states that ethnography is the act of describing a culture from the native's point of view as perceived by the researcher. Culture is defined by Spradley (1980, p. 5) as, "the

acquired knowledge that people use to interpret experience and generate social behavior." Leininger (1970) reports on the "emic" and "etic" components of the ethnoscientific method. The "emic" component describes the cognitive structural units of the people and the structural classes to which they belong. The "etic" approach focuses on aspects which may belong to more than one culture. Furthermore, a classification method may have some universal features which may lead us to broad domains of knowledge about man.

The ethnographic interview is seen as a field technique for gathering data. The ethnographic interview is a systematic, and organized way of revealing linguistic domains from informants. Spradley (1979) lists important elements in the ethnographic interview. These include:

1. interviews involving preparation and direction,
2. explanations to the informants, and
3. descriptive, structural or contrast questions used by the researcher.

Data analysis includes domain analysis, taxonomic analysis, componential analysis and theme analysis.

Goodman (1970) validates the fact that children are excellent informants. According to Spradley (1979), because of children's availability, they make good informants. Furthermore, the face and construct validity of descriptions of behavior in ethnographic monographs has been known in the past.

According to Leininger (1979), to accurately describe and explain health and illness behavior is a challenging task for health professionals. The challenge is in understanding how the child perceives his/her illness, how he/she desires to help himself/herself and to be helped. Furthermore, just like clients who come from culturally varied backgrounds approach their health practices and beliefs in unique ways, health providers bring with them their own health practices and beliefs about what they think can help clients.

Ethnography involves the generation, not the testing of hypothesis. Aamodt (1982) stated that ethnographic research provides a technique for the discovery of middle range theories in nursing in which the greatest contributions will be developing nursing theories related to needing, taking care and/or giving care to others.

Drawings as a Methodological Tool

Children's drawings have long been studied and analyzed in order to perceive the child's view. Dennis (1966) hypothesized that children's drawings reflect social values, and can be used as a tool to gain additional information about the child's perceptions of his world. He went on to say that a child's drawing reflect emotions or delineates objects that have meaning or value to the child.

According to Koppits (1968) and Omwake (1963), the child will draw fairly realistic representations of himself and his family if the association is positive and distort and disguise the figures if the reverse is true. The child may change the size and position of family

members or omit and substitute on a drawing. Drawings of such nature offer insight into the child's view of his surroundings. Furthermore, expressing one's emotions through drawings can be by far less threatening than other conventional methods. Like Koppits (1968) and Dennis (1966), Omwake (1963) suggests children's drawings mirror concepts, feelings, perceptions and knowledge. Lindzey (1961) states that it is important to use all available cues in the interpretation of children's art.

Informants

The informants for this study included six school-age children who are currently being followed in a regional cancer center in a southwestern city of the United States. Prospective informants were identified with the aid of the pediatric nurse/social worker. Also, input regarding prospective informants was obtained from the staff at the pediatric oncology clinic. The following criteria were used:

1. The informant is between the ages of six and eleven.
2. The informant belongs to the Mexican-American culture (see definition)
3. The informant may speak and understand English or Spanish.
4. The informant is willing to participate in the study.
5. The informant has been on a chemotherapy treatment regimen for leukemia.

Initial contact was made with parents of the prospective informants via telephone or during clinic visits. A brief explanation

of the study was given. At the initial visit the consent form (Appendix A) was read to the parent or guardian of the prospective informant, and signatures were obtained. An assent form was read to the prospective informant and he/she was asked to sign the form (Appendix A).

Human Subjects Consent

The procedure to protect human rights during this investigation followed the guidelines set forth by the Human Subjects Committee of the University of Arizona. The purpose of the study, method of data collection and potential uses of the study were explained to the parent and informant. Informants were informed that participation is voluntary and withdrawal is possible without any effect on the care they receive or the relationship with health care personnel at the clinic. Families of prospective informants were informed that by coding data and limiting access to it, identities will not be revealed and confidentiality maintained. Prospective informants and their parents were encouraged to ask questions. Permission to conduct the study was obtained from the Human Subjects Committee prior to asking prospective informants and parents for participation (Appendix B). Parents were required to sign a consent form and prospective informants signed an assent form (Appendix A).

Data Collection

The Ethnographic Interview

Interviews were held either at the child's home, or at the clinic. During the first interview, time was spent developing rapport with the child informant.

"Grand tour" questions were then asked to facilitate data collection. According to Spradley (1979), the interview's explicit purpose, ethnographic explanations and ethnographic questions are the three most important elements of the interviewing process.

Ethnographic questions of the descriptive, structural and contrast type were all used in the interview. It is important to note that the ethnographer at all stages of the interview process made an attempt to encourage informants to speak to others in their own "cultural scene" (Spradley, 1979, p. 59). Following is a discussion of the types of ethnographic questions, and examples of questions which were used in this research study.

Descriptive questions utilize language to construct a setting. Their goal is to elicit a variety of information from the informant in his own language. Furthermore, they are intended to stimulate discussion on a particular cultural scene. According to Spradley, one key principle includes the expansion of the question, in order to expand the length of the response. Although a question like, "tell me about being healthy" is an example of a descriptive question, it needs expansion. Instead, questions like "Could you tell me about feeling good?,"

tell me about the kinds of things you do for yourself?", elicited more information from the informant. Another example of a descriptive question is: Can you tell me about what it is like to go to the clinic?

Structural questions represent alternative ways to verify the existence of a folk domain. Structural questions will be used to identify domains. Examples of questions to be used are: tell me about the kinds of things you do to yourself when you get up in the morning, tell me about the things you like to do for yourself, tell me about the things you do not like to do for yourself.

Contrast questions aim to discover how the meaning of symbols are different from other symbols. This, according to Spradley (1979), is based on the fact that the meaning of folk terms depends on what it does not mean. Contrast questions will identify differences between domains. Examples of questions to be asked are: What are some other words you might use when you say you are feeling well? ...ill? What is the difference between being sick and being well? Tell me the difference between the types of shots you get at the clinic?

Children's Drawings

The child was asked to remember a time when he was feeling good and was asked to draw a picture. After the child finished the drawing, he/she was asked to tell a story about the things that make him/her feel well. White sketching paper was used with a thick lead pencil. Comments made by the child about the drawing were tape recorded. Informants were asked to draw during the second interview or at any

other time when the interviewer felt it could facilitate communication. The primary purposes for using drawings in this research was to validate information given by informants and to facilitate communication.

Data Analysis

Spradley defined ethnographic analysis as "a search for the parts of a culture, the relationships among the parts of a culture, the relationships among the parts, and the relationships to the whole" (Spradley, 1979, p. 142). Spradley goes on to identify four kinds of ethnographic analysis:

1. Domain analysis enables the researcher to begin to organize the basic parts of cultural knowledge. It identifies symbolic categories containing three parts: cover term, included term, and semantic relationships. For example, medication is the cover term; chemotherapy is a smaller category within the drug domain. The two are linked by a semantic relationship; chemotherapy is a type of medication. Figure 2 is an example of a type of domain identified.
2. Taxonomic analysis helps identify the internal contents of a domain by categorizing the terms and forming them into subsets. It is differentiated from domain analysis because a taxonomy shows more of the relationships among terms within the cultural domain.
3. Componential analysis is the discovery of elements associated with a particular cultural symbol.

The meaning of being sick	being different	
	feeling "kinda awful"	
	being "bored"	"staying inside"
		"playing with yourself"
		"watching TV"
	being "weak"	"falling down"
		"having bruises"
	having headaches	
	having stomach aches	

Figure 2. Domain of Meaning:
The Meaning of Being Sick

4. Theme analysis involves the cognitive principles which represent the whole of the cultural system (Opler, 1945). Cultural themes portrayed a broader picture of the cultural system used by Mexican-American children with cancer.

Summary

This chapter discussed the research design and informants. Tape recordings were analyzed according to Spradley's (1979) protocol. Domains of meaning were identified.

CHAPTER 4

PRESENTATION AND ANALYSIS OF DATA

This chapter addresses data collection and informants. It also presents data from interviews and informant's drawings. Cultural themes derived from the analysis are also discussed.

Data Collection

The process of data collection is presented in the following sections: selecting informants, interviews, and the researcher informant experience.

Selecting Informants

Four of the informants were originally contacted by phone. A brief explanation of the research project was given and interviews were then scheduled. Explanations of the research were given to both the child participating and at least one parent. During the first interview, a consent form was given to parents and assent forms were given and explained to the children (see Appendix A). Any questions relevant to the study were answered at that point. The other two children were contacted by a person at the Outpatient Oncology clinic. They too were given a brief explanation and were asked to read and sign the consent and assent forms. Questions were answered and interviews were scheduled.

Originally, Mexican national children had been selected to participate in the research. However, since these children came to the clinic only once a month, it was not practical for the researcher to travel 200 miles one way for interviews. For that reason, no Mexican national children participated in this study.

The parent of one prospective informant refused to have her daughter participate. The reason this parent refused participation included: mi hija no sabe nada de su enfermedad (my daughter doesn't know anything about her illness), and no me gusta que hable de esas cosas (I don't like her to talk about those things).

The total number of participants included six children. Ages ranged from 5.6 years to 11.6 years of age.

Interviews

The interviews were scheduled upon initial contact with the informants and parents. With the exception of one interview, which was conducted at the Outpatient Pediatric Clinic, all interviews were conducted at the children's home.

With the exception of one informant, all others participated in at least two interviews lasting 30 to 50 minutes each. The first interview was initiated by questions like: "Tell me about the clinic" or "Tell me about being well". Other interview techniques outlined in Chapter 3 were used. Children's drawings were also used to validate and facilitate communication.

The informants were reminded at each interview session of the purpose of the study and their unique knowledge of the culture of the

Mexican-American child with cancer. Confidentiality was reinforced throughout the interviewing process. Children were asked to choose their own code name.

Informants were interviewed during a four week data collection period. With this scheduling arrangement, each informant was interviewed once a week.

The initial session usually lasted longer than the others. The length of the interviews ranged from 30 minutes to one hour and 15 minutes. The taped interviews were held at the children's home with the exception of one which was held on the Oncology clinic. The settings varied within the children's homes. Locations included the child's bedroom, parent's bedroom, the back yard and the front yard. Since three of the informants had previously been known to the researcher, building rapport was not an issue. Rapport increased with time with the other three informants.

After the first interview, the tape recordings were transcribed and analyzed for domains of meanings. After initial analysis, several areas that needed clarification were identified and questions were formulated for the subsequent interviews. Grand tour questions were used to initiate interviews since they provide broad information about the culture. Examples of grand tour questions included: "Tell me about going to the clinic..., What is it like?", "If I were the new kid on the block, what would I need in order to make it through the clinic visit?" Domains that emerged from these questions include: "Steps in

the clinic visit," "Things kids think about before the clinic visit," and "People that take care of me".

Questions like "Tell me about being well/sick" generated the domains of "taking care of myself" and "the meaning of being sick/healthy". Structural questions like "What do you do about being scared"? and "Tell me about the last time you got a shot" elicited additional terms to other domains.

The third interview was used to clarify and contrast the components of meaning of the included terms. With some children, the use of contrast questions was useful. The youngest child had great difficulty with this type of question.

Problems Encountered in the Field

Identifying cultural differences presented unique challenges to the researcher. All researchers know that when research is conducted, the researcher brings with him/her a certain amount of biases and style into the research. In this case, identifying cultural differences that characterize self-care patterns was an obvious exercise in frustration for the researcher since the researcher herself is Mexican. Perhaps if the researcher had been a member of a culture other than the one under investigation, more distinct cultural patterns would have been identified.

Interviews were best conducted at the child's home particularly the child's room. On one occasion, an interview was conducted in the back yard of one of the informants. This particular back yard happened to be a farm. Trying to keep the chickens from making all kinds of

creative noises and the dogs from barking so that I could later transcribe the recording was an interesting experience. Maintaining the informants interest in our interview was a particular challenge.

One interview was conducted at the clinic, and although it was the most practical setting for the informant and researcher, it brought its share of difficulties. It was particularly difficult to free the child from the preoccupation of what was going to happen during her clinic visit that day. In this instance although the setting was practical, the results were minimal.

An additional difficulty was encountered because of the time constraints imposed by the researcher. Had it not been for the time limits, more subjects who had previously consented to participate would have been included. Also, Mexican national informants would have had an opportunity to participate.

During the last interviews, the subjects became less and less interested in the project. The researcher would ask clarification questions and the informant would say: "Sometimes you are so dumb, I'm sure I answered that question before". Contrast questions were another source of difficulty for the informants. It was viewed as an exercise in repetitious frustration. On many occasions the child would say "I don't know" or stare into space with a puzzled silence.

Informants

Each participant will be described in the following pages. Figure 3 represents the demographic characteristics of the informants.

Code Name	Age	Sex
Judy Marie	8 yrs. 3 mos.	F
Teresa	8 yrs. 9 mos.	F
Snoopy	11 yrs. 6 mos.	M
John	8 yrs. 4 mos.	M
Laura	5 yrs. 6 mos.	F
Carlos	8 yrs. 7 mos.	M

Figure 3. Subjects by Age and Sex

Judy Marie

The most outstanding characteristic of Judy Marie was her ability to express her thoughts. She was a very articulate eight year old who greeted me at her house with a big smile. She had freckles over the bridge of her nose, and her reddish brown hair somehow always got in the way of her bright playful eyes. She was diagnosed with acute lymphocytic leukemia five years ago, and is presently in remission. Her detailed descriptions of the "kinds of shots" that she got were most enlightening. Her curiosity for life, and her "toughness" she said, were the things that have gotten her through her illness.

Judy Marie is diagnosed as a long-term survivor of childhood leukemia. The interviews were conducted in the privacy of her somewhat messy but organized room. Judy preferred to relate stories about how things at the clinic happened. It was less threatening for her to play out some of the experiences that she had had at the clinic. Judy Marie was particularly curious about the other boys and girls that had been interviewed, and wondered how their experiences had been different from hers.

"When I grow up", she said, "I want to be nurse because I like to help people."

Teresa

Teresa is an eight year old girl who was diagnosed with acute lymphocytic leukemia when she was two and one-half years of age. She has been in remission for three years, and is presently being followed at the clinic. She is a mildly obese girl who was interviewed in her

home. She was very eager to show me the back yard of her house, and then went on to tell me about her love for animals. She insisted I interview her in the back yard. My biggest challenge was to keep the dogs from the tape recorder and the other animals quiet so that I could hear the tape recordings afterwards. Her inability to maintain some kind of eye-to-eye contact was indicative of her shyness and her low self-esteem. Her most outstanding characteristic was her timidity.

Her mother described her as "somewhat isolated most of the time" but one who "after all has taken it real well". She said that she had been sick ever since she can remember.

Teresa's grandmother had been a very influential person in her life. Teresa related how she wanted to take care of her Grandmother when she was sick, and she stated that "I couldn't see or visit her". "After that", she stated, "they chopped her leg and then she died."

Teresa was second generation Mexican-American. Teresa herself stated that she does not speak Spanish, but is able to understand it well. She stated that every one in the house speaks "normal" (English), but her "Nana" (Grandmother) talks to her father in Spanish.

Snoopy

I first met Snoopy at Summer Camp and had the opportunity to hear some of his thoughts since we shared the same camp site. I very eagerly traveled 75 miles north of Tucson to interview Snoopy. This eleven year old welcomed me into his somewhat organized room which contained some very personal touches.

On the right side of the room above his bed hung a poster of a toddler inside a toilet and it read, "Life's a bummer". He welcomed me into his bedroom which was filled with Snoopy paraphernalia from the curtains to the sheets. It was clear that Snoopy was this child's favorite character. When asked about how he came to like Snoopy, he related how "The first time I went to the hospital my only friend was Snoopy, he stayed with me all the time."

He was a quiet young pre-adolescent who related how tired he was of driving for an "hour and fifteen" minutes every time he had to go to the clinic. To Snoopy, "IVs and things" were "kinda fun" and he considered them part of his life. His greatest preoccupation before going to the clinic was that his "blood would be ok".

During Camp Sunrise, Snoopy shared with some of the other campers how children at school used to call him "bald eagle" since he had lost his hair as a result of the chemotherapy he had received. Snoopy showed anger as he talked about the things that made him "different" from other kids because of his leukemia.

John

John was a quiet eight year old boy who was interviewed at his home 100 miles away from Tucson. We sat at the front porch of his house overlooking the Apache mountains from which the Apache Indians once leaped.

His mother described him as "slow since he started the chemo". John had two other brothers with whom he seemed to share his experiences. His long black lashes served as a vizor for his big brown shy

eyes. As he talked about the clinic, the sparkle in his eyes would vanish and he would suddenly change the subject. For John, laughing was a way to forget about pain.

My conversations with John centered largely around his preoccupations and fear of "bone marrows". Mother described him as a "very aggressive" and "moody" but lovable child. She stated that he is quiet, and often is "sentimental about things in general". John's mother explained how on the days that John gets chemotherapy, John often feels fatigued. She explained that at night, John would want to talk to her about why he has to get chemotherapy and would often cry himself to sleep.

John's mother spoke half in Spanish and half in English. Although John could understand Spanish, he said he did not like to speak it. The interview was conducted in English.

Laura

Laura was a five year old girl whose mother said "she wouldn't let me forget how much medicine she's supposed to take". She was diagnosed with leukemia only a few months prior to when this project was started. Laura was one of our patients who benefitted greatly from engaging in fantasy via visual imagery which was a ritual before and after every bone marrow aspiration. For her, the louder she screamed, the less the bone marrow hurt. Big fat tears rolled down her chubby cheeks every time a part of her body was invaded, but somehow she always managed to smile after it was all over.

She was interviewed at the clinic before she was seen by the doctor. My biggest challenge with her was to re-direct the conversation, as she was preoccupied with what would happen when the doctor got there. Laura was interviewed only one time. Questions were not easy for her, partly due to her age, and partly due to the fact that she too was fairly new to childhood cancer.

Laura's parents were a young upwardly mobile Mexican-American couple, both educated at the college level. They as well as Laura took a very active and assertive role in learning about leukemia. They were well informed about treatments, medications, and side effects. Interestingly enough, in spite of their education and knowledge about what the treatment for leukemia was, it was very important to them that they be able to practice some of their traditional folk beliefs pertaining to health. This interview was conducted in English.

Carlos

Carlos is an eight year old boy whose major and most noticeable characteristic were his eyes. He had been diagnosed with leukemia for four years. His mother spoke in Spanish half of the time, and English the other half. Carlos himself knew how to speak Spanish but he really did not like to.

He was a well behaved boy whose main interest was in school. He hated being sick because it took time away from his studies. For him also, the treatments were an example of the cruel realities of pain. He liked other children, hated pain, and "spinals". Carlos said that if he

had to be an animal he would be a tiger because tigers were strong, fierce animals.

Ethnographic Data

The following domains of meaning are a result of the interviews which were conducted. The domains represent the language of the informants. Quotes are used to represent direct statements from the informants. When quotes are not used, the statements have been taken from the informants but have been modified in some way.

Figure 4 represents a list of the domains of meaning which have been identified. These domains are organized under three main categories: pain and illness as corollaries to wellness, encounters in the oncology clinic, and dimensions of caring. The cultural domains will be explained within each category.

Pain and Illness as Corollaries to Wellness

This category represents cultural domains of meaning informants identified as being significant in their illness and wellness. In general, pain, suffering and illness for these children come with the package of leukemia, and are things that one must endure in order to get well.

Pain and illness were seen as unfavorable conditions that would eventually lead to wellness. Pain and illness were seen sometimes as endurable, and something you "kind of get used to". Detailed descriptions on each domain of this category will follow.

PAIN AND ILLNESS AS COROLLARIES TO WELLNESS

The meaning of being healthy
The meaning of being sick
What makes kids feel better
Things kids don't like
Kinds of feelings related to needle sticks

ENCOUNTERS IN THE ONCOLOGY CLINIC

Things kids think about before the clinic visit
Steps in the clinic visit

DIMENSIONS IN CARING

People that take care of me
Taking care of myself

Figure 4. Domains of Meaning of the "Taking Care of Myself" Phenomenon in Mexican-American Children with Leukemia

Figure 5 represents the domain of meaning of being healthy. For Snoopy, the 11 year old, being healthy meant "being able to do things for yourself". For him wellness meant independence. All six informants defined being healthy as "being happy" and "being happy" as "being able to play". Teresa stated that when she feels happy she feels "like playing, .. like I'm ok".

Four categories of "being happy" were identified. Being able to play was the most common one. While Snoopy, John and Carlos played baseball and football, Teresa, Judy and Laura chose games like "hide and seek", house, or played with toys.

Visiting people was another meaning of happiness for the informants. John's eyes would light up as he related stories about going over to see his friends. Teresa expressed sadness as she talked about "Nana", her grandmother who died some years back.

Going outside to play was the most significant characteristic of "going places." Places depended upon the child's experiences and where they lived. They ranged anywhere from the Dairy Queen close to John's house to the frequent trips to Tucson that Snoopy and his family took. Climbing the trees was a popular activity with the boys. The girls preferred jumping and bicycling.

For Snoopy, being healthy was being stronger. Snoopy as well as John idolized friends or cousins because of their strength. Snoopy said: "When I go out and play ... I think about how I don't get out as much as I want to." He related how he felt "different" in some ways and because he was ill, he said he "couldn't run very fast, but I'm getting

The meaning of being healthy	"being able to do things for yourself"		
	"being happy"	playing	football
			baseball
			"house"
			hide and go seek
			"with organ"
			"with toy typewriter"
	"being happy"	visiting people	"Nana"
			Cousin
			Grandma
			friends
	"being happy"	going places	"restaurant"
			"out of town"
			"outside"
"being happy"	being active	"climbing trees"	
		running	
		bicycling	
		jumping	
"being strong"	"lifting weights"		
feeling better			

Figure 5. Domain of Meaning:
The Meaning of Being Healthy

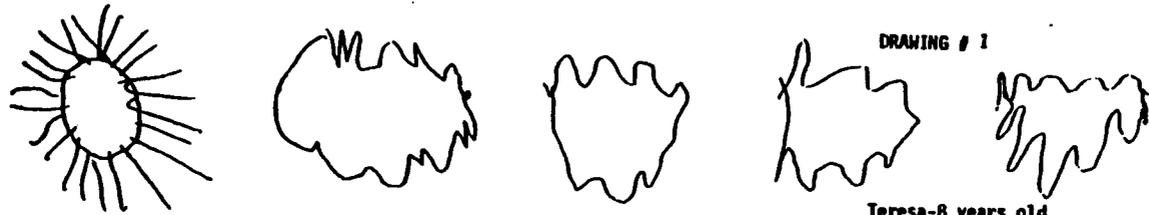
stronger because I lift weights." The informants explained how being strong is different from being happy. They said that one can lift weights, but sometimes "I'm not happy when I do it, I do it because it makes me strong."

Other terms used by the informants to say they were healthy included "feeling better." Perhaps the best way to explain this domain is through Drawing #1. This drawing was done by Teresa who explained that being happy is being able to go outside and play.

The Meaning of Being Sick. Figure 6 represents the illness end of the health continuum. This domain of meaning talked about the general feeling of isolation that children in general feel when they are sick.

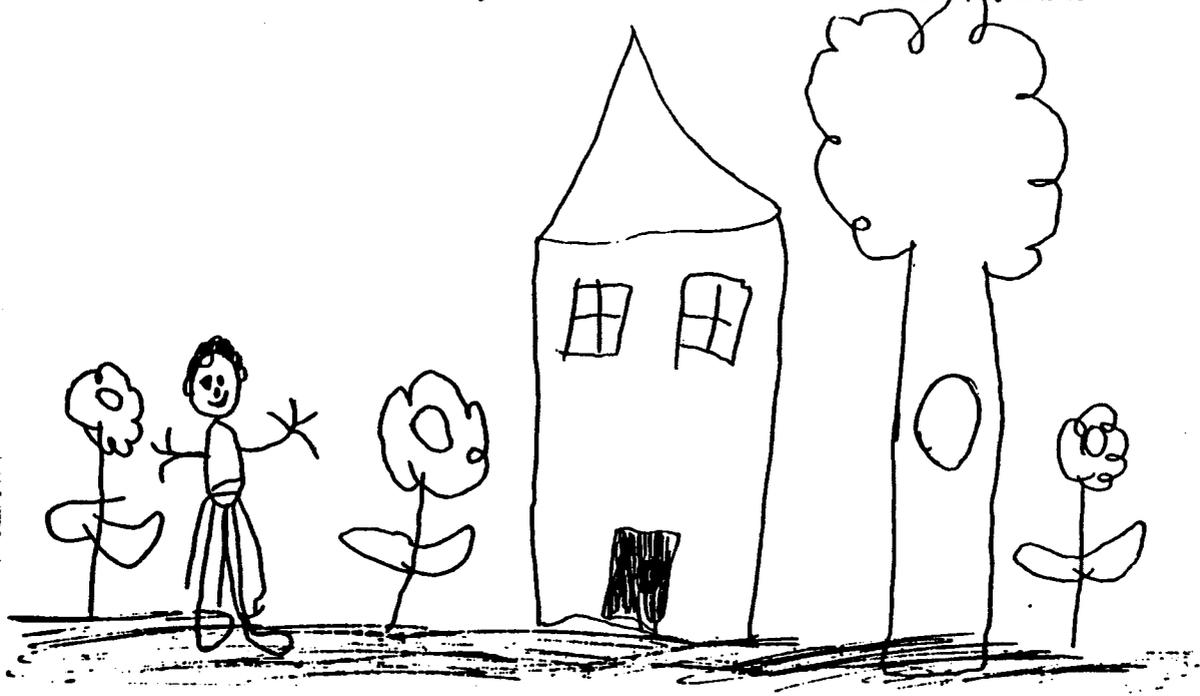
All informants talked about "staying inside" when you are sick. Staying inside means one will be bored. Judy related how when she's sick, she likes to watch television which makes her bored, and then she plays by herself which makes her even more bored.

Snoopy's concerns for the physical changes in his body resulting from leukemia were so obvious. For him, falling down the stairs and having bruises signified physical weakness and lack of strength. All children talked about being weak when being sick. This data bit is not at all surprising since the top five complaints of children at the time of diagnosis with leukemia include fever, bone or joint pain, fever without infection, purpura and weight loss. Headaches and stomach aches were also common physical complaints reported by the informants.



DRAWING # 1

Teresa-8 years old
"Being healthy, is
being happy, . . .and
being happy is being
able to play outside"



The meaning of being sick	feeling "kinda awful"	
	being "bored"	"staying inside"
		"playing with yourself"
		"watching TV"
	being "weak"	"falling down"
		"having bruises"
	having headaches	
	having stomach aches	

Figure 6. Domain of Meaning:
The Meaning of Being Sick

Things That Make Kids Feel Better. The domain of meaning of the things that make kids feel better is represented in Figure 7. Eight cover terms were identified as things that make kids feel better when they are sick. These included, "crying, getting mad, sad, and scared, getting used to it, holding still, making faces, screaming real loud, talking to people, and laughing".

All six informants mentioned in some way or another the concept of getting used to things. "I used to cry because it used to hurt" said Judy, "but now I get used to it". "When they stick the needle all I say is 'ouch' because it doesn't hurt that much". When the researcher asked Teresa what she thought about when she was hurting, she responded, "I'm thinking that I would much rather have a needle in my arm than in my back..." Snoopy responded with: "They give you shots in the arm and those are fun because it doesn't hurt, you get used to it ... but the shots in the back I don't like."

Laura, John, Teresa, and Judy all felt that "holding still" in some way or another makes kids feel better. For Snoopy, "making faces" when he got stuck with needles helped him cope better. Laura, the 5 1/2 year old, was an expert at screaming. For her, the louder she screamed, the less it hurt.

All six kids stated they talked to a variety of people who helped them understand things better. Figure 8 represents the people kids talk to. As can be seen, all children talked to their mothers. Only 50% talked to daddy or nurses, while only two of the children talked to doctors or grandmothers. Approximately 83% of the children

Things that make kids feel better	"crying"	
	getting a feeling	"mad"
		"sad"
		"scared"
	"getting used to it"	
	"holding still"	
	"making faces"	
	"screaming real loud"	
	"talking to people"	Mom and Dad
		Brother/Sister
		Grandmother
		Doctor
		Nurse
"laughing"		

Figure 7. Domain of Meaning:
Things That Make Kids Feel Better

Subject	Mom	Dad	Grandmother	Brothers/ Sisters	Doctor	Nurse
Judy	X	X		X		X
Teresa	X		X	X		
Snoopy	X			X		X
John	X	X	X	X	X	
Laura	X	X		N/A	X	X
Carlos	X			X		

Figure 8. People Kids Talk To

talked to their brothers or sisters, and the sixth informant was an only child.

The final included term in this domain is "laughing". John said that laughing makes you "forget about pain".

Things Kids Don't Like. The domain of the things kids don't like included: needles, shots, "all the blood to come out", stitches, everyone to see, and being punished. This domain is pictured in Figure 9.

A certain amount of ambivalence was demonstrated when it came time for informants to express their feelings about needles. They hated getting stuck with needles, although they preferred arm and leg sticks versus spinals and bone marrow punctures. "Spinals and bone marrows" presented a unique kind of anxiety for all kids.

Perhaps another thing that produced just as much anxiety as bone marrows and spinals was "all the blood to come out". All children except for Laura expressed concern about the "blood out". This term represents the informants' awareness of blood being taken out of their bodies.

Judy talked about stitches and said it was "disgusting". She as well as other informants related how "I hate getting stuck with needles, it's like everyone is looking and everybody goes into the room to see how the needle is going in".

A less anxiety producing but nevertheless not liked event was "being punished". John and Teresa alluded to how they really did not

Things kids don't like	needles	"getting stuck with needles"
		"looking" at the needle
	shots	"spinals"
		"bone marrows"
	"all the to come out"	"from my arm"
		from "everywhere"
	"stitches"	
	"every one" to "see"	
	"being punished"	

Figure 9. Domain of Meaning:
Things Kids Don't Like

like being punished, but they knew that sometimes they really needed to be punished.

Kinds of Feelings Related to Needle Sticks. Seven feelings were mentioned by informants in relation to needle sticks. Figure 10 represents this domain. They included: "hate, don't like, scary, crowding, hurt, get used to it, like sponge, and like hoses".

"Crowding" was described by Judy as she talked about the kinds of things that make her feel better when she hurts. She said: "looking the other way helps, if I look at my arm I'll feel disgusting ... it's too crowding in my arm, and it's like everyone is looking and it is crowding". "Crowding" she said is like "everyone goes into the room to see how the needle is going in".

All children talked about getting used to needle sticks. The exceptions to this included bone marrows and spinals. Snoopy talked about feeling like a "sponge" one time when nurses had to stick him three times to get an IV. He said he felt "full of hoses" and denied being scared about that feeling, he was used to it.

Encounters in the Oncology Clinic

This category pertains specifically to the experiences the informants had which revolved around the clinic where they are being followed. This particular clinic is an ambulatory clinic for pediatric patients only, and is located in a teaching institution on the third floor. In this category, children relate their perceptions of what it is like to go to this clinic, and some of the events that occur within this setting.

Kinds of feelings related to "needle sticks"	"hate"
	"don't like"
	"scary"
	"crowding"
	"hurt"
	"ok"
	"get used to it"
	"like a sponge"
	"like hoses"

Figure 10. Domain of Meaning: Kinds of Feelings
Related to "Needle Sticks"

The category of encounters in the oncology clinic includes two domains of meaning. These are: things kids think about before the clinic visit, and steps in the clinic visit.

Things Kids Think About Before the Clinic Visit. Figure 11 represents the domain of the things kids think about before the clinic visit. Part of the culture of the child with cancer can be explained by the feelings children experience prior to clinic visits. "Not wanting to go" was a thought all informants experienced. Snoopy, the oldest of the informants, talked about "wishing his blood would be ok" so that he would not have to have a bone marrow, and maybe not go to the clinic any more.

Feeling tired about "waiting, getting stuck, coming to the hospital, and being sick" was a common theme among informants. While the informants felt tired of "getting stuck", they also thought about "getting better".

As John was drawing a picture of what it was like to go to the clinic he explained: "I start feeling funny even before I get there". "I feel like throwing up and I think I don't want to go, but I also want to get better". (See Drawing #2, child waiting, "looking at fish while two nurses are walking in the hall without really knowing what to do".)

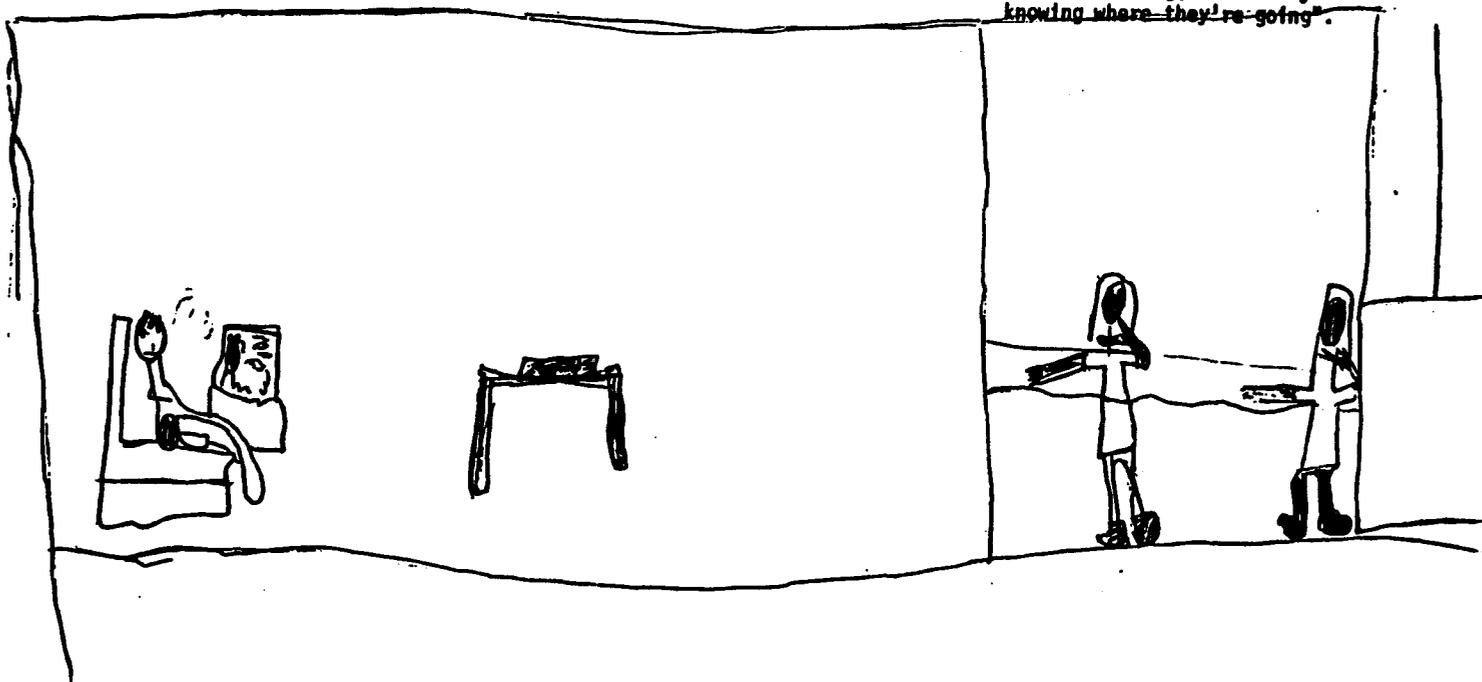
Steps in the Clinic Visit. Figure 12 denotes the steps in the clinic visit. The informants were aware of many of the ritualistic behaviors that took place during clinic visits.

Things kids think about before the clinic visit	"not wanting to go"	
	"wishing my blood would be ok"	
	feeling tired	of "waiting"
		of "getting stuck"
		of "coming to the hospital"
		of "being sick"
	"getting better"	
	"getting the needle the first time"	
	feeling "funny in my stomach"	"throwing up"
		"everything is upside down"

Figure 11. Domain of Meaning: Things Kids Think About Before the Clinic Visit

DRAWING # 2
John- 8 years old
Steps in the Clinic Visit

"I'm waiting and waiting,
meanwhile, I'm looking at the
fish in the waiting room. . .
the other two people, are the
nurses in the hall, . . .
They're walking, not really
knowing where they're going".



Steps in the clinic visit	waiting	"watching the fish"
		"talking to the people"
		"going to the cafeteria"
	taking you in	"weighing you"
		"measuring you"
		"taking your blood pressure"
	giving you shots	"in the arm"
		"in the leg"
		"in the back"
		"on the finger"
		"bone marrows"
	giving you things	"notebooks"
		"stickers"
	going home	
	coming back	

Figure 12. Domain of Meaning: Steps in the Clinic Visit

The first step in the clinic visit was to wait until one is taken inside. Informants related how once taken in, they were weighed, measured, and their blood pressures were taken (See Drawing #3). After that came the shots, shots in the arms, legs, fingers, bone marrows, and shots in the back. After children get shots, they are often rewarded by personnel giving them things like stickers and note pads. The next step is going home.

Coming back is the last step mentioned. The informants stated how the process is very cyclical in nature, and although the order of events presented in Figure 10 is the most common, they can occur in a different order.

Dimensions of Caring

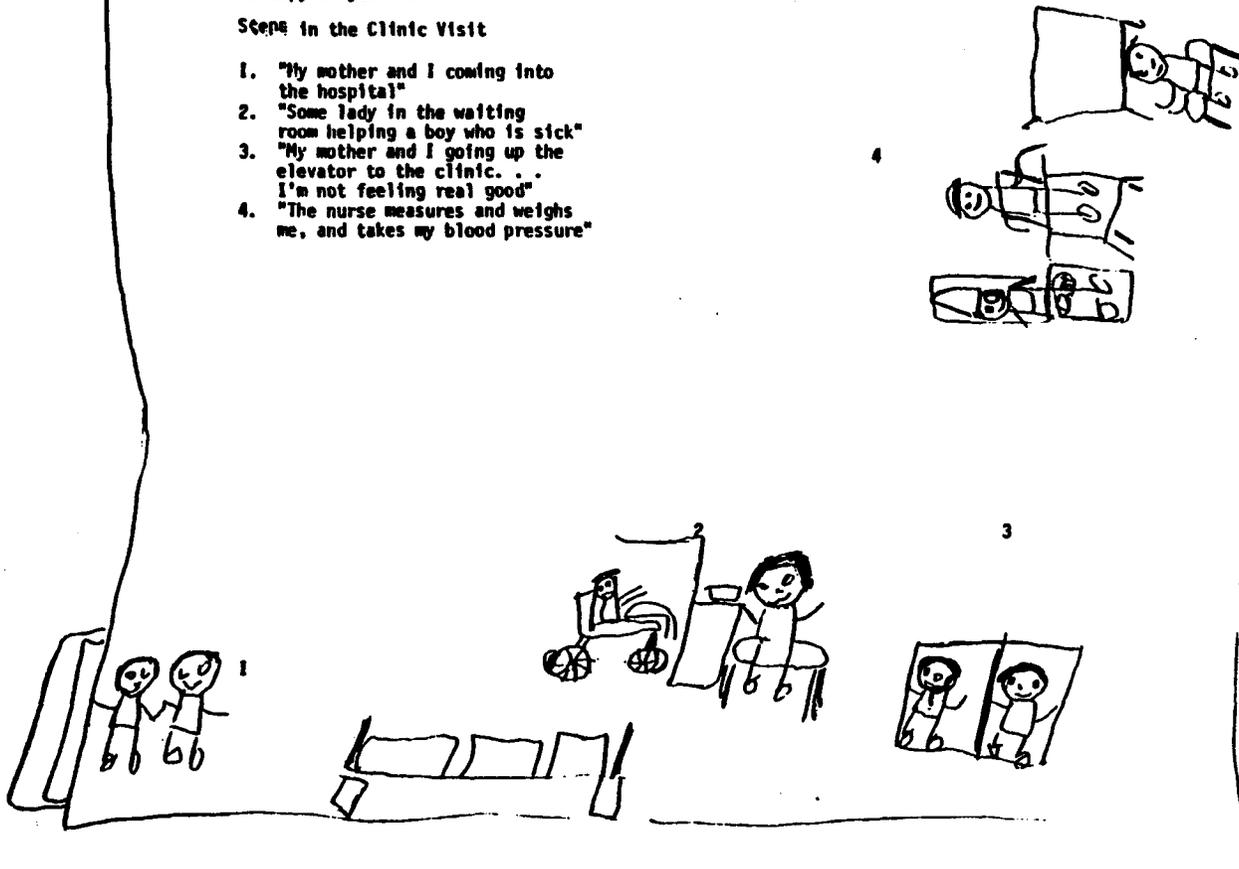
The third category to be discussed is dimensions of caring. Figures 13 and 14 represent two different care dimensions. These domains include the phenomenon of taking care of myself as well as being taken care of by someone other than the self.

People That Take Care of Me. Figure 13 represents the domain of meaning of the people that take care of me. Four types of people were mentioned in this domain. Nurses, doctors, and mom and dad all talked to the child. Informants did not perceive doctors as talking to their mothers. While doctors checked on the informants by looking into their eyes, ear or mouths, nurses helped them cope with the procedure. Nurses helped informants by helping them hold still and not cry. Mom and Dad talked to the informants about "hurting" and also helped them hold still.

DRAWING # 3
Snoopy-11 years old

Steps in the Clinic Visit

1. "My mother and I coming into the hospital"
2. "Some lady in the waiting room helping a boy who is sick"
3. "My mother and I going up the elevator to the clinic. . . I'm not feeling real good"
4. "The nurse measures and weighs me, and takes my blood pressure"



People that take care of kids	Doctors	"talk to me"	
		"talk to Daddy"	
		"check on me"	"look in my eyes"
			"look in my ears"
			"look in my mouth"
		"give you a special medicine"	
	"get your blood"		
	Nurses	"give you shots"	
		help you	"help you hold still"
			"so you won't cry"
			"so it won't hurt"
	"talk to you"		
	Mom & Dad	talk to you about	"hurting"
"what happens"			
help you "hold still"			
Friends	"play with you"		

Figure 13. Domain of Meaning: People That Take Care of Kids

Taking care of myself	At home	In the morning	eating fruit	
			eating vegetables	
			taking a shower	
			doing what mom says	
			doing what mom doesn't tell you	
		During the day	taking medicine	big pills
				pills
				yellow medicine at right time
		Asking for help	brothers	
	sisters			
	having my mom and dad			
	staying inside when sick			
	not wetting your hair when sick			
	Before going to bed	eating special foods		
		taking a shower		
brushing your teeth				
going to the bathroom				
At the clinic	Waiting	talking to people	doctors	
			nurses	
			friends	
	Getting shots	holding still	for the needle	
			for the x-ray	
		having a little board		
		looking the other way		
		crying		
		laughing		
		saying "ouch"		
getting	mad			
	sad			
being scared				
screaming real loud				

Figure 14. Domain of Meaning:
Taking Care of Myself

Taking Care of Myself. The last domain of meaning of taking care of myself can be seen in Figure 14. This domain discusses two main settings where taking care of oneself occurs within this culture. One includes the home and the second one is at the clinic.

At home in the morning, informants take care of themselves by eating breakfast and carrying out hygiene rituals like showering. During the day, taking your medicine at the right time becomes an important issue. For example: taking the "yellow medicine" (prednisone) is important.

For all informants, asking for help from their family was important in taking care of themselves. All of the six children stated how one would stay inside the house when sick. Going out with your hair wet or wetting your hair when sick were two behaviors that could potentially make one sicker. The "before going to bed activities" centered mainly around hygiene rituals.

The activities that children carried out at the clinic which they considered caring behaviors were categorized under waiting and getting shots. "Talking to people, holding still, crying" and the other included terms have been discussed in previous sections. Notice that the same information has been placed within the context of the "taking care of myself" phenomenon.

Cultural Themes

The development of cultural themes is an exciting and challenging opportunity for the investigator to represent the connection among domains through what Spradley (1979, p. 185) calls the "inventory

approach". Since the individual parts must be equal to some kind of final whole, cultural themes in a sense represent general concepts of the culture being described.

Six cultural themes were identified:

1. "Take care of me and allow me to take care of myself"
2. "Being happy is being healthy"
3. "Sometimes I really need to cry"
4. "In the world where I live, one learns to take things as they come"
5. "Being sick makes you different", and
6. "First, I ask my family to help me".

"Take care of me and allow me to take care of myself"

This domain explains the independency/dependency phenomena expressed by Mexican-American children with leukemia. It is illustrated in several of the domains identified, and clearly demonstrates children's need for both internal and external locus of control.

As "Snoopy" the 11 year old related to me, being healthy for him is "being able to do things for yourself". On the other hand, having Mom and Dad help you "hold still" is just as important in a child's ability to "survive" the bone marrows. All the informants expressed in some way or another their need to openly express their emotions while undergoing invasive or fear provoking precedures.

In the domain of "people that take care of kids", children identified doctors as giving "you a special medicine", "checking me", and "talking to me". When asked to tell a story about the nurses,

invariably children answered with "give me shots" and identified shots as "helpful". In essence, these statements represent the child's cognitive awareness of care giving behaviors expressed by people around their culture. "Crying", getting "mad, sad, and scared", "getting used to it", and "screaming real loud" represent recognition for the need of independence and longing for control by the nurse.

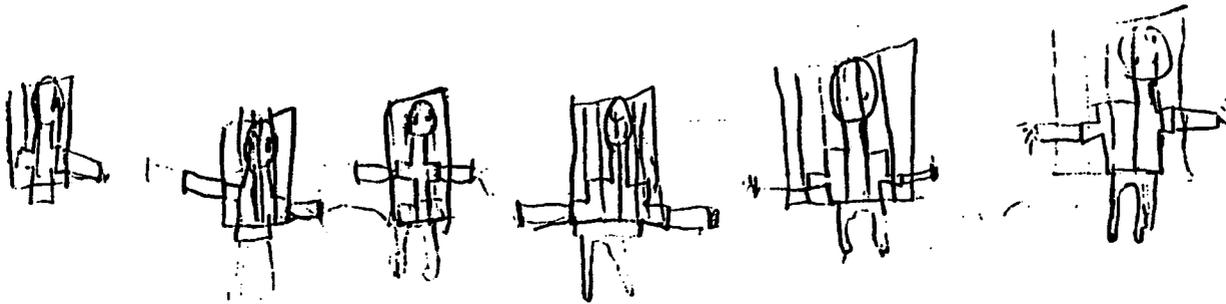
The importance of self-care taking behaviors is further illustrated by the variety of behaviors that children express in the "taking care of myself" domain. "Staying inside when sick", "taking medicine", "taking a shower", and going "to the bathroom" are care taking behaviors that Mexican-American children express as being vital to their existence.

"Being healthy is being happy"

Being healthy is being happy is the second theme identified in this project. John stated how after he was out of the hospital, he felt happy because he was able to go outside and play. Laura reported that when things hurt, she screams and pretends "it doesn't hurt and then it feels better and I'm happy".

Figure 5 represents the domain of the "meaning of being healthy" and presents data that support this theme. The domain of the "meaning of being sick" (Figure 6) also represents data to support this theme. Furthermore, Drawing #5 of one of the informant's family, as well as Drawing #1, validate this theme. Drawing #5 represents an informant's family out on a swimming pool having fun. And as John stated, "if you are not well, you can't go out and play".

DRAWING # 5



John- 8 years old

"My family and I in the swimming pool"

"We are all happy, because we are playing"

Being healthy and being happy were concepts that were correlated. For the informants, happiness was something that could be found within as well as outside of oneself.

The feeling of healthiness and happiness comes from within oneself by "being able to do things for yourself". The same feeling could be found outside of oneself through a variety of outdoor activities. Those activities were categorized into four categories which included: playing, visiting people, going places, and being active.

"Sometimes I really need to cry"

"Sometimes I really need to cry" is the third theme identified in this project. Informants valued healthiness and happiness and as a result felt that some things have to be compromised when one lives in the culture of childhood cancer. At the other end of the spectrum, informants viewed crying as a real necessity. The things kids don't like (Figure 9), kinds of feelings related to needle sticks (Figure 10), and things kids think about before the clinic visit (Figure 11), all set the stage for why children sometimes need to cry to feel better.

"The things that make kids feel better" (Figure 7) include: crying, getting mad, sad, and scared, getting used to it, holding still, making faces, screaming real loud, talking to people and laughing. While crying was not the first response of most informants when confronted by intrusive and fear provoking procedures, it was the most common response.

Informants most commonly reacted to pain with responses other than crying. It was when faced by bone marrows and spinals when children really needed to cry. As Teresa said: "nurses help you hold still when they give you the shot in the back, they help you so you won't cry, but sometimes, I really need to cry".

"In the world where I live, one learns to take things as they come"

This theme is supported in many different ways. A variety of statements in all of the domains validate this cultural theme. Perhaps the most powerful concept which speaks for this cultural theme has to do with the concept of "getting used to IVs and things". Informants referred to the feeling of "getting used to things" as one of the things that makes kids feel better. While informants are faced with needles and blood, and shots in the arms and in the legs, and in the back, sometimes the best thing to do is to make faces or laugh or scream. Usually, just getting used to it and taking it as it comes, makes things hurt less.

Learning to take things as they come is just another coping mechanism which is different from crying. Informants often stated that while they may not like IVs in the arms and shots in the legs, they are "OK". These types of shots are at least considered to be less painful than spinals and bone marrows.

Another example of how learning to take things as they come is important can be illustrated in Figure 10 in "steps in the clinic visit". Informants saw some of these steps as not very favorable, but

in spite of the shots and the long hours of waiting, they all learned at some level to create in their mind thoughts of anticipated feelings that could help them either remain in the clinic or to go back for the next visit.

"Being sick makes you different"

"Being sick makes you different" is a cultural theme that can be validated by the informants' meaning of being healthy and sick (Figures 5 and 6). The contrast that these two domains represent speak for the many ways in which being sick makes kids different.

Being sick makes you different because it makes one feel "kinda awful". A point which was strongly stressed by all informants is that being sick makes one feel isolated, whether the isolation is in one's room, within the confinements of their home, or the feeling of not being able to do what everybody else is doing; it all means isolation.

The informants see themselves as being different because they have cancer. Whether or not they felt different because they were sick and Mexican-American is a statement which cannot be supported by the data in this research.

"First I ask my family to help me"

First I ask my family to help me is a theme that is culturally relevant to the world of the Mexican-American child with cancer. The domain of meaning of the people that take care of me (Figure 13) will be discussed in order to support this cultural theme.

Four categories of people were included as those who take care of people. These included doctors, nurses, mom and dad and friends. For purposes of this cultural theme, the category of Mom and Dad will be expanded.

When it comes to the subject of who takes care of Mexican-American children with leukemia, family members were mentioned most frequently as people who take care of kids. Figure 8, which represents "the people who kids talk to", illustrates clearly for whom within the support circle kids confide in most.

During the interviews, children were asked to remember a time when they were really sick and were asked who the people that took care of them were. The most common first response to this question included a family member. The initials F.R. in Figure 15 are placed in the blocks to represent the first person that takes care of each informant. Four out of the six informants stated their mother was the first one to help them. Teresa stated her Dad takes care of her first, while Snoopy's first response included his sister.

Doctors and nurses may be considered important contributors in taking care of the Mexican-American child with cancer. In the child's eye however, Mother is the most influential in taking care of the child.

Summary

This chapter has discussed the informants, how they were selected and the interview procedures. Difficulties in the field were

Subject	Mom	Dad	Grandmother	Brother/ Sister	Other
Judy	F.R.				
Teresa	X	F.R.	X	X	X
Snoopy	X			F.R.	
John	F.R.			X	
Laura	F.R.	X			
Carlos	F.R.				

Figure 15. Family Members That Take Care of Me

also discussed. Nine domains of meaning were identified and placed into three categories:

1. pain and illness as corollaries to wellness,
2. encounters in the oncology clinic, and
3. dimension in caring.

Cultural themes identified included:

1. take care of me and allow me to take care of myself,
2. being happy is being healthy,
3. sometimes I really need to cry,
4. in the world where I live, one learns to take things as they come,
5. being sick makes you different, and
6. first, I ask my family to help me.

CHAPTER 5

CONCLUSIONS

This chapter discusses the relationship of the findings to the conceptual framework, recommendations for nursing practice and recommendations for further study.

Relationship of the Findings to the Conceptual Orientation

The constructs within the conceptual orientation were culture and care. These were followed by the Mexican-American health care system, culture of childhood, and care behavior in childhood. At the empirical level were the Mexican-American folk knowledge about self-care, the Mexican-American child's view and the self-care practices of the Mexican-American child with cancer.

This exploratory study undertook the task of examining how Mexican-American children with leukemia take care of themselves. The cultural themes identified are representative of significant factors within the culture of the Mexican-American child with leukemia. The cultural themes were:

1. "take care of me and allow me to take care of myself",
2. "being happy is being healthy",
3. "sometimes I really need to cry",
4. "in the world where I live, one learns to take things as they come",

5. "being sick makes you different", and
6. "first, I ask my family to help me".

It was proposed that:

1. children view their world in a significantly unique manner that is separate from that of adults,
2. children are capable of being their own self-care agents, and
3. Mexican-American children's patterns of self-care are influenced by cultural factors.

The previously cited propositions were explored within the world of the child with leukemia. The discussion of the relationship of the findings to the conceptual orientation will be addressed in conjunction with the three propositions under investigation.

The proposition that children view their world in a significantly unique manner from an adult can be supported through some of the cultural themes identified. Figure 16 represents the world of the Mexican-American child with leukemia. As can be seen, the way in which the child perceives his world is largely affected by his/her culture. The culture is neither the Mexican-American health care system or the cancer world.

The model depicted in Figure 16 was derived from a combination of the conceptual orientation and the findings of this project. This model was designed to present the findings of this project within the context of the constructs and concepts investigated. Furthermore, it was designed to represent the "whole picture" of the world of the Mexican-American child.

THE WORLD OF THE MEXICAN-AMERICAN CHILD WITH LEUKEMIA

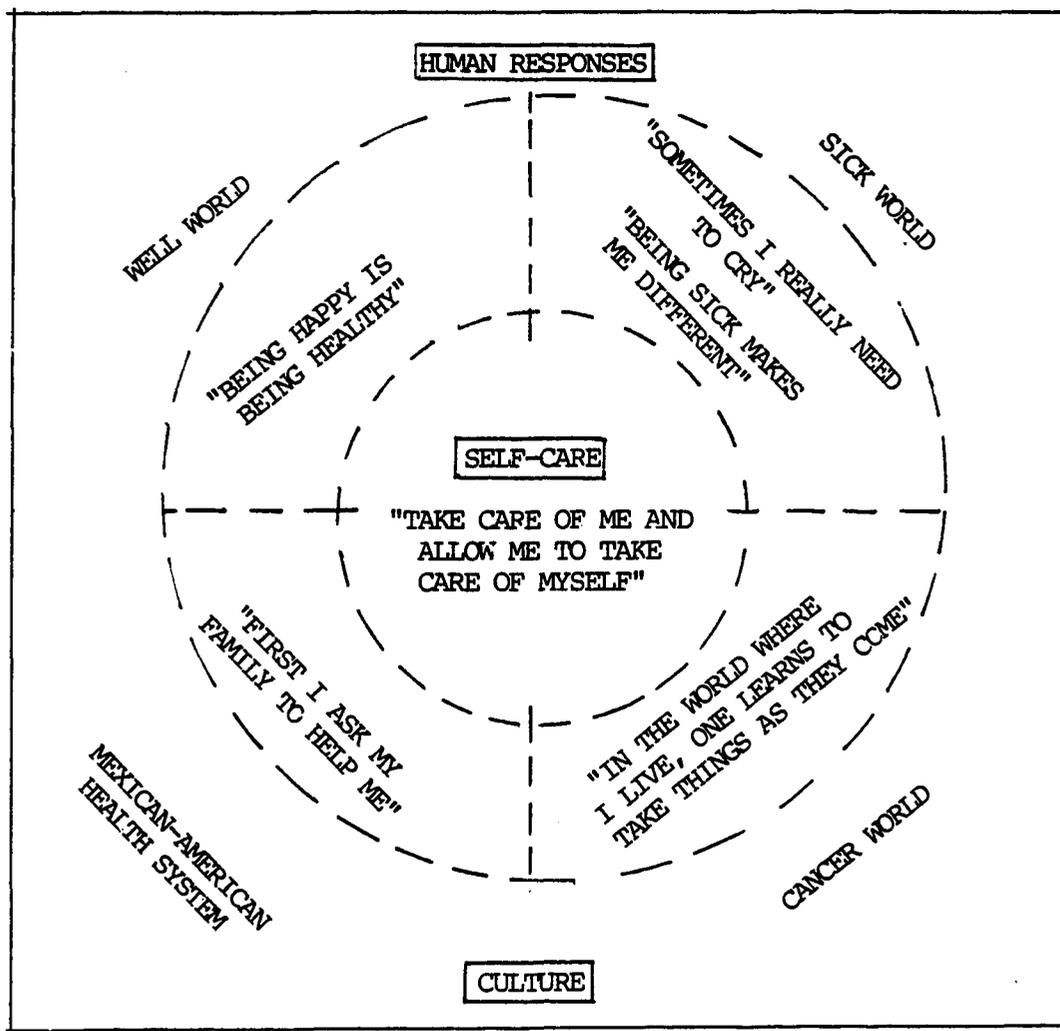


Figure 16. Relationships Between Cultural Themes and Concepts

Cultural theme #4 speaks for the cancer world; "In the world where I live, one learns to take things as they come". Learning to take things as they come is of importance when learning to survive within the world of cancer. It is the feeling of this researcher that perhaps because there are so many things to deal with when one is a cancer patients, and the uncertainty involved is so great, that children learn to take a passive acceptance attitude towards their world.

Perhaps the most significant concept that speaks for this passive acceptance attitude is the "getting used to" included term listed in the domain of "kinds of things that make kids feel better" (Figure 7). While many other coping techniques were used by these children, accepting things as they come as a major one.

In the world of these children, pain and illness were seen as corollaries to wellness. For the informants, being healthy meant that pain and illness would have to be endured. Since being healthy was considered being happy; in their eyes, pain and illness were worth the end result, happiness.

The second proposition, "children are capable of being their own self-care agents", will now be discussed. The concepts of interaction between the child, family, and the way in which the culture views health will be discussed to support this proposition.

Whether or not, or how and when a child decides to take care of himself, is largely dependent upon several factors. How the child responds and/or perceives the well and the sick world as depicted in Figure 16, affects the way in which he/she will care for himself/herself. In addition, the way in which the child perceives the cancer

world as previously discussed, will also affect the way he will react to health care. Furthermore, the child's cultural health care system; that is the Mexican-American health system, also influences the way in which a child will respond when he/she is sick.

Mexican-American children with leukemia in this study viewed the well world as one surrounded by happiness. The cultural theme "being healthy is being happy", speaks well for this conceptualization. Drawing #1 is also a good example of what wellness meant to these informants. For these children being able to go outside meant one was well. Domain #5 represents "the meaning of being healthy". Perhaps the most indicative statement that speaks for children's abilities for taking care of themselves is the definition of being healthy according to one of the informants. For Snoopy, being healthy was "being able to do things for yourself".

How and the kinds of things kids do for themselves are represented in Figure 14. The "taking care of myself" domain explains what and how children with leukemia perceive self-care. For them, a variety of behaviors constitute self-care at home when well, and at the clinic when sick or when maintaining their health. As an example, taking their medicine was seen as behavior contributing to their health during the day. Meanwhile, holding still, crying, or laughing were seen as self-care behaviors at the clinic visit.

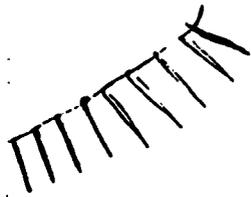
Whether or not the child will be his/her own self-care agent is also influenced by the way he/she perceives the world of the sick. As seen in Figure 16, the cultural themes of "sometimes I really need to

cry" and "being sick makes you different", represent the way in which the Mexican-American child view the world of the sick.

When the child with leukemia is sick, sometimes these children "really need to cry". This represents the opposite of the "being healthy is being happy" phenomenon. The "things kids don't like" (Figure 9), "kinds of feelings related to needle stick" (Figure 10), and "things kids think about before the clinic visit" (Figure 11), all support the theme of why sometimes these children really need to cry. Among some of the behaviors that Mexican-American children with leukemia mentioned that make them feel better include: crying, getting mad, sad, and scared, getting used to it, holding still, making faces, screaming real loud, talking to people and laughing. While crying was not the first response of most informants when confronted by intrusive and fear provoking procedures, it was the most common response. The first response most informants gave when asked what they did when they hurt involved some kind of contact with a family member. Even though children expressed mixed feelings about crying when things hurt, they all agreed that at times, kids with leukemia really "need to cry".

The other cultural theme that was classified within the sick world is: "being sick makes you different". The best way to show what this means can be shown in Drawing #4. This drawing was done by John who went on to say that he was pictured off to the side because "I'm just not like my brothers".

The contrast of domains #5 and #6 ("the meaning of being healthy/sick") represent the ways in which children felt different when they were sick. The most outstanding characteristic of being sick was

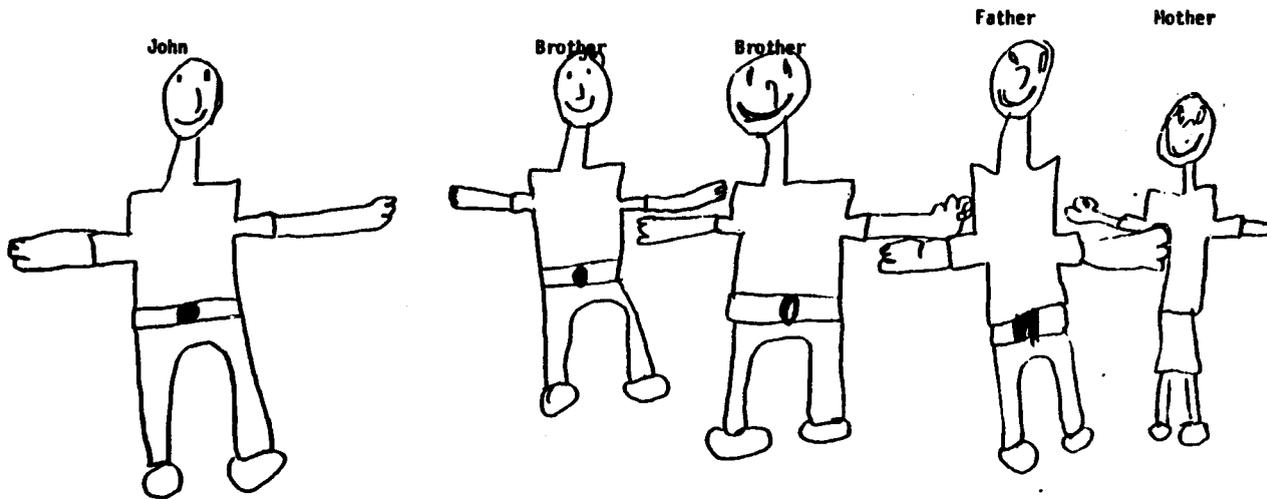


DRAWING # 4

John- 8 years old

"My family and I"

"I'm on the other side,
because I'm different, . . ."



isolation. All informants agreed on the fact that being sick means not being able to go outside and play. It meant restriction of activities, and confinement to their homes or hospital.

It is very likely that the combination of having cancer and being of a different culture might contribute to their feeling different. This statement however, cannot be supported with data from this research.

The cultural domain of "take care of me and allow me to take care of myself" represents Mexican-American leukemic children's conceptualization of self-care. As stated before, how they view self-care is partly influenced by their perception of the sick and well world, and their responses to these cultures. This cultural theme is one of the most significant findings in this study. It represents the need for independency/dependency that Mexican-American children expect in order to carry out what they perceive as self-care behaviors. The domain of "taking care of myself" (Figure 14) represents some of the behaviors Mexican-American children view as self-care behaviors. While at home their behaviors are representative of routine hygiene activities, self-care behaviors are indicative of coping patterns/styles in the survival of the cancer experience. It is interesting to note that while children view taking their medicine, and taking it at the right time important, not a single one of the informants related any self-care behavior relative to side effects of their medications. It is also interesting to allude at this time to the fact that in leukemia, one of the most common causes of death is hemorrhage and several of the informants expressed concern about "the blood coming

out". Protecting themselves from infections was a common denominator in the informants.

The phenomenon of "taking care of myself" in this instance is closely correlated with being taken care of. Being taken care of is conceptualized in this study as a second dimension of care. Figure 13 represents the "people who take care of kids". Among them are doctors, nurses, Mom and Dad, and friends. Doctors as well as nurses were seen by children as educators. Doctors check on children by checking their ears, eyes, and mouth. Doctors give special medicines and nurses give shots. Nurses help children by helping them hold still, and helping children so they "won't cry or hurt". Nurses, like doctors, also talk to children. Mom and Dad talk to children about "hurting" and about what happens at the clinic.

When asked to remember a time when they were really sick and who the people that took care of them were, the most common and the first response to this question was a family member. Four out of six of the informants stated their mother was the first one to help them. Teresa stated her daddy "takes care of her" first, while Snoopy's response included his sister.

This section has discussed the six cultural themes identified in this research. Figure 16 represents an open system. Self-care for the Mexican-American child with cancer is influenced by any one of four worlds; the well, sick, cancer, and Mexican-American health care world. Children's reactions to the well and sick world represent their human responses, while their reactions to the world of cancer and the Mexican-American children with leukemia care for themselves.

Recommendations for Nursing Practice

The following recommendations are made based on the findings of research.

First, children of school-age are capable of being their own self-care agents. The findings of this research indicate that while children may be able to take care of themselves, they do it in a way which is particular to their experience and culture.

The way in which they will take care of themselves is influenced by their cognitive appraisal of the surroundings. These children viewed their cancer world in relation to health as being either happy or sad. When one is healthy, one is happy, and when not, one is miserably sad. The implication for health professionals is that nurses must teach children that while being sick is not fun, it can be a stimulating experience and an opportunity to learn about their health and bodies. The opportunities to carry out patient education are many, and nurses should take advantage of these opportunities to teach the children as well as the parents. As found in this study, the amount of information that children know about their illness is minimal. If we expect clients to carry out part of their care, they must be well informed about their illness and wellness. Nurses should also take every opportunity to learn not only about the disease entities they deal with from day to day, but they should also learn about teaching-learning skills that are essential in order to communicate effectively with clients. This becomes particularly important when we are dealing with children of different developmental and cognitive levels.

Children's drawings can be used as an effective way of communicating with the child. The significance of drawing to nursing practice is based on the premise that expression through art is a therapeutic way of communicating highly threatening emotions. This technique should be exploited in order to perceive a realistic view of the world from the child's point of view. The information that nurses will obtain from this method of communication can potentially be used to educate and prepare the child into taking a participative role in his/her health.

The cultural theme of "sometimes I really need to cry" is children's way of asking for acceptance to express their feelings. "Bobby doesn't need to cry because he's a big boy" is an unsympathetic statement towards such acceptance. To these children, the necessity to cry is very real when confronted by pain, illness and death. Nurses must understand therefore, that while children need to play sometimes, they also need to cry.

The passive acceptance to invasive procedures can be interpreted as a sign of courage and adequate adjustment. On the other hand, it could be a sign of detachment that results from resignation and not healthy adjustment. Nurses should be aware of changes in behavior of children and communicate and consult with other members of the health care team when the situation warrants it.

Our task as nurses is to help the family and encourage them to understand that children are capable of taking care of themselves. However, before this is done, the nurse needs to know how the particular family views health and illness within their culture. The role that sick individuals play within the context of the family and culture is

important. Consider for a moment the family who sees the sick as totally dependent individuals. If a child is getting all the attention and care from all of their support system, why should he/she or anyone even attempt self-care? How the family reacts to the sick role and the strokes the sick child may get from being ill may influence when and how self-care is initiated.

In the discussion of the selection of informants it was related how a parent of one of the prospective informants refused to have her daughter participate in the study. This parent stated that mi hija no sabe nada de su enfermedad, no me gusta que hable de esas cosas (my daughter doesn't know anything about her illness, I don't like her to talk about those things). This may be an example of the type of caring behavior that Mexican-American parents exhibit towards their children. If this is so, does this indicate the limited degree of openness and understanding that Mexican-American parents have towards the needs of their children regarding knowledge of their illness?

Another point that may be culturally relevant was brought up earlier. Two of the subjects stated how "sometimes they really need to be punished". The question is whether this response is culturally relevant, related to the child's cognitive level of understanding or both. If it is culturally relevant, do these children believe their illness is a punishment for something they did wrong? Conclusions on these two observations can not be made at this point. However, they represent interesting questions for further research.

Although this project was partially designed to explain culturally relevant phenomena in this type of population, few

conclusive data were actually found related to the Mexican-American self-care behavior of these children. Some researchers take the position that it takes a researcher of the same culture under investigation to identify culturally relevant phenomena. Others think that the researcher must be outside of the culture in order to be objective and identify certain culturally relevant behaviors. Therefore, the lack of culturally relevant findings in this project can be explained by taking either one of these positions. Furthermore, the manner in which the researcher was viewed by the informants and his/her parents could have influenced the findings of this project. If the researcher was seen as a representative of the western culture and as a member of the health profession, did the subjects respond with what they thought the researcher wanted to hear.

In my opinion, the informants and their parents viewed me as a nurse who came from Mexico but is now a member of the Western culture. I feel children were quite open in their conversation. Lack of sensitivity on the part of the researcher in identifying subtle cultural changes is possible.

It is difficult to conclude with a statement how one should communicate with children and parents who are Mexican-American. However, in communicating with clients, nurses should be aware of the cultural differences and be open to these. It would certainly be helpful in my opinion, to adapt the attitude of hermandad which I alluded to in the introduction. When communicating with a family who is Mexican-American, expect to spend more than the average time with them. When communicating with the Mexican-American child, bear in mind his/

her close family ties, and the concept of hermandad applies to the child as well.

Another recommendation is to increase the level of awareness towards the needs of children with cancer and of other cultures. Although awareness of death has increased over the past century, it may be this fear of the potential death associated with childhood cancer that may discourage some health professionals from working with this population. However, for those of us who have accepted the challenge, our priority should be to help the child and his family achieve a level of functioning that will allow them to have the highest quality of life possible. Of particular importance are valid and reliable tools that would enable nurses to detect early those children and their families that will need additional patient education in order to carry out their own care. One benefit would come from identifying potential problems that could lead to a lack of compliance with the health regimen.

Nurses should continue to use ethnographic research to discover other factors affecting children with cancer in the Mexican-American culture. Such valuable research would aid in the development of a valid assessment tool.

Recommendations for Research

The following recommendations for further research are offered:

1. Study the self-care behaviors of:
 - a. Mexican children with cancer for comparison,
 - b. children with other chronic illnesses,
 - c. healthy Mexican-American children for comparison,

- d. children of other cultures for comparison.
2. Develop an assessment tool to measure degrees of ability to conduct self-care.

Summary

This chapter included a discussion of the relationships between the cultural themes and the concepts utilized in the conceptual orientation. Recommendations for practice and suggestions for further research were discussed based on the findings of this research.

APPENDIX A

CONSENT AND ASSENT FORMS

PARENTAL CONSENT FORM

Research: The "Taking Care of Myself" Phenomenon in Mexican-American Children with Leukemia

I understand that I am consenting for my child _____ to take part in a research project that is designed to explore how children with leukemia take care of themselves. My child is selected because he/she is receiving health care services from the staff in this treatment facility and is six to ten years of age.

Children who have been off chemotherapy for a specified period of time will be interviewed. They will be asked about their thoughts and feelings about being sick and well, and the things they do to make themselves feel better. The interviews will be tape recorded. I am informed that all material is to be kept indefinitely for possible use at another time. However, the identity of my child is not to be revealed. The interviews will be done in the hospital, the College of Nursing, or in our home.

I am informed that I am free to question the interviewer about any aspect of the study. I understand there are no physical discomforts or known risks to my child, and my child and/or I can talk with the nurses and doctors at the clinic at any time. All information will remain strictly confidential, anonymous, and there is no cost to me. I also understand that my child's participation in this research will assist nurses and doctors to better help other children. Findings of this research will be available in nursing literature.

This research has been explained to me and my child. I understand that I am free to ask questions and withdraw my participation at any point. I have been duly informed and understand what participation involves. I consent to my child being a participant in the research.

Parent or Guardian _____ Date _____

Witness _____ Date _____

Maria Isela Luna, RN
623-8938

CHILDREN'S ASSENT FORM

Research: The "Taking Care of Myself" Phenomenon in Mexican-American Children with Leukemia

I am asking you to help me with this research project about the things that you do when you feel well or ill. I want to know about the kinds of things you would like to tell me about taking care of yourself. For two or three times I will ask you to talk to me and to talk into a tape recorder. Each time will take about half to one hour. An hour is the time it takes for two cartoon programs to be on TV.

I think what you will tell me will help doctors and nurses because they will know things that make you feel better. Also, they will know what we need to teach you. I think that what you tell me will help us help other boys and girls to take better care of themselves.

You can decide for yourself if you want to do this or not. Whatever you say is what I will do and it won't make any difference in the kinds of things we do for you. There is no reason, that I know of, that any of this will hurt you in any way. You will not need to pay us, and you will not be paid any money. You can ask any questions you like and I will answer them. You can talk with your nurses and doctors in the clinic at any time.

When I am finished asking you questions I will write about what you have said, but I will not use your name. This means that there's no way other people can know the things you have told me. I will keep what you have said in a safe place. I want you to remember that any time you don't want to do this, you tell me. You don't need to say why. I will then stop asking questions and the doctors and nurses will keep on taking care of you just like they always have. I want you to keep a copy of this form so you will know what I have said to you.

I understand what has been written in this consent. What it means has been explained to me. I know that I may ask questions and stop helping when I choose and this will not make a difference in the things doctors and nurses do for me and my family. I understand that this consent will be kept in a safe place and only the research people can see it.

Subject's Signature _____ Date _____

Witness Signature _____ Date _____

Maria Isela Luna, RN
623-8938

APPENDIX B

HUMAN SUBJECTS APPROVAL LETTERS



THE UNIVERSITY OF ARIZONA
HEALTH SCIENCES CENTER
TUCSON, ARIZONA 85724

HUMAN SUBJECTS COMMITTEE
1609 N. WARREN (BUILDING 220), ROOM 112

TELEPHONE: (602) 626-6721 or 626-7575

30 April 1986

Maria Isela Luna, B.S.N., R.N.
College of Nursing
Arizona Health Sciences Center

Dear Ms. Luna:

We are in receipt of your project, "Patterns of Self-Care of Mexican-American Children with a Chronic Illness", which was submitted to this Committee for review. The procedures to be followed in this study involve an interview format that poses no risk to the participating subjects. However, regulations issued by the U.S. Department of Health and Human Services (45 CFR part 46, Subpart D) require that projects of this type be reviewed and approved by this Committee when the study population includes minor subjects. Although full Committee review is not required, a brief summary of the project procedures is submitted to the Committee for their information and comment, if any, after administrative approval is granted. This project is approved effective 30 April 1986.

Approval is granted with the understanding that no changes or additions will be made either to the procedures followed or to the consent and assent forms used (copies of which we have on file) without the knowledge and approval of the Human Subjects Committee and your College or Departmental Review Committee. Any research-related 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
Human Subjects Committee

MN/jm

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

 **University Medical Center**

1501 North Campbell Avenue
Tucson, Arizona 85724
Nursing Administration

July 25, 1986

Isela Luna, BSN, RN
Graduate Student
College of Nursing
University of Arizona
Tucson, AZ 85721

Dear Ms. ~~Luna~~ *Luna*:

It is a pleasure to approve your request to conduct your research, "Patterns of Self-Care of Mexican-American Children with a Chronic Illness". Your contact person is Tim Viccaro, Director of Pediatric Nursing, phone number 626-7256, or beeper # 873.

We will look forward to having your report your results and providing us with an abstract of your findings. Please contact us if you have questions or concerns (626-6353).

Sincerely,



Ada Sue Hinshaw, PhD, RN, FAAN
Director of Nursing Research



Dawn Apperson, MS, RN
Nurse Resident in Research

ASH/fp

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