FATHERING AND THE PEDIATRIC CANCER EXPERIENCE

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To Dad, who did not live to see the completion of my thesis, but who has been and continues to be a primary influence in my work and my life. My interest in fathers began with my own family and the special father I had.

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ABSTRACT

A descriptive study was conducted to answer the question: What is the cultural knowledge that informs the behavior of fathers in interaction with their children during the pediatric cancer experience. The concepts of the culture of the father, the fathers' role in the family, and the crisis of the pediatric cancer experience formed the basis of the conceptual framework.

Ethnographic interviews were conducted with four fathers of children being treated at a medical center in a large southwestern city. Tape recordings of the interviews were transcribed and analyzed between interviews.

From analysis of the recordings, taxonomies were developed of which "kinds of things fathers do with children" and "kinds of things fathers do when they monitor the health of children" are examples.

Five cultural themes were identified: (1) being there, (2) education on a day to day basis, (3) recreation, (4) fear, and (5) quality of life. Fathers were found to be deeply involved and therefore their views need to be emphasized in the nursing care of children.

CHAPTER 1

INTRODUCTION

This study is concerned with fathers whose children have cancer. Research dealing with parenting has to date emphasized mothers and their children. The mother, by popular acclaim, is the primary parent in actual household practice and in the minds of students of the family. Child care is traditionally viewed in the realm of mothering, not fathering. Fathers and siblings and their relationships are less well understood.

Keshet and Rosenthal (1978, p. 13) remarked, "Men have been studied as workers and professionals, but not as fathers and husbands." Fathers are bankers, architects, doctors, lawyers, steel workers, presidents, and astronauts. Media portrayals of the father's role in the family are few. Media in the past, e.g., television's "Father Knows Best" portrayed the father as a kindly person to be humored by the real leader of the family, the mother. Since child care has traditionally been considered part of mothering, research concerned with children and the developing family has dealt with the mother-child relationship. To the traditional family situation with its crisis of development this study adds the stress of a child with cancer.

In an attempt to rectify the present lack of information regarding fathering, the specific focus of the study is the information

reported by fathers about their activities with a child during the day-to-day experience of cancer. In this study the experience of cancer is conceptualized as involving three phases: diagnostic, chronic, and terminal. The phases are not viewed as totally discrete entities but with overlapping between the phases. The concern of this study is the activities engaged in during the middle or chronic phase of cancer, specifically activities surrounding the father-child relationship. During the chronic phase of illness there appears to be less emphasis on worry about the diagnosis characterized by the initial phase or the hope and comfort crucial to the terminal phase. During the chronic phase of cancer the emphasis is on day-to-day living with the illness as it affects the family and most particularly, for this study, the father-child dyad.

Observations of activities of a pediatric oncology clinic for several months provided an opportunity to classify activities involved in the chronic stage of illness. In addition to bi-weekly attendance at the pediatric oncology clinic, I attended a monthly parents group consisting of the parents of children with cancer. The following statements provide a short summary of activities, discussion, problems, and questions stemming from treatment of a child with cancer. All children with cancer followed by the clinic report for periodic assessment visits. The length of time between clinic visits ranges from weekly to yearly with monthly visits more the routine. Going to the clinic entails for the child, at minimum, probing questions by the physicians, a definite reminder that the

child is not normal; at maximum, clinic visits involve phlebotomy, painful lumbar puncture, or bone marrow aspiration, replacement therapy of blood and/or blood components, and admission to the pediatric inpatient units. Arrangements need to be made by one or both parents, relative, or significant other to bring the child to clinic for appointments. Appointments require the scheduling of other family activities around trips to the clinic. School, school-related activities, and other extracurricular activities are missed or postponed. Exposure to children in different stages of illness with all forms of cancer occurs at each visit. Clinic visits involve waiting in the clinic for varying lengths of time.

The waiting period lends itself to discussions among the families. Topics discussed are varied, focusing on money, employment, and effects of the illness on the parents, the children with cancer, and the siblings of the children with cancer. Parental concerns regarding the cost of clinic visits, medication, and treatment are aired. Insurance coverages are frequently compared. Ability to retain employment in the face of increased family responsibilities is discussed. Parents, generally mothers, discuss their inability to maintain any degree of social activity as a marital couple. Effects of the cancer and its treatment on the involved child with regard to playmates and siblings generates discussion on the handling of behavior problems or cruelties of playmates. Cruel behavior directed at the children with cancer generally has to do with physical appearance. Children receiving treatments for cancer encounter nausea, vomiting,

weight gain, and alopecia. These side effects of the drugs and/or radiation become part of the child's way of life. Problems of adjustments of siblings of the children with cancer are discussed. the effect on the sibling of the necessity to give more than time and energy to the child with cancer is another area of voiced concern.

In summary, most of the research to date regarding children with cancer has dealt with the mother-child dyad, mothers being considered the primary parent. Fathers have not been studied or portrayed. The area of concern in this study is the father-child relationship that develops when a child has cancer. Cancer, in this study, is viewed as a chronic illness. The chronic illness of cancer involves numerous activities and concerns as seen by the discussion of the activities of the pediatric oncology clinic.

Statement of Problem

The problem for this ethnographic investigation was: what is the cultural knowledge that affects the behavior of fathers in interaction with their children during the pediatric cancer experience?

Statement of Purpose

The purpose of the study was to determine elements of fathering behavior in fathers of children with cancer. Increased knowledge of father-child relationships can be an aid to care givers in supporting therapeutic activities and guiding growth fostering activities. Further explanation of the father's role in the family

will facilitate optimal utilization of health-care resources available to the child such as siblings and the extended family.

Significance of the Study

All children begin life with a biological mother and father. The mother has been the parent who has been studied. Emphasis on mothers may lead people to erroneously conclude that fathers are important to children only for their biological function. Growing up today in an ever changing world, children need as much love, guidance and support as is possible. Fathers can and do give love, guidance and support. Perhaps the form of the love, guidance, and support is different from that given by mothers.

If chronic illness is added to the normal crises of growth and development, the child's added needs from parents increases. Although roles of parents are not as clearly defined as in years past, fathers are still the major breadwinners, who must deal with the rising cost of medical care. With chronic illness, the end of payment for medical care frequently cannot be seen. The system seems to see the need for emotional support of mothers, but fathers are left to their own resources.

Treatment for cancer is physically, emotionally, and financially draining. With advances in treatment the survival time for children with cancer has increased. Cancer needs to be considered a chronic illness.

Raising a family is a challenge to any set of parents. The world continues to change at a pace which is stupifying for parents.

How can any set of parants and/or family prepare for the years to come? Nursing as a profession has the task of dealing with the children with cancer and their families. Information regarding family interactions both between the family member and in society can help nurses, as health team members, provide care from a position of increased knowledge and understanding. Fathers, as well as mothers, need to be recognized in planning the care of the children as outpatients or inpatients.

Conceptual Framework

This study deals with the fathering of a child with cancer. The concepts concerned with building the conceptual framework are the culture of fathering the family and father's role in the family, and the cancer experience as a crisis in the family.

The concept of culture as used in this study follows the work of Spradley (1979, p. 5), and his definition that it is "acquired knowledge that people use to interpret experience and generate social behavior". This research proposed to look at fathering from the father's point of view, that is the emic view, utilizing the method of ethnographic interview as outlined by Spradley (1979). Fathers as informants defined what constitutes fathering within their cultural context. Fathers as members of the larger family can verbally diagram their activities involving the child with cancer within the framework of their subculture.

Unlike much of the limited amount of work that deals with fathering, this research dealt directly with the source of the fathering

activities, the father. This study pertains to how the father categorizes, encodes, and defines the world in which he lives. Specifically, this study deals with that part of the father's world involved in the father-child relationship.

The family is one kind of social group defined and organized by society. The nuclear family, composed of a mother, father, and the children, is the major family unit of American society. Mothers and fathers communicate with each other in different ways. Most research questions focus on the mother-child relationship (Klaus and Kennell, 1976; Brazelton, 1969; and Bowlby, 1969). How fathers relate to and communicate with children, how they do things for, to and with children, and how children relate to fathers is less well understood.

What role does the father play? Mead (1949) has contributed some knowledge on variation in nurturing activities of male and female adult members of a family. She suggested that whereas a woman's nurturing behavior is rooted in biology, fathering is a learned social cultural phenomenon. For example, Mead discovered that in families universally permanent arrangements were made whereby male assist females in nurturing children while they are quite young:

> Somewhere at the dawn of human history, some social invention was made under which males started nurturing females and their young. In every known society, everywhere in the world, the young male learns that when he grows up, one of the things which he must do in order to be a full member of society is to provide food for some female and her young [p. 189].

Men can and do provide food for women and children. Often, the provision of food is not related to the man's biological paternity of the children. An exception to the rule that men provide for women and children is men of monasteries who feed or provide for each other.

Mead (1949) pointed out that women's nurturing of children is rooted in actual biological conditions of conception, gestation, birth, and suckling. Women need only meet and subscribe to a social arrangement to fulfill their biological role. According to Mead (1949), for example, the social arrangement of marriage in American society, generally precedes the fulfilling the biological role for motherhood for women. Only under complicated social conditions, e.g., those of the Mundugumor, who ostracize women during childbearing, does the role break down. Men, on the other hand, must learn to want to nurture. An important consideration is that learned behavior can disappear under social conditions that no longer teach nurturing effectively or facilitate its development.

Learning how to be a father is a basic task for individuals who choose to become the father figure in a family. The concepts of socialization and expressive and instrumental roles need to be considered when discussing the task of learning how to be a father. Parsons, cited by Johnson (1963), stated that development of a personality in a child involves making a series of successive identifications with increasingly specialized and differentiated social roles. Parsons (1958) defined identification as internalization not of the total personality, but of a reciprocal role relationship. The girl repeats,

on a higher level, infantile identification with her mother. She is precluded from taking over mother's role in relation to father by her membership in the child generation. At around age 4 years, a boy must break with earlier identification with mother to identify with his father. Identification, therefore, can be considered in part what is occurring in the father-child dyad, the focus of this study. The task of new identification for the boy is made difficult by the fact that father's role in our society is played largely outside the home.

In considering roles, Parsons (1958) made a distinction between the instrumental and expressive role. The instrumental role player is oriented toward securing a beneficial relationship between the system and the environment. The expressive role player is oriented toward relationships among family members. In other words, the expressive role player is concerned with attitudes, emotions, and problems of the family unit (Johnson, 1963). In our present-day American society, mother remains the expressive leader most of the time and father the instrumental leader.

Present-day American society is changing with the expressive and instrumental roles of the mother and father evolving into roles which are not as clearly defined as in years past. One major factor in the clouding of these clear delineations of expressive and instrumental roles is that according to the U.S. Bureau of the Census (1978), 46.6% of married women in America were in the labor force as of 1977 and 77.4% of the total population of married women in the labor force have children 1-17 years old. Mothers are not at home the length of time

they were in 1950 when 23.8% of married women were in the labor force (U.S. Bureau of Census 1978). Although the increase of married women in the labor force is large, most married women do remain outside the labor force and perhaps play the stricter expressive role than their working counterparts. Fathers continue to remain in the labor force.

As expressive role leader, mother is concerned that the children respect the feelings of each other regarding privacy. Father is concerned, for example, that the views of his family are represented in the city council. Generally his personal views as to the adequacy of public school education are synonomous with his "family views." As instrumental leader the father is not primarily oriented to the emotional needs and reactions of his individual family members.

As instrumental role leader of the family, father represents the outside world with its, at times, harsh demands. Through father, who plays a large portion of his role outside the home, the children are exposed to the world outside the family unit. The father's involvement with the outside world and learning of his instrumentality came from his own father. In review of basic psychology, Freud, as interpreted by Hall (1954), reported that identification of boys with their fathers is based on fear. Fearing their father, the boys identify with father to deal with that fear. As their fathers were instrumental and dealt with society for the family's best interest, the boy will grow up to repeat his father's instrumentality with his own sons and daughters.

The child is seen then as a member of the father's environment. The activities directed at the child from the father are generally

considered fathering. Fathering activities continue and tend to expand under the stress of cancer in the child. Simple logistics almost demands increased involvement by the father with his children during the chronic illness of cancer. Child-care duties are more divided than in a family with no stress of cancer. Biller (1974, p. 2) maintained that:

> Man's curiosity, his sensitivity to tactile stimulation, and a basic nurturant instinct which emerges under certain conditions, predisposes him, or at least allows him to find fathering stimulating and gratifying. The ability to appreciate imitation by another is also a fundamental reinforcer of fathering.

The cancer experience does not occur in a vacuum, nor does it occur only to the child with the cancer diagnosis. Cancer cannot be considered an isolated event in the family. Cancer is a day-to-day experience that affects the entire family. As a family happening, the coping strength of the entire family must be considered when studying the cancer experience. Stress of the cancer experience affects each member of the family, including the child with cancer. Stress also affects the family as a unit. Although the study deals only with the father-child relationship during the cancer experience, full knowledge is maintained of the social context of the father-child relationship working within a family in the culture of the family.

Stresses endured by the family involved in the cancer experience are many of the same stresses verbalized by the groups in the clinic; e.g., frequent clinic or hospital visits, finances, employment, and the effects of the illness on all the family members. Each family, as well as every individual involved, is different from all other families. Generalizations regarding stresses of the cancer experience and family

reactions can only be made with knowledge of the extreme individuality of each case, each individual. Cancer does cause change. The crisis (cancer) can precipitate, if not produce, profound family strife. The necessity of repeated contacts with a health-care system necessitates, at the minimum, time and financial support. In the following paragraphs stresses encountered by fathers will be discussed.

However, it is prudent to remind the reader that roles in a family tend to be not as clearly delineated as earlier in history. Stresses felt by fathers are also felt by mothers and other family members. Fathers are the focus of this study; therefore, stresses of fathers alone are delineated.

Fathers' stresses concerning fathering of a child with cancer include change in self-conept, change in relationships, and financial stresses. Mikkleson, in a personal communication to Travis (1976), stated that the crisis of cancer endangers the father's self-concept dealing with responsibility for his family and of fending off harm. Cassileth and Hamilton (1979) added to the change of self-concept idea by labeling the situation a feeling of helplessness. Destiny of the child and his family is uncontrollable, contrary to a basic tenet of American society that hard work and perseverance brings success. Fathers are no longer all powerful. Fathers are reduced to the rank of human beings. Frequently, they cannot alleviate pain in the children or understand why God is allowing this to happen. Fathers are sources of knowledge for their children. A question can be asked: What type of resource is a father who does not understand the disease or treatment of his child?

Closely associated to the change of self-concept is the idea of changing relationships between family members. Realistically fathers frequently are unavailable for doctor visits. Their work must continue. Mikkleson (1978) pointed out that fathers learn about their children's progress through mothers, not firsthand. Very simply, mother and the child become closer to the exclusion of the father. A concerted effort on the part of the family members must be launched to keep fathers in the relationship. As mother spends time and energy with the child, the mother-father relationship suffers (Cassileth and Hamilton, 1979). They described the changing relationships within the family that the crisis promotes and also detailed the necessity of changing relationships outside the nuclear family. Perhaps the mother-in-law is required to move in with the family to help with the remaining children and household chores. The nuclear family is expanded by need, not choice, to include extended family members. Family friends are called on to aid in daily chores with no hope of repaying these acts. Father's book of checks and balances no longer applies.

Financially, father needs to continue to work. Cassileth and Hamilton (1979) addressed the idea of financial stresses. Insurance, grants, and aid only pay for a portion of the medical cost incurred by the child through his treatment for cancer. The family, with father commonly breadwinner, is ultimately responsible for the cost of treatment. The cost of treatment can compromise the family's standard of living and restrict social contacts. Long-range educational plans of the other children may be curtailed or at least altered by the

financial drain of the illness (Cassileth and Hamilton, 1979). The study operates with the knwoledge of these stresses on the father as the focus of this study. These categories of stresses on father are not total nor mutually exlusive.

In summary, the conceptual framework regards the culture of fathering as viewed from the emic view; i.e., the father's view, the family and the father's role in the family are viewed using Parson's expressive vs. instrumental roles, the cancer experience is seen as a crisis in the family, with particular attention paid to the stresses endured by the father.

Limitations

The limitations of the study were:

1. Only English-speaking fathers were included in the study.
2. No control was attempted as to sex of child, diagnosis, or overall duration of the illness.
3. The data reflected what the fathers say they do not what they do.
4. The families were specifically selected because they were intact families.

Assumptions

The following basic assumptions were made in the study:

1. A diagnosis of cancer in a child will have an effect on the family, including the father-child dyad.

2. Fathers engage in distinct activities with their children. Fathers can communicate to the investigator the substances of these activities.
3. Roles used by the fathers in associating with their children are rooted in the father's language.

CHAPTER 2

REVIEW OF THE LITERATURE

The review of the literature for this study included two areas: fathering and chronic illness as it affects the family.

Fathering

Review of the literature reveals that little research to date has been done on fathering, the activities and the influences on American society. Research that has been done suffered from numerous problems, two of which were the unavailability of fathers for interviews regarding their fathering activities and the tendency in American child development research to stress the all-prevailing importance of the mother-child relationship. Areas of concern discovered by a review of the literature on fathering were: fathers' potential for influence, shielding of children from painful experiences, time and quality of interaction with infants, the effect of fathers on nursery school children, the effect of fathers on adolescents, the effect of fathers on college students, and finally, the effect of fathers on successful business women.

Hamilton (1977) viewed the father as potentially, if not actually, the second greatest influence on his children's development. The father's potential for influence is not realized if mothers and teachers remain unaware of the potential. He proposed that a proportion

of fathers have spent extra time away from their homes, have left the guidance of their children to the mothers, or have been unreliable in interactions with children because they view their fathering role as inconsequential.

In a true life account, John Gunther in Death Be Not Proud (1949) clearly delineated fathering activities in caring for his own son, Johnny. Johnny was diagnosed as having a brain tumor. Fathering for Gunther was not inconsequential. Fathering involved increased contact with Johnny, trips to work with his son, reading/critic sessions with Johnny, and tutoring Johnny to help him keep up with physics. Most vitally, fathering to John Gunther meant "shield him from definite, explicit knowledge, since his greatest asset by far --his only asset aside from his youth--was his will to live" (Gunther, 1949, p. 32). The Ngoni tradition of Malawi supports the function of shielding for fathers. Tradition of the Ngoni dictates that fathers keep the knowledge of death away from the children by shielding them from the burial hut and the funeral (Read, 1968).

Time spent in interaction of fathers with their children was the focus of several research studies. Lynn (1974) found that the average family spends only one hour a day together. Although some fathers spend up to two hours per day in direct contact with their 9-month-old infants, most of the fathers studied by Biller (1974) spent little more than 10 to 15 minutes a day during the week in direct contact. Rebelsky and Hanks (1971) studied 10 infants, age 2 weeks to 3 months. For a 24-hour period every 2 weeks a microphone was

attached to the infants' clothing. The study was begun to determine the amount of verbalization the fathers directed toward their children. According to the results of the study, fathers average less than 40 seconds of verbal interaction per day with their infants. A fault of the study was that it failed to measure non-verbal communication.

The study of quality of interaction between the father and his child guided Dr. Ross Parke in his study of infants and their fathers (cited by Hersh and Levin, 1978). When left alone with their infants, the fathers of Parke's study were sensitive to infant needs, skillful in handling of the infants and affectionate with their infants. A follow-up study, 9 months later found that infants of fathers involved in early child care coped with the stress of strangers better than those infants of fathers not involved in early child care (Hersh and Levin, 1978).

Spelke et al. (1973) studied 36 first-born, Caucasian, 1-year-old children. Her hypotheses had to do with the effect of father interaction as related to protest from the child when separated from one or both parents. The study involved an interview in the home with the father and two sessions with the parents and the child in the laboratory. Fathers were rated on their interaction by the amount of time spent with the child, the amount of caretaking of the child, and sensitivity of the father to the child. One laboratory session involved the child-subject sitting on the mother's lap as visual stimulation (cube, light, and doll) were presented in unusual manners. In the second and final laboratory sessions, the child's responses to those movements were recorded. Those children with high

father interaction cried minimally at being left with a stranger and attended to the unusual stimuli without becoming bored as easily.

Paternal absence was the subject of two well-controlled studies. Hetherington (1972) explored father absence effects on girls' development. White, adolescent, first-born, without brothers were divided into three groups according to the family situation. The girls were divided into the intact family group, father absent by divorce and father absent by death. Results revealed that all three groups interact well with women. The effects of father absence on the girls during adolescence were evident, especially if the fathers were absent before the girls were 5 years old. The father absence effects were manifested as an inability to interact appropriately with males rather than deviations from sex-typing or problems in interaction with females. Lessing, Zagorin, and Nelson (1970) conducted one of the most extensive investigations concerning father absence and cognitive functioning. The Weschler Intelligence Tests were given to 311 boys and 122 girls. The children, 9 to 16 years old, were being seen as part of the diagnostic evaluation of the Institute of Juvenile Research during the period 1960-1966. Father absence of 2 or more years correlated highly with low ability in perceptual motor and manipulative spatial tests. In lower-class children, father absence was also correlated with decreased verbal functioning.

Studies of nursery-school-age children and their fathers were reported by Goodenaugh (1957) and Radin (1972). Goodenaugh (1957) interviewed parents of 40 children 2 to 4 years, utilizing six

open-ended questions. Mothers' replies were more personal regarding their children. Fathers were more ideational regarding their children's futures. Fathers showed a greater interest and intensity in their differientation of boys' and girls' behaviors than mothers. Forty-two boys, half of the group from middle class and half from lower class, constituted Radin's (1972) sample of 4-year-old boys. Fathers were interviewed and observed in their homes to determine their level of nurturance towards the subjects. Paternal nurturance was described as the seeking out of the child in a positive manner by the father during the time of the home visit and asking information of the child. One to 4 weeks after the home interview a psychologist administered the Stanford-Binet Intelligence Test and the Peabody Picture Vocabulary Test to the subjects. The study found that nurturance was positively correlated to the Stanford-Binet IQ test and Peabody Picture Vocabulary Test with a Pearson r .49 and .51, respectively, at the .001 level of significance (Radin, 1972, p. 356).

Adolescence was the area of concern for Biller (1974) and Bronfenbrenner (1961). Biller, in an unpublished 1966 study reported in his 1974 book, looked at high school boys of superior intelligence who were functioning below their grade level. The purpose of the interaction with the researcher was to motivate the students to perform at the level of their potential. A majority of the boys involved were alienated from their fathers. The boys viewed their fathers as successful in work, devoting more time to work than to their family. Bronfenbrenner's (1961) exploratory study of 400 tenth graders

in a medium-sized city of upstate New York generated hypotheses but did not produce quantifiable results. Of merit is Bronfenbrenner's acknowledgment of the probable differences based on social class. He used father's educational level as the index of social class.

Bronfenbrenner (1961) studied leadership and responsibility of all the tenth graders at high school on the one day of the research. He used the health and English teachers ratings of each student on the Teacher Rating Scales. These scales of 22 variables of adolescent behavior had not been previously tested for reliability. Students completed the Parent-Activity Inventory of 100 items proposed to measure 20 different dimensions of parent-child relationships. Again the inventory had not been tested. Bronfenbrenner delineated weaknesses, poor teacher interrater reliability, reliability of student perceptions, possibility of response set bias from the teachers' middle-class orientation, in his design and nowhere proposed to present hard facts from the study Bronfenbrenner (1961, p. 268-269). proposed the following hypotheses regarding fathers that need further study.

1. Fathers show greater individual differences in parental behavior than do mothers and thus account for more of the variations in the behavior of their children.

2. Lack of involvement in child rearing by fathers impedes development of responsibility and leadership in sons.

3. Boys tend to be most responsible when father is the principal agent of discipline.

Of merit is Brofenbrenner's attempt to control the social-class variable by grouping the final sample.

An abundance of studies of fathering dealt with collage-age students (Sopchak 1952; Helson 1967; MacDonald 1971; and Wright and Tuska 1966). Sopchak (1952) looked at 108 second-semester elementary psychology students, utilizing the Minnesota Multiphasic Personality Inventory (MMPI). The students, 78 men and 30 women, were required to answer the MMPI as they would answer it and as their fathers and their mothers would answer it. Each of the three MMPIs were administered one week apart. For both men and women, failure to identify with their fathers was more closely associated with trends toward abnormality than failure to identify with their mothers.

Helson (1967) studied 51 college senior women considered to have creative potential for work in the arts, sciences, and humanities. Good grades and character and leadership were not considered. Seniors were asked to write sketches of their parents, and their parents were given adjective checklists and questionnaires about the girls' childhood. In the analysis, creative women had more availability of their fathers for models. Location of locus of control was MacDonald's (1971) interest in studying 427 undergraduate students from intact families. High paternal nurturance, (supportive behavior) was associated with an internal locus of control. Internal locus of control designates the feeling that a person has about his control of the events occurring in his life. External locus of control designates the feeling that other persons control the occurrences in your life. MacDonald's (1971) study utilized the students' perceptions of the parenting received. The scale used has yet to be validated.

Femininity was self-rated for the 2650 middle-class college and university women of Wright and Tuska's (1966) study. From the two groups developed, "very feminine" vs. "slightly feminine or masculine" results gathered showed that feminine women have satisfactory relationships with their mother and a favorable image of their father in his masculine role. Masculine women's images of their fathers were not favorable.

Finally, Hennig and Jordim (1977) conducted an in-depth study of 25 successful women who held the title of president or divisional vice-president of nationally recognized firms. Twenty-two fathers also held managerial positions, while 3 of the fathers were college administrators. Mothers of these women were as well or better educated than fathers. Twenty-four of the mothers were housewives. All of the women considered their childhood happy and that they were special in their parents' eyes. All of the women experienced special relationships with their fathers, including activities generally considered for fathers and sons such as fishing trips. Fathers were models with whom their daughters could identify, but they were always to their fathers. These same women had no specific memories of their mothers. They rejected the constructing of the societal definition of femininity.

Chronic Illness and the Family

Mattsson (1972, p. 801) defined chronic illness as a "disorder with a protracted course which can be progressive and fatal, or associated with a relatively normal life span despite impared physical and mental functioning." Of children ages 1-18 years, 30-40% suffered

from one or more chronic illness, including visual and hearing defects, mental retardation and speech and behavior disorders (Futterman and Hoffman, 1973). Futterman and Hoffman (1973) proposed that the crisis of chronic illness tends to promote maintenance of emotional and inter interpersonal equilibrium. That equilibrium is maintained through (1) adherence of familiar routines, (2) continuation of usual patterns of family interactions, and (3) reaching out for emotional supports.

In reviewing the literature dealing with chronic illness the following topics were discussed: programs to deal with chronic illness, emphasis by the family on the disease process, division of the family's world, feelings of the family, and concepts used in helping the family.

The effect of chronicity of an illness on families has prompted the utilization of parental consultation programs. As reported by Wright (1970), these programs treat children indirectly by increasing the parents' skills. Parents become the agents of change. The article cites Friedman's work involving three family sessions in which parents are aided in conceptualizing their role in child development and their role in helping the child adapt to medical difficulties. The University of Oklahoma utilized 15-20 sessions with parents in which they are taught principles of behavior through group discussions. The need for early intervention with families of the child with chronic illness is the topic of Kaplan et al.'s (1978) article. In their work with hospitalized patients and their families, Kaplan et al. attempted early contact with the families. Studies of the crisis that chronic illness promotes show that individual and family reactions to

the threat of prolonged illness are fashioned from one to four weeks after the diagnosis was confirmed. Each family member, including the child, must redefine his role with respect to relationships, duties, and expectations. If parents, who lead the family in coping behavior have opposing views regarding the illness and the involvement by other family members, the coping by all family members is in jeopardy.

Families, especially parents, become immersed in the problems precipitated by the illness, to the extent that normal developments of the child is ignored. Gyulag (1978) wrote of the frequent occurrence of ignoring the involved child's developmental milestones and non-medical needs. In chronic illness, all attention is focused on the disease process at times forgetting that the child is an individual. A monumental task of parents of chronically ill children is learning to deal with restrictions, Mattsson's (1972) work led him to conclude that dealing with the challenge of raising a chronically ill child means only realistic and necessary restrictions will be enforced, self-care and regular school attendance will be encouraged, and reasonable physical activities will be promoted.

Maintaining the correct balance is a monumental task. Futterman and Hoffman's (1973) work detailed the process whereby parents attempt to return to normalcy when the children are in remission. Parents and children both tend to redirect their energies toward relationships and interests that relapses in the children's disease process interrupt. Heffron (1973) described the phenomenon as parents dividing their lives into the sick world and the well world.

Dealing directly with families involved in the sick world Mikkelson (1978), Weiner (1970), and Craig (1975) described feelings these families have. Mikkelson (1978) interviewed 18 families of 19 children 4 to 11 years old with cystic fibrosis. From the interviews came various reactions of anger, pain, relief, hope, and peace. The anger had to do with the "Why me? Why my child?" Pain was associated with knowing the diagnosis. Parental groups continually verbalize the importance of knowledge to them regarding the disease as a defense of intellectual mastery (Weiner, 1970). Hope of a cure or continued remission universally occurs. Peace involves knowing that as a family everything was done. Peace also involves a feeling of closeness, specialness that families feel when they all work together and every-day is considered a special day.

Craig (1975) reported an underlying anxiety for families with children with leukemia. The anxiety involves questioning their compe-tence to give adequate care to their child with special needs. The anxiety can undermine their confidence in life itself and in the worth of the marriage that produced the child who is chronically ill.

Finally, Steinhauer, Mushin and Rae-Grant's (1974) work with children in the Hospital for Sick Children in Toronto, Canada, brought to light concepts that need to be considered when attempting to help families of children with chronic illness. Chronic illness of one child affects the health, relationships, and existence of the entire family. The more quickly family members resolve their feelings caused by the diagnosis of the involved child, be they anger, guilt, anxiety, the more able the needs of the child and family can be met with minimal

damage to the family unit. A clear diagnosis explained by health personnel and information readily and repeatedly available to the family aid the family to make realistic plans. Health professionals must realize that what the family hears and understands, especially at the time of diagnosis, differs from what they are told. Continual assessment is needed of families understanding the disease process and treatment. The child's understanding and feelings of the disease process and treatment need to be explored. Continual updating with the child and his family of restrictions and expectations should occur. School and peer relationships are important to the children with cancer and with the siblings. These relationships should be maintained.

Basic to work with families is the health professional's knowledge of the importance of the family unit when dealing with the child with a chronic illness. The child is not treated in a vacuum and the family unit can potentially be disorganized by the threat of chronic illness on the life of one of its members. Especially during the acute crisis periods, such as diagnosis and exacerbations families as a unit or individual family members tend to vent feelings such as anger and guilt at the health-care members who happen to be available. The attack is not personal and should not be viewed as such, with avoidance of the family as the consequence. Management of the child in the family involved in chronic illness is no easy task. A team of professionals is necessary to provide the care the child and family requires.

The preceding review of the literature on fathering and chronic illness does not attempt to suggest that all pertinent books, articles,

and research were included. The review does suggest the need for further information on both topics of fathering and chronic illness and the family. Research on fathering continues to rely on mothers' and children's views of fathering. No research reviewed dealt with father's views of his own activities of fathering. Although a few studies dealt with the effect of fathering activities on well children of various ages, no studies were found that included the effects of fathering on any children with illness. Possible changes in the effect of fathering on any women devoted to the independence and equality for women has not been explored. These gaps in the literature serve as a basis for the present investigation.

CHAPTER 3

METHODOLOGY

Research Design

This descriptive study was launched to answer the question: What cultural knowledge informs the behavior of fathers of children with cancer?

Following the format of the ethnographic interview suggested by Spradley and McCurdy (Spradley, 1979; and Spradley and McCurdy, 1972), fathers were interviewed and categories of information were developed and organized as they emerged. Four fathers were selected for participation in the study. Each father (informant) was interviewed on four different occasions for periods of 30-60 minutes. The following concepts are necessary to the medthodology of the ethnographic interview: culture, ethnography and informant. Culture, as defined in the Introduction, is Spradley's (1979 p. 5) definition "acquired knowledge that people use to interpret experience and generate social behavior". This study most specifically dealt with the fathers' culture. Ethnography is the work of describing a culture concerned with the meaning of actions and events to the people studied. Ethnography strives to construct an understanding of all cultures through the eyes of those who live the culture (Spradley, 1979). The end product of studying a culture is an ethnography of which this research is an example.

Informants are the individuals, along with the investigator, who construct the ethnography. In addition, informants, according to Spradley (1979), are native speakers, models, and sources of information.

This style of research, involving informants, focuses on the following questions: What do informants know about their culture that the investigator can understand? What concepts are used by the informants to classify their experience? How are the concepts defined by the informant? and What folk theory is used to explain experiences?

This chapter will present the selection of the informants, the protection of human rights, data collection and analysis, the role of the investigator, and the summary of data analysis.

Informants

The informants were fathers of children during a cancer experience who were presently undergoing treatment by the staff in a pediatric oncology clinic. The clinic utilized as the source of fathers is a part of a university medical center of a large southwestern city. Permission to conduct the research was obtained from the hospital. A letter of support (Appendix A) was written by the pediatric oncologist of the clinic.

Informants were chosen according to the following criteria: the father was willing to participate in the study; the child was regularly followed by the staff of the oncology clinic; the child was not in the diagnostic or terminal phase of cancer; the father spoke English; and the father, mother, and the child had lived together before the time

of diagnosis. Informants were selected with the assistance of the medical and nursing staff.

Protection of Human Rights

The procedure followed in this study for the protection of human rights of the subjects was in accordance with the guidelines of the Human Subjects Committee of the university hospital. Each informant was required to sign the subject consent form (Appendix B). The consent was reviewed together by the investigator and the informant. Participation by the informant was totally voluntary. All informants were informed of the purpose of the study, as outlined in the consent form, and the method of data collection. Informants were told that participation or refusal to participate would in no way affect the care their child received. Confidentiality of identity and replies were assured. The informant was briefed on the persons having access to the coded data. The informants also were advised as to the potential uses of the study. Questions by the informant were encouraged.

Data Collection and Analysis

Data collection for this study followed the guidelines for the ethnographic interview set forth by Spradley (1979). The methodology of the data collection and analysis followed the protocol of the ethnographic interview was devised by Spradley. The procedures for locating the informant and conducting the interview were the two major tasks in the data collection process.

Criteria of Spradley (1979) were utilized in selecting informants. These criteria include (1) thorough enculturation, (2) current involvement, (3) member of a cultural scene unfamilar to the investigator, (4) adequate time, and (5) a nonanalytic informant. A good informant is knowledgeable and throroughly enculturated into the cultural scene, the object of the investigations. Enculturation of the fathers is a natural process they undergo in learning the culture of fathering. Fathers differ widely in their level of enculturation.

Specific fathers were chosen as informants because of continous involvement in family activities to reduce the variability of enculturation. An assumption was made that the fathers were knowledgeable of their own role. Ethnographic interviews entail descriptions of contemporary activities, feelings, and opinions. Fathers presently involved in the care of a child with cancer and presently experiencing feelings, opinions, and activities were the only individuals approached for participation in the study. Fathers selected for the study were present in the home and had been a part of the family at least since the time of the diagnosis. The cultural scene involved was fathers and fathering. Fathers, themselves, were viewed as knowledgeable about the cultural scene of fathers. The investigator being female and single had minimal knowledge of what fathering entails. Therefore, the cultural scene was generally unfamiliar, another criterion suggested by Spradley (1979) for conducting an ethnographic interview. Ample time for the interviews was allotted by the fathers. At the onset the amount of time required for this study was explained. A good

informant describes his culture in the language of his culture. Fathers of the study were selected because of their willingness to talk in a non-analytic manner.

The interviewing process began when the informants were contacted. Once the informants were contacted, the interviews were conducted in their homes or in the clinic at a time convenient for both the informant and the investigator. Each of the informants was interviewed over a period of 5 weeks. The contents of the ethnographic interview, according to Spradley (1979), involves three elements: explicit purpose, ethnographic explanations, and ethnographic questions.

Discussions of these three elements will include the component parts of interviewing the informant as proposed earlier. Explicit purpose deals with the idea that at every interview the investigator informs the informant (father) of the purpose. An interview consequently is more formal than conversation. The first interview was used to establish the ongoing rapport and to elicit general ideas of what constituted fathering activities. Crucial to the ongoing interview sessions were the ethnographic explanations. Ethnographic explanations involved five different types of explanations to the informant. Repeatedly the reason for the project was explained. Interest of the investigator in fathers and fathering activities during the chronic phase of the cancer experience for their children was repeatedly reiterated. The reason for notes and tape recording was explained. Informants were reminded to speak using their own terms. Later in the interviewing sessions explanations included reasons for triadic card

sorts and lists. When the type question being asked changed the informant was told the reason for the change.

The core of the ethnographic interview consisted of three main types of ethnographic questions: descriptive, structural, and contrast. Descriptive questions enabled the investigator to collect an ongoing sample of the informant's language. Throughout the entire group of interviews descriptive questions were used. Structural questions deal with domains into which the information the father possesses is divided. For this study, the investigator proposed a general domain of fathering activities. Answers to structural questions determined how the information regarding the fathering activities was organized by the father. Contrast questions deal with the meaning various terms used by the informants have for the informants. For example, if the informant described picking up drugs, sitting with a child in the clinic, or taking a child to the toilet at night as activities of fathering, then the informant was asked which of the activities were most alike. This example illustrates a contrast question.

The procedure for the interview followed from descriptive to structural and contrast questions. The father was asked first to describe a typical day in his life from the time he arose until he retired. The question proposed to the father was a descriptive, grand tour of the informant's day. The second question asked was: What kinds of activities are there that you do with and for your child? The second question is an example of a structural question. Only through analysis of responses to the beginning grand tour questions and the structural questions was the investigator able to devise

further structural and contrast questions appropriate for the informant's culture.

Analysis of the responses given by the informants was accomplished after each interview and before the next interview. The interviews were tape recorded, the tapes transcribed and reviewed before the next interview. Spradley (1979) defined ethnographic analysis and the search for parts of the culture and their relationships as conceptualized by the informant. Analysis, according to Spradley, is defined by the four types of analysis; domain, taxonomic, componential, and theme.

Domain analysis is the search for larger units of cultural knowledge called domains. These domains are analyzed by developing relationships between (strict inclusion and cause and effect). For example, picking up drugs is a kind of activity that fathers do for their children with cancer. Taxonomic analysis searches for the structure within the domains. A model is developed of all activities in a specific domain. In componential analysis, the investigator looks for attributes that differentiate symbols of the domain. Contrast within the elements of the domain are developed in a model. Finally, theme analysis searches for the relationships between domains and how the relationships between domains are linked to the culture.

Role of the Investigator

The investigator took the role of interested party, learner or student, in a quest for information concerning fathering activities. Fathers were the experts. Mothers were not contacted, nor was

knowledge of mothering activities of interest. The investigator explained her interest in fathers and fathering at the beginning of the interviews. The need for knowledge about the father's world for quality intervention was used in the explanation as the rationale for the study.

Summary of Data Analysis

The interviews with the fathers were geared to elicit knowledge and beliefs these fathers held regarding fathering activities initiated in response to their children with cancer. Tape recordings and notes of the interviews were analyzed following the methods of analysis proposed by Spradley (1979). Definitions of categories and their meaning to the fathers were described and related to ways fathers utilize the information in their fathering activities. A summary was written with the domains and themes discovered from the interviews with the four informants.

CHAPTER 4

PRESENTATION AND ANALYSIS OF DATA

The topics to be discussed in this chapter include: collection of the information, informants, analysis of the data and ethnographic data.

Collection of the Information

The interviewer worked in the pediatric oncology clinic for ten months prior to beginning the contact with fathers as prospective informants for this study. During the ten months, the investigator had personal contacts with many fathers of the clinic. In the beginning of the research, the investigator compiled a list of prospective informants for the study according to the criteria set forth. With a list of prospective informants in mind, the investigator informally reviewed the list with the pediatric oncologist, nurse-social worker, and the clinic head nurse. The purpose of this review was to ensure that the sample chosen was representative of the clinic father population. Time and energy prevented utilizing fathers who lived out of the immediate area of the city. Two of the fathers, Norman and Ben, were contacted at the time of their child's clinic visit. Steve and John were contacted by phone for tentative permission. Explanations of this study were given at the clinic or over the phone and again at the

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*Pseudonyms are used for all personal referents.

first interview. Explanations were given as needed and as requested during the course of the interviews.

Three of the four fathers work outside the home. Interviews were scheduled around their work schedule. As John's job required numerous trips out of town, Saturday worked well as an interview day. Ben's job required rotating shifts. His interviews were done during his daughter's clinic visits or on his days off. Steve is presently acting as houseparent during this year as his wife, a nurse, returns to the unversity. Norman worked in a family partnership, which allowed him flexibility in his schedule.

Norman and Martin, his son, require special consideration in the way of an explanation. When Norman was first contacted Martin was in remission from his cancer. Before a first interview could be scheduled, Martin relapsed. Limits of time and energy on the investigator's part, plus a feeling of commitment to Norman prompted the investigator to treat Norman as a special case. The formal of his three interviews (all that time allowed) did not follow closely the techniques described by Spradley (1979) for ethnographic interviews. Norman will be discussed more fully in the next section.

The interviews were set up at a time mutually convenient for the father and the investigator. All interviews, except two of Norman's were tape recorded. Only five of the interviews were conducted in the clinic. Interviews in the clinic were conducted at the desk in the examination rooms with the informant and the investigator sitting on either side of the desk. The tape recorder was placed between both individuals. Generally, during the time of setting up of the tape

recorder the investigator and the informant exchanged greetings and pleasantries.

The first interviews in the home were conducted in comfortable chairs in the living room. After the first interview, lists and card sorts were used, so that sitting at a table seemed more practical. Privacy of the interviews was accomplished through John's and Ben's wives keeping the children in other parts of the house. Steve's children were outside playing or at school during the interviews.

At the first interview, the fathers were required to verbally tour with the investigator a day's activities. The day picked to tour was left to the father's discretion. In utilizing the grand tour question, the investigator hoped to accomplish several things: (1) obtain a sample of the informant's language, (2) begin to understand how the informants view and organize their day's activities, (3) get a feel for the beginning relationship between the informant and the investigator, and (4) attempt to put the informants at ease in the interviewing process. From that question, the father's interests, feelings and attitudes were first elicited. The second question involved listing activities done with and for their children. With this question, lists were begun for the father to add to later, correct, and subtract from. The further development of these lists will be discussed under Analysis of Data.

Informants

All study fathers were interested in their children. This was ascertained by virture of the fact that the investigator had met

each father in the clinic at times before selecting him as an informant for the study. The investigator made no attempt to contact any father of a child in the clinic whom she had not met before. Ethnographic interviews require at least a minimal commitment and an interest on the part of the informant. Ethnography strives to talk about the findings; i.e., the taxonomies and the themes, discovered with only that particular group, the informants.

Four fathers were selected as informants. They are here named John, Steve, Ben, and Norman. Each father is presented individually in the paragraphs that follow. How they viewed the interview is either implicitly or explicitly stated.

John

John is the father of Kathy, a 4-year-old girl with leukemia, diagnosed 17 months ago. Kathy has two older sisters and one younger brother. At this writing, Kathy has been in remission since her induction therapy in April 1978. John's professional activities include counseling people. Communication with his children is important. He differentiated "good solid communication" in the morning and the directive communication of the evening. "Good solid communication" requires attentiveness, a "non-hassled" atomsphere, energy, and exchange of ideas. John was aware that Kathy and an older daughter were not normally as verbal as Kathy's younger brother and older sister and that "they had trouble expressing themselves, feelings and things like that." John differentiated "individualized communication" from simple verbal exchange. His example was that reading a book to Kathy was not

on the same level as talking with her. In talking with Kathy, John's energies were going to figure out what to say to her and to say it in a way that she can understand. Being in the room with her for procedures is considered communication, albeit subtle.

Steve

Steve is the father of Louis, a 6-year-old boy with leukemia, diagnosed 2 years prior to the interviews. Louis has one younger sister. Louis had been in remission since his initial induction therapy. Steve was spending this year as a houseparent while his wife, a nurse, studies at the university. The family was in the Southwest only temporarily until they return to their permanent home in a northwestern state. Steve is in the construction business and at all times maintained active and frequent involvement in the activities of the home.

Steve's fathering of Louis has been influenced to a certain extent by Steve's relationship with his own father. Steve's father died before they could be adults together and share adult activities. In his own family, Steve's father was not physically demonstrative. Steve sees the importance of a physical demonstration of affection.

> I personally think it's an important thing for them to be touched and to know that affection is there. You can never verbalize it. These kinds of things, it counts for more than words.

In the interviews with Steve, the investigator realized that Steve had considered, at length, the relationship to his son. The father-son relationship was differentiated from the relationship to his daughter. Steve was the only informant who made mention of the

sex difference in interactions with children. Fathers, according to Steve, desire different things for a son than a daughter and tend to "protect" daughters more than sons. Steve saw a natural division of activities with sons and daughters. His example was that he would go into the woods with Louis, while his daughter would remain at home with his wife. Steve helped the investigator list an analysis of his activities with Louis which included such phrases as:

- Louis learns.
- I learn.
- We spend time together doing an activity that has the same object.
- I reexperience my own childhood is seeing Louis grow up.
- I make up for loss felt with own father.
- Louis feels that a certain activity is his own activity.

With the evident consideration of the father-son relationship, Steve was also the father who answered the question: What do you hope your child tells his son about you? The answer, "There is nothing I wish him to tell his son about me." This answer suggested something special about Steve and his relationship to his son.

Steve was not an easy person to understand. During the first interview, his answers were generally very brief, if not brusque. When asked what Louis would say was his favorite activity with his father, Steve's answer was, "I don't know you'd have to ask him." The other informants had definite ideas in answer to questions of that nature. In a subsequent interview, Steve became very open and verbal regarding his relationship with his own father and how that affected

his relationship to Louis. Frank and verbose responses from Steve came generally by chance, apparently when he was ready and needing to verbalize. Perhaps on the occasion of revealing himself to the degree Steve did during the interchange on his own background, he felt the need to distance himself from the investigator for a period after that.

Ben

Ben is the father of Carrie, a 4-year-old girl with Ewing's sarcoma of the pelvic area, diagnosed in May 1979. Carrie has one younger sister. Ben works rotating shifts in a nearby copper mine. Since Ben is hard working and ambitious and had worked for the mine for 9 years, he frequently acted as shift foreman. The importance of giving attention to the child pervaded the interviews with Ben. All of his interactions with Carrie were viewed as at least partially educational, including doing "silly stuff," teasing, and chasing around. "Attention" to Ben in large part meant spending the time and the energy to answer Carrie's question.

> I think if you give her the wrong answer, she might go around with the wrong attitude about something, and it might be harder to correct later on. I could try to take the easy way out. . .they continue doing it the way you really don't want them to do but yet you took the easy way out. I'd rather sit down and take time to explain things and maybe try to get her to think about it the first time. If it comes up again, we go over it again.

In Ben's own childhood, his parents, who were older, struggling to exist, and ill, did not answer his questions. He feels a loss and is committed to answering all of his children's questions as best he can.

Norman

Norman is the father of Martin, a 9-year-old boy with non-Hodgkin's lymphoma diagnosed in May 1978. Martin has an older brother. Norman is a partner with a brother and brother-in-law in a retail food business. The business is successful and has made the partners wealthy men. Because of his son's relapse, Norman is under much pressure. He is mobilizing his resources to provide his son with the best possible treatment. For Norman, a wealthy and influential man, this means trips and calls to medical centers all over the United States.

Time is at a premium for Norman, but the investigator sensed that Norman had a need to talk about his activities and his relationship to his son. Norman felt pressed for time during the times of the interviews and somewhat threatened. Norman stated he felt that because of the pressures he was experiencing he would not be fair to the investigator if he tried to participate in this study. At the same time the investigator spent a great deal of time with the family supporting Norman, his wife, and Martin. When Norman felt confortable, the interview occurred. When the taped interview was complete, Norman said, "We sure did talk a lot, didn't we?" He had verbalized during the entire 50 minutes with only minimal direction and encouragement from the investigator. Themes emerging from the interviews will be presented in the ethnographic data section.

Analysis of the Data

Analysis began with the first interview and continued for the entire data collection period. The first interviews provided language

samples for the tour questions and structural questions obtained in each of the subsequent interviews. Informants listed activities they had done with their children. These served as tentative domains from which taxonomies developed.

A domain is a symbolic category including other categories. For example, "plan a special day" is a kind of thing done with a child. A taxonomy develops a domain one step further. In the preceding example of "plan a special day," the subset includes, "go on a picnic," "feed the ducks," and "fish." Taxonomies can eventually show relationships between all folk terms in all domains of a culture.

Beginning with the second interview, the investigator developed additional lists from the interviews. At subsequent interviews, the informants were given these lists and the informants were asked to add and subtract from the lists and monitor the wording. Examples given by the informant in an earlier interview were verbalized utilizing a structural question: You mentioned earlier that you chase around, roughhouse, and play ball with her? Miniature golf was the reply, which was then added to the taxonomy. Repeatedly they were reminded that the object of ethnographic interviewing was to obtain their phrasing and wording of statements. "Silly stuff" when defined by the informant meant tickle, make faces, and roll around.

The written lists were used at interviews 2 through 4. New lists were developed at the later interviews. During all interviews, the lists were referred to in order to achieve completeness. At the end of the interview, the investigator verbally reviewed the lists for

completeness. Both the actual tapes and the transcriptions of the tapes were reviewed before each subsequent interview. From the review, the investigator followed the taxonomies as they were developing. Questions to check suspected trends were developed.

Each of the three informants (Norman is the exception) were given cards to sort. The developing lists were converted to 3x5 cards for the informants to sort into any number of piles they desired. One informant sorted cards of ways to monitor his child's health into three piles: signs that the immediate family would know, signs that others would know, and signs not necessarily related to the cancer. After the lists were sorted into piles and were explained by the informants, the investigator asked for triadic sorts of the same cards representing the lists. Here with the three cards, the informants picked which two of the three were more alike. The reason for choosing the two cards was then elicited. This provided insight into the characteristics the informants use to differentiate similiarities and differences in the developing taxonomies. An example of one kind of analysis is presented in the paradigm of activities in a clinic visit.

John worked with the investigator to develop a paradigm (Figure 1) of activities involved in clinic visits with his daughter Kathy. A paradigm, according to Spradley (1979, p. 176), is a "schematic representation of the attributes which distinguish members of a contrast set." In developing a paradigm, John listed all the activities involved in a clinic visit. Later, he differentiated the activities in the three type clinic visits. He considers Kathy's three

	TYPE VISIT								
	Bone Marrow Days			Heavy Medicine Days			Clinic Days		
	before	during	after	before	during	after	before	during	after
have her sleep in my arms	no	no	yes	NA	NA	NA	NA	NA	NA
listen to her when she talks about the pictures in the book	yes	no	yes	yes	no	no	yes	no	no
help her collect her things	NA	NA	yes	NA	NA	yes	NA	NA	yes
get a doughnut	no	no	yes	no	no	yes	no	no	no
tell clinic staff that she doesn't want a sleepy shot	yes	no	no	NA	NA	NA	NA	NA	NA
bring her extra clothes for after the bone marrow	yes	NA	NA	NA	NA	NA	NA	NA	NA
hold her hand	yes	yes	yes	yes	yes	yes	yes	yes	yes
get a coke	no	no	yes	no	no	yes	no	no	yes
go in the room with her	no	yes	no	no	yes	no	no	yes	yes
read to her	yes	no	yes	yes	no	yes	yes	no	yes
talk to her	yes	yes	yes	yes	yes	yes	yes	yes	yes
provide a surprise after the bone marrow	NA	NA	yes	NA	NA	NA	NA	NA	NA
make sure the clinic doesn't waste a vein	yes	NA	NA	yes	NA	NA	yes	NA	NA
be present for bone marrow	no	yes	no	NA	NA	NA	NA	NA	NA

Figure 1. Paradigm of activities involved in clinic visits

type clinic visits as "bone marrow days," "heavy medicine days," and "doctor visits." "Bone marrow days" include bone marrow, lumbar puncture, physical examination, blood test, intravenous medicine. "Heavy medicine days" include blood tests, physical examination, and intravenous medication. "Doctor visits" include physical examination and a blood test.

Activities done with and for Kathy change according to the type clinic visit. When John at a later interview was given cards to sort of activities he had listed regarding the clinic visit, he sorted the cards by the type of visit and time-relationship to the procedure. Even later in the interviewing, the investigator presented John with the paradigm. He corrected and filled in missing data. Of note is the fact that the constant activities involved in clinic visits are holding hands with and talking to Kathy. These two activities occur at all three types of clinic visits and at all times during the visits. "Get a doughnut" is an activity involved with "bone marrow days" and "heavy medicine days," but not with "doctor visits." To "get a doughnut" appears to be more special than to "get a coke," which occurs after each clinic visit.

Finally, cultural themes were developed from the categories repeated in the various domains, taxonomies, and paradigms. Previous transcripts were also reviewed. Further interviews elicited information from informants about feeling/ideas they had during their cancer experience. The investigator prepared a tentative list of cultural themes for validation by the informants. The investigator also elicited examples so that the affirmation of themes by the

informant was not just a positive mind set. The themes to be presented in the Ethnographic Data section have been developed through the collaboration of the informants and the investigator.

Ethnographic Data

This portion of the paper will include a discussion of the taxonomies developed during the interviews. They are:

1. The most important tasks involved in being a father
2. Kinds of things fathers want for their children
3. Kinds of things done with children
4. Kinds of things done for children
5. Kinds of things fathers do when they monitor the health of children
6. Kinds of things fathers do with and for children in and about the clinic visit.

A brief synopsis of Norman's special case will be presented. Finally, an analysis of the cultural themes developed from the ethnographic data will be discussed.

Taxonomies

Six taxonomies are presented in this section (Figures 2-7). The first two taxonomies (Figures 2 and 3) presented are the result of the informants' answering the specific questions for the taxonomy. The remaining four taxonomies were developed over the entire course of the interviewing. A discussion of each taxonomy is presented

help run the house	bring home the bacon being there when they need me seeing to their needs
instill the right kind of values	honesty trust integrity manners
showing them what life is about	
caring	
loving	

Figure 2. The most important tasks involved in being a father

successful treatment	long life easy course to remission minimal side effects
healthy life later on	
success in life	success in marriage success in any endeavor
independent mind	
good death	good to have her as long as we did quality of life worth staying around for

Figure 3. Kinds of things fathers want for their children

- play games
  - ball
    - softball
    - baseball
    - catch
  - hide and seek
  - horsey
  - chase around
  - miniature golf
  - rough house
- hug
- do silly stuff
  - tickle
  - make faces
  - roll around
- go to the cafeteria in the hospital
- come to the clinic
- plan a special day
  - picnic
  - feed the ducks
  - fish
- just be together
  - sit around
  - walk around a little bit together
  - ride around
- read stories
- take trips
  - to the woods and cut wood
  - to Kitt Peak
  - to the park
  - to see friends
  - to breakfast
  - to the store
    - grocery
    - hardware
  - to church
  - to town for lumber
  - to Dad's office
- wake up together
  - exchange ideas
  - start the day
- swim

Figure 4. Kinds of things done with children

education on a day-to-day basis	watch while she shows me what she has done during the day show her something teach by example teach her to count try to explain things to her answer questions
give attention when she asks	
listen to child's story	
go to clinic with the child	
pick up from nursery school two mornings a week	
give medicine on weekends	
do daily chores	meet the school bus fix breakfast make sack lunch brush child's teeth see that he's properly dressed make sure buttons are buttoned see that he gets on bus in morning bathe son remind to go potty
use assertive communication	move her off to bed tell her to get her jammies on encourage to straighten up the house
try to be a normal parent	don't allow to stay late on school nights curb profanity in front of child don't deal with illness all the time monitor health
find out what surprise she wants for her next bone marrow	

Figure 5. Kinds of things done for children

listen to child	when she says she doesn't feel well when she says she hurts	find out if hurt medicine related Find out if hurt disease related
	what he tells us	
	when she complains of soreness in her leg	
check eyes	puffiness bright and shining	
watch	blood count behavior temperature	
	general coloring	pale flushed
	disposition	cranky irritable just his attitude I think I can tell
	energy level	incidence of day napping responsive
	diarrhea crying nitpicking kinda sadness in her face	
look him over carefully every day		splinters mosquito bites
keep an eye on her discover that she doesn't eat all day long be more solictous when finding out what the problem is		

Figure 6. Kinds of things fathers do when they monitor the health of children

have intellectual grasp of the situation	know all about disease and medicine know what to expect from treatment know effects of medicine listen when they tell us about medicine and treatment
be involved with the medical treatment	review the medical records during the clinib visit confer with doctors make sure no slip-ups make sure he is not used as a guinea pig catch medicine mistakes make copy of chart watch child's growth curve keep record of all medicines cooperate benefit from someone else's experience
be involved with the nurses	tell nurses child does not want sleepy shot make sure he is only stuck once make sure nurses don't waste vein

Figure 7. Kinds of things fathers do with and for children in and about the clinic visit

go into room with child	hold child for procedure be held by child for procedure talk to child held child's hand bring special toy of her choice from home
go into room with child for bone marrow only if wife not available	
help her collect her "things" after procedure	
provide some treat after the bone marrow	get a doughnut get a coke
Occupy child during visit	read to her listen while she talks about the pictures in the book have her fall asleep in my arms

Figure 7. -- Continued

The Most Important Tasks Involved In Being a Father. In one of the last interviews, the investigator asked the fathers to list what they consider the most important tasks involved in being a father (Figure 2). John feels that "bringing home the bacon" is important, but also "helping run the house" is important. "Helping run the house" included many traditionally mothering functions--bath, dressing. "Helping run the house" did not include washing dishes or clothes. In answering this question and developing the taxonomy, the informants tended to use abstract terms. When questioned further, they were able to define a number of these terms. Trust conveys to the informant the feeling of the child knowing that her father would be available to help her sort out her problems as she grew to adulthood.

Kinds of Things Fathers Want for Their Children. To elicit an idea of what fathers want for their children, the investigator phrased her inquiry in the following manner: The fairy godmother is ready to grant you three wishes regarding your child. What would those three wishes be? The investigator was surprised when not one of the three fathers wished the cancer away (Figure 3). The fathers all dealt realistically with a fantasy-type question. The fathers were concerned with the length of the children's lives, but also with the quality of life. Successful treatment involved extension of life, but also the wish for minimal side effects. John hoped that the nausea and vomiting from the chemotherapy was minimal. He also was concerned about the effect of chemotherapy on organs of the body. If medical

science could not save the child, fathers had wishes concerning the death.

> If she isn't going to make it, that the process is easy enough and we're able to provide the kind of life for her that we could look back and say that it was still . . . it was good that we had her as long as we did. The quality of life was worth staying around for.

Kinds of Things Done with Children. This taxonomy (Figure 4) involves a large degree of physical activities: games--horsey, miniature golf, ball; trips--park,woods, stores. The taxonomy also reflected the informants' awareness of the need to be together with their children with no planned activity in mind; e.g., hug, "do silly stuff," "just be together." In developing this taxonomy the informants, in revealing the activities, did not realize the extent of their involvement until the lists were actually compiled and placed before them. "Silly stuff" as defined by Ben meant tickling, making faces, and rolling around. At first Ben seemed at a loss when asked to list activities involving his daughter. After verbally touring a day, the lists developed.

Kinds of Things Done for Children. "Education on a day-to-day basis" is placed in high importance by all three fathers (Figure 5). The methods and emphases were different as the reader will see when "education on a day-to-day basis" is presented and discussed as one of the cultural themes. Nevertheless, to be emphasized here is the fact that all three fathers see the need for involvement in education. Steve is presently acting as houseparent while his wife is attending the university. Daily chores are a large part of Steve's

daily interaction with Louis. "I interact with him 24 hours a day." Even before this year of houseparenting, Steve was in a position to arrange his schedule to allow for large blocks of time at home. "Kids drive me nuts sometimes. I would dearly like to be away from them, but it's all a question of balance. When I'm away from them I miss them and I want to be with them."

John describes his commands/directions as "assertive communication." He uses "assertive communication" to move Kathy to bed. At the same time he is aware that there are several types of communication with different goals. His goal with assertive communication is helping run the house, an important task of his fathering activities.

Kinds of Things Fathers Do When They Monitor the Health of Children. The taxonomy (Figure 6) includes items that health-care workers monitor; e.g., "diarrhea," "temperature," "coloring," but fathers also monitor signs strangers may not be aware of. Ben sees a "kinda sadness in her face"; John notices Kathy's eyes do not look "bright and shining"; and Steve proposes that by "just his attitude I think I can tell." In trying to understand the sign of "kinda sadness in her face," the investigator had Ben describe the phenomenon in more detail. "Kinda sadness" involves drooping eyelids and long face. "Kinda sadness" lasts longer when the cause is sickness rather than when she is upset over not getting her way. The "kinda sadness" is greater when Carrie is sick. The informants were very comfortable in monitoring these subjective signs which strangers might have difficulty doing.

Kinds of Things Fathers Do With and For Children In and About the Clinic Visit. The activities labeled "have intellectual grasp of the situation," "be involved with the medical treatment," and "be involved with the nurses" sound abstract. Careful inspection of the taxonomy (Figure 7) reveals that the informants have concrete and detailed information as to what the overall heading of "have an intellectual grasp of the situation," for example, means. The "intellectual grasp" and involvement items are really activities done for the child, not necessarily with the child. The three informants were very open in revealing that through these activities they are better able to deal with the uncertainties and seeming unfairness of a diagnosis.

> It's important for me to be able to be involved to a certain extent. It gives you some feeling of usefulness. You can do something. You have some control when basically the situation is out of control.

Activities done with the children involve more personal activities of hold, read to, and talk to. All three fathers felt that trips to the clinic with their children were necessary for various reasons:

- To give mother a break
- To be involved
- To increase understanding
- To help the father tolerate raising a child with cancer.

Norman's Special Case

Normal presents a special case for several reasons. Martin, his son, is no longer in the chronic phase of illness as are the other children of this study. Norman was in the greatest need to talk about

his fathering but needed the most "space" and time to accomplish the talking. Because Norman did not strictly meet the one criterion of the study, i.e., child with cancer in the chronic stage, he further presents a special case.

Norman and the investigator met in the clinic several times before the period of time designated for data collection. Norman's actual interviews did not closely follow the techniques ethonographic interviews as described by Spradley (1979). Norman was interviewed for data collection three times, but circumstance allowed the tape recording of only one session. Notes were made of the other two interviews. Understanding and analysis of Norman were based on earlier clinic contacts and a transcript of the 50-minute taped interview. Themes of that one taped interview were three: command, family, and self-questioning of Norman's ability to "handle it."

Norman is a partner in a profitable business. The business began at the bottom and through ingenuity and hard work was built into the multimillion dollar concern that it is today. Norman has been an extremely "in command" person. That feeling of command has changed.

> Always been in command . . . always known exactly what I'm doing at all times. When I found a situation that I couldn't handle, a simple telephone. If I don't understand something, I get somebody who does understand it, can handle it, can solve it. When you get in a situation like this. . . .

Norman repeatedly made references to his family in earlier visits to the clinic and at the taped interview. He felt that it was important for the investigator to understand his ethnic background and his family. The family is Lebanese. To the Lebanese people, family is important and families are partriarchial. "Fathers want

sons." Norman has two sons. The extended family is totally involved in Martin's care. Norman felt the closeness to a degree that he equates his life to "living sort of in a glass bowl." He particularly felt close to his own brother. The Lebanese boys are taught to rely on their brothers.

> They're taught the only one that you depend on is the family and in times of trouble the only one you turn to is your brother. He'll be the only one that will be there.

Finally, Norman seriously questioned his ability to "take it." Norman's extended family has experienced deaths of its members; e.g., Norman's father and uncle. The men of the family have, by history, taken the deaths poorly. In the 50-minute taped interview, Norman made seven references to the feeling "Could I handle it?" Norman openly worried about his ability to handle the loss of a son. "I'm going to need an awful lot of help." The worry over his abilities appears to overshadow worries of how his wife and other son will handle the death if and when Martin dies. In a non-taped subsequent interview, Norman continually referred to his numerous health problems; e.g., sinus blockage, ear pain.

Norman is a father not living with a child with the chronic illness of cancer. Norman is living with a child with the realistic possibility of dying. Steve spoke of control through involvement but also felt that he had a real measure of control only as long as Louis stayed in remission. Perhaps all fathers feel out of control during the terminal stages. In summary, no comparisons are attempted regarding Norman, whose status of father of a child with chronic illness changed rapidly to father a terminally ill child. Norman is

presented to attempt to illustrate concretely the variety of problems and setbacks the investigator experienced while interviewing fathers for this study. Norman needed to talk, but time and energy were expended before he was able to allow himself the opportunity to talk.

Analysis of the Cultural Themes

A cultural theme, as defined by Spradley (1979, p. 86), is "any cognitive principle, tacit or explicit, recurrent in a number of domains and serving as a relationship among the subsystems of cultural meaning." Five themes developed from the interviews with the three remaining informants, John, Steve, and Ben. The themes were "being there," "education on a day-to-day basis," recreation, fear, and "quality of life." Each theme is discussed in detail below.

"Being there," the theme, can be demonstrated in all taxonomies. Not all examples of "being there" will be cited, but the idea of recurrence is apparent. The informants list "help run the house" as an important task of fathering (Figure 2). Part of "help run the house" is "being there when they need me." "Being there" is appreciated when considering a list of activities done with the child from games to picnics to "just be together." "Being there" involved all levels of involvement from planned to spontaneous, physical, and emotional. "Being there" from the taxonomy of kinds of things done for children (Figure 5) consists of restrictions of bedtimes and curbing profanity so as to provide the proper identification figure. Monitoring health (Figure 6) can be done only if informants and their children are in contact so the informants can listen, check, watch, look, and discover.

Clinic visits (Figure 7) promotes physical closeness of hand holding and talking with, but also this prompts the interaction of the informant and members of the health-care team. Informants are there on behalf of the children. In summary, what the investigator discovered was that "being there" is the theme that encompasses the other four themes. This discovery was supported in discussions of the four remaining themes. Although this investigator believes that "being there" is the encompassing theme, the remaining themes are of a magnitude to warrant separate discussions.

"Education on a day-to-day basis" means more than sending the children off to school for teachers to educate. Formal education, of course, is part of the process. The informants have enrolled their children in school or are attempting to enroll them in some type of formal education. "Showing her what life's about" means spending time interacting with children, i.e., "Being there!" Steve succinctly stated what he and the other informants feel regarding education.

> Teaching is something that just goes on all the time. Teaching is part of everything. The way to teach is by example.

Ben adamantly maintained that education was part of all activities. The investigator asked him if his feeling held true for education as for the case of tickling (Figure 4). "She has to know when to stop." Tickling is seen as education.

In restricting activities (Figure 5) informants are acting as models for the children to learn. "Being there" is not always enjoyable; Steve restricts Louis' bedtime to the usual protests. John does

not enjoy communicating in an "assertive" manner but sees the need to maintain order in the home.

> One of the tough jobs of being a parent is to say, now you really shouldn't do that.

Education of fathers benefits both fathers and the children. Each informant had the desire to know about the cancer experience. What each of the three informants desired to understand differed. Steve labored to understand about the disease, about research concerning the disease, and about the chemotherapy. He is aware of Louis' protocol and along with his wife discovered a medication error. Louis was given too little of one particular drug before he came to the university. John wanted to know the side effects of the chemotherapy and treatments. He has achieved a grasp of the schedule for chemotherapy, blood tests, and bone marrows. He classified the clinic visits according to the schedule. He is not, however, interested in understanding the disease, leukemia, or the present theories of causation.

Fathers are known for considering roughhousing as recreation. The informants listed similar activities (Figure 4). Clinic visits required keeping the children occupied with stories. Energy level for activities was one method informants utilized for monitoring health (Figure 6). With the occurrence of painful procedures, informants saw the need to do something "fun" as a means of reward. Together the informant and his child engaged in an enjoyable activity. Informants were there for the fun times and plan these fun times.

> I'll spend as much time with them as I can. We plan a day and we'll go to the park, we'll make popcorn or take old bread and feed the ducks.

The theme of fear was felt throughout the interviews. Although the word fear was not listed on the taxonomies the informants spoke of fear. References to fear were varied:

- I'm thinking about it all the time
- always the wondering
- fear is going to remain even after she is treated
- fear came later on . . . at first it was more of anger.

In effect Steve denied feelings of fear, "I don't think they're particularly productive." At the same time he made numerous references to "even if he lives." Fear was there, if not verbalized. Informants handle the fear through involvement, "being there." Understanding the cancer experience as much as humanly possible helped the informants work with their fears. Generally, fears were not ignored.

Finally, the quality of life theme reflects "being there." Informants verbalized their "wishes" that reflected verbally the quality of life (Figure 3). Informants worked toward giving their children an active life with trips and games. Striving for normalcy, informants placed restrictions on their children's lives as to bed-times, school attire (Figure 5). Not only do the parents strive to understand the cancer experience, they work to help the children understand what is happening in the children's immediate world (Figure 3). Quality of life is addressed in the taxonomy regarding the clinic (Figure 7). The informants are very aware of the necessity to protect the children from unnecessary trauma; e.g., extra venipunctures. The

children were not to be used as guinea pigs. Quality of life involved the understanding by the children that their fathers would be with them for the bad times; such as, bone marrow, and the good times, such as, get a doughnut.

> You know, I'm here. I'm right here to see that he gets on without any problem.

Summary

In summary, this chapter discussed the method of collecting the information. The actual mechanics of contacting and interviewing fathers was detailed. The four fathers, as informants in this study, were individually presented. Presentation of the individual informants attempted to clearly illustrate the backgrounds that influenced the informants' responses. Analysis of the data included presentation of John's paradigm (Figure 1) developed around activities in the clinic. The methods used in developing taxonomies were discussed. Ethonographic data included discussion of the six taxonomies. Finally, the five themes were discussed.

CHAPTER 5

CONCLUSIONS

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

This was a descriptive study. The statement of the problem was: What is the cultural knowledge that informs the behavior of fathers in interaction with their children during the pediatric cancer experience. Ethnographic interviews with four fathers were conducted to obtain insight into the cultural knowledge of the informants, the fathers. Conclusions were drawn based on the investigator's interpretation of the data.

Relationship of the Findings to the Conceptual Framework

The three concepts utilized in developing the conceptual framework of this study were:

1. The culture of the fathers.
2. The fathers' roles in the family.
3. The crisis of the pediatric cancer experience.

The Culture of the Fathers

Fathers see their children as desired participants in their existence. Being aware of the children as members of their life,

fathers were acutely aware of the differences in the children as individuals. The general quality of the responses given in the interviews illustrated that fathers had spent time and energy considering their relationships with their children. Children were an integral part of their lives.

In collaboration with the informants, the investigator developed six taxonomies and one paradigm. The paradigm surrounding the clinic visits developed with John's assistance illustrates the methods used by John to organize his thoughts and his actions around the time of the clinic visit. The levels of probable anxiety and pain the child must endure helped to determine the reward planned for the child. John had a surprise waiting at home for Kathy following the bone marrow visit. The constants of all the clinic visits, holding Kathy's hand and talking to Kathy, reveal that John remains close to his daughter in an expressive role.

Two of the taxonomies developed after answers to single questions were organized. Direct questions to fathers, for example: What would your three wishes concerning your child be and what are the three most important tasks involved in being a father? brought taxonomies of Figure 2 and 3. The remaining four taxonomies reveal the extent of the involvement of fathers with their children. Figure 5 dealing with monitoring children's health illustrates that fathers are aware of the subtle clues their children emit regarding wellness-illness. "Just his attitude--I think I can tell" is an example of the subtle clues fathers use to monitor their children's health.

The study fathers, however, did not idolize their children. They understood and loved them despite their frailities. "She has always been kind of whiny," was used by one father to describe a daughter he realized was not always happy.

Fathers were much influenced in raising their children by two conditions: their own backgrounds and their life situations. Steve and Ben, in particular, revealed that because of losses they felt from their childhood, they raised their children to conpensate for the shortcomings. Steve received little physical affection as a child and Ben did not receive answers to his questions. Steve utilized physical contact with Louis, and Ben took the time to explain and answer questions posed to him by Carrie.

In addition to the influence of childhood experiences, fathers are influenced in their fathering activities by the environment. John communicates with people as part of his employment and saw the necessity of communication with his children. Kathy, 4 years old, was prepared for her bone marrow by making sure that she knew she would have the bone marrow and talking about it when she came home.

Finally, in view of the fathers' awareness of their children and their influence on these children, these same fathers had no expectation that their insight and opinions were important. Repeatedly, the investigator had to state that her interest was in the informant, not in his wife or in the doctors' opinions. Certainly, the informants continue to question the import of their opinions and insights.

The Fathers' Role in the Family

The concept of the fathers' role in the family was also illustrated in the view the fathers held of their role and their statements such as "How could what I say about children be important?" In review, Parsons (1958) described child care as part of the expressive role. Mothers, as expressive role leader, are concerned with interaction between the family members. Instrumental role leader, father, is more concerned with the interface family and society. In summary, the rigid divisions of expressive and instrumental roles did not exist in families of this study. Some of the expressive roles remain for the mothers as the instrumental remain for the fathers. In general, the fathers viewed the couple as a partnership.

For the sake of division, fathers, in this study, were able to delineate their views of the manner in which mothers differ from fathers:

- picks up different things in the doctor's explanation.
- knows how to answer child's question better because she spends more time with them.
- mothers are less assertive
- mothers are more tolerant
- mothers make an attempt to devote more time to children.

The spouses of Ben and John were housewives. They spent more time with the children because Ben and John worked full time. The assertiveness of fathers was expressed by John and Steve. The role of father as expressed by them belongs with the instrumental tasks of Parsons.

A clouding of Parsons' roles is made graphic when Steve's role in the family is considered. Steve is a houseparent who completes all the daily tasks included in housekeeping with two children and a wife who is a student. Steve feels that housparenting is "Just carrying on the daily activities . . . just what has to be done. Someone has to do it."

Their roles in the family are a partnership. Even in Ben's and John's families where the couples' tasks are more traditional, the roles are not completely polarized. For example, John, when asked what the most important tasks of fathering are, listed the instrumental-type tasks of "instilling values" and "bring home the bacon." In addition, John also mentioned "helping run the house" as his third important task. Explanation of helping run the house involved working with the children in whatever manner necessary.

A partnership surrounding running the house was seen in the homes of John, Steve, and Ben. John cares for the younger two children when his wife goes on Girl Scout campouts with the older girls. Ben cares for the younger daughter when Carrie and her mother go to dance class. Although Steve carries out most of the daily chores because of his wife's student status, she helps with those chores whenever possible to allow time for family outings.

The study fathers were completely confortable in the expressive role of loving, caring, and seeing to their children's needs. One father stated that at age 4 his daughter saw "Mommy and Daddy as kind of an entity." He was particularly committed to giving the same messages to the children that his wife gave.

Crisis of the Pediatric Cancer Experience

The fathers of this study are all members of strong families. Despite the solidarity of the families, stresses were apparent in viewing these families. Ben, Carrie and the family had just finished 5 weeks of radiation therapy when the interviews began. Therapy involved 5 weeks, of 35 visits, to the hospital. The expense and inconvenience of going to the hospital represent some of the responsibilities of the father. Ben's life revolved around the treatment schedule. These families saw the clinic staff more often than they saw some of the family friends. Ben mentioned that he and his wife do not get out as a couple as frequently as before the cancer diagnosis. At a family meeting with Ben and his wife and their extended family, one relative voiced concern over the precaution she would need to take when baby-sitting with Carrie. Many of her fears were unfounded, but they illustrate fears others have about children with cancer.

The study fathers were openly concerned at maintaining a "normal" life for their children and the other members of the families. They were concerned that all their children be treated similarly. Naturally, Carrie, Louis, and Kathy all received treats after difficult procedures. Notation was made of the reason for the treats, so there could be no misunderstanding of the gift.

Fathers of this study felt that one way to deal with the situation was to attempt to understand it. This monumental task was not completed by any of the families. Travis (1976) proposed the idea that the crisis of cancer has, in part, to do with the idea of responsibility delegated to the fathers. A father is responsible for

controlling outcomes for his family. Steve felt control only because Louis was in remission. Norman, whose son was in relapse, felt totally powerless, a feeling described by Cassileth and Hamilton (1979). Is the factor for control the situation of remission versus relapse? The fathers did bemoan the fact that they were unable to help the children escape the unpleasantness of procedures. "It's just the unpleasantness of it. I don't like to see him cry and suffer. He's just a little boy. It disturbs me and upsets me to see him have to put up with it. He will put up with a lot from now on."

Throughout the cancer experience, the fathers have remained involved. They have learned of the child's progress firsthand through attendance at the clinic. Both of the parents of the family came or the parents alternated visits. This finding is unlike that of Mikkleson (1978), who reported that fathers learn about their children's progress through the mother.

Financial involvement of the father in the children's care was not discussed by the informants and the investigator. These fathers are obviously not stressed and none has applied for financial aid. The investigator does not assume that the financial drain was not real. The fathers were very aware of costs of medical treatment.

Relationship of the Nurse and the Father

As a pediatric nurse with 9 years experience, the investigator has had numerous contacts with parents. Appreciation did not develop as quickly for fathers as for mothers. The investigator's basic

nursing education stressed the importance of parents in pediatrics. However, by "parents" the educators more often meant mothers, not fathers.

In Marlow's Textbook of Pediatric Nursing (1969) father is pictured only three times and is never pictured alone with the child. Data developed in this study support the premise that fathers can no longer be ignored in the manner seen in Marlow (1969). Fathers felt as shown by the data; they are aware. They should be allowed and expected to react. They must be kept informed through telephone calls if necesary. Mothers are relatively new members to the health-care team. Fathers also need a place on the team. When referring to parents on the health team both mothers and fathers should be considered. Referring to parents and meaning mothers no longer should apply. Fathers, as well as mothers, are untapped resources. The study fathers possessed insights into their children's feelings and behavior that nurses would do well to learn more about. Nurses relying on parents both together and individually to help increase understanding of children receive a more in depth view of the children.

Considering the commitment and involvement of fathers, nurses have an obligation to teach fathers. A review of the sources of fathers information regarding children brings only one source of light, the experiences of their own childhood. Those experiences are helpful, but should not be the extent of the fathers' education. How many fathers are encouraged to attend classes regarding children? Experts direct their comments toward mothers. Fathers have not been expected to participate. When are fathers questioned about normal children's

behavior? Nurses can and should begin work in hospitals and in the community to help educate the fathers. Methods of instruction would need to be varied to suit the occasion. One-to-one instruction and classroom instruction can both be utilized.

An enlightened father can then spread the wealth of knowledge to other fathers. Not all fathers need or desire instruction. Neither do all mothers need or want instruction. The expectation of behavior should be there. Fathers, as well as mosthers, should be accountable for basic knowledge about their children's health and welfare.

Recommendations for Further Study

The following recommendations for further studies are suggested:

1. Replicate the study by interviewing fathers more than four times and thereby adding to the detail.
2. Replicate the study using fathers of children with the same type of cancer to see if there is differences in the kinds of fathering activities.
3. Replicate the study using fathers of children with other types of chronic illness.
4. Replicate the study using fathers of children in all three phases of cancer: diagnostic, chronic, and terminal.
5. Replicate the study separately interviewing the father and mother of the same child.
6. Replicate the study interviewing separately the father and his child.

7. Replicate the study utilizing a male interviewer who is a father.

APPENDIX A

LETTER OF SUPPORT

THE UNIVERSITY OF ARIZONA
HEALTH SCIENCES CENTER
TUCSON, ARIZONA 85724

DEPARTMENT OF PEDIATRICS

August 8, 1979

MEMORANDUM TO: Milan Novak, M.D., PhD.
Chairman
Human Subjects Committee
College of Nursing

FROM: John J. Hutter, Jr., M.D.

SUBJECT: Letter of Support

I have read and support the proposed research "Fathering and the Pediatric Cancer Experience." Patricia Damler, Graduate Student, Child Nursing, has been working in the Arizona Health Sciences Center Pediatric Oncology Clinic with the children and their families since October 1978.

I understand Patricia Damler's study requires interviewing fathers of children with cancer. The interviews will take place in the clinic or in the families' homes at a time mutually convenient for both the subjects and the student.

Access to medical records for the selection of subjects will be available to the student for her project. The content of the individual father interviews will be viewed as confidential. However, Ms. Damler plans that fathers will be encouraged to seek support from their primary caretaker in the clinic following the interviews.

JJH/mas

APPENDIX B

SUBJECTS' CONSENT FORM

Fathering and the Pediatric Cancer Experience

I am requesting your voluntary permission to participate in this study entitled "Fathering and the Pediatric Cancer Experience" because you are a father of a child with cancer. I am exploring activities fathers do with and for their children.

The purpose of the study is to increase the understanding of nurses and doctors about the way fathers and children behave as a vital part of the family unit. Your participation will be most valuable as you are the expert in this area. You will be asked to participate in approximately four interviews during the next six weeks. The interviews will last 30-60 minutes each and will be conducted in the clinic or at your home as most convenient for you. I will ask to tape record the interviews to aid me in obtaining an absolute record of your responses.

To protect you and the confidentiality of the information gathered, all forms will be coded to maintain anonymity. After the data has been analyzed, the results may be submitted for publication and will be retained for use in future studies. Again, your anonymity will be protected.

There are minimal medical, social, or psychological risks involved in this study. There is no cost or recompense to you for participation in the study. You are free to ask and to receive answers relevant to questions at any time. You may withdraw from this study at any time without affecting your child's care. A copy of this consent form is available to subjects upon request.

I have read and understand the above consent form. I agree to participate in this study, realizing that my participation is voluntary and that I may withdraw at any time without affecting my child's care. I also realize that there is no monetary benefit due me for my participation.

I understand that in the event of physical injury resulting from the research procedures that financial compensation for wages and time lost and the cost of medical care and hospitalization is not available and must be borne by the subject. I understand the investigator will provide more information upon my request.

I understand that this consent form will be filed in an area designated by the Human Subjects Committee with access restricted to the investigator or authorized representatives of the particular departments.

Subject's signature	Date
Witness' signature	Date

REFERENCES

Biller, Henry. Paternal Deprivation: Family, School, Sexuality and Society. Lexington, Mass. D. C. Health Company, 1974.

Bowlby, John. Attachment and Loss: Volume I. New York: Basic Books, Inc., 1969.

Brazelton, T. Berry. Infants and Mothers: Differences in Development. New York: Delacorte Press, 1969.

Bronfenbrenner, Urie. "Some Familial Antecedents of Responsibility and Leadership in Adolescents." In M. Petrillo and Bass (Eds.). Leadership and Interpersonal Behavior. New York: Holt Rinehart, and Winston, 1961, 239-272.

Cassileth, Barrie, and Jane Hamilton. "The Family with Cancer." In B. R. Cassileth (Ed.). The Cancer Patient: Social and Medical Aspects of Care. Philadelphia: Lea and Febiger, 1979, 233-247.

Craig, Yvonne. "The Ward Wants to Know Where Dad is . . ." Nursing Mirror, 53-54, October 23, 1975.

Futterman, Edward, and Irwin Hoffman. "Crisis and Adaptation in the Families of Fatally Ill Children," In E. J. Anthony and C. Koupernik (Eds.). The Child in His Family--the Impact of Disease and Death. New York: John Wiley and Sons, 1973, 127-142.

Goodenough, Evelyn W. "Interest in Persons as an Aspect of Sex Differences in the Early Years." Genetic Psychiatric Monographs, 55:287-323, 1957.

Gunther, John. Death Be Not Proud. New York: Harper and Row, 1949.

Gyulag, Jo-Eileen. The Dying Child. New York: McGraw-Hill, 1978.

Hall, Calvin S. A Primer of Freudian Psychology. New York: New American Library, 1954.

Hamilton, Marshall. Father's Influence on Children. Chicago: Nelson Hall, 1977.

Heffron, Warren. "Group Discussions with the Parents of Leukemic Children." Pediatrics, 52:831-840, December, 1973.

Helson, Ravenna. "Personality Characteristics and Developmental History of Creative Women." Genetic Psychology Monographs, 76:205-226, 1967.

Hennig, M. and A. Jordim. The Managerial Woman. Garden City, New York: Doubleday, 1977.

Hersh, Stephan, and Karen Levin. "How Love Begins Between Parent and Child." Children Today, 7:2-6, 47, March/April, 1978.

Hetherington, E. Mavis. "Effects of Father Absence on Personality Development in Adolescent Daughters." Developmental Psychology, 7:313-326, 1972.

Johnson, Miriam M. "Sex Role Learning in the Nuclear Family." Child Development, 34:319-333, 1963.

Kaplan, David M., Aaron Smith, Ross Grobstein, and Stanley Fischman. In C. A. Garfield (Ed.), Psychological Care of the Dying Patient. New York: McGraw-Hill Book Company, 1978, 245-256.

Keshet, Harry F. and Kristine Rosenthal. "Fathers: A New Study." Children Today, 8:13-17, May/June, 1978.

Klaus, Marshall H. and John H. Kennell. Maternal-Infant Bonding. St. Louis: The C. V. Mosby Company, 1976.

Lessing, Elise, Susan Zagorin, and Dorothy Nelson, "WISC Subtest and IQ Score Correlates of Fathers' Absence." Journal of Genetic Psychology, 17:181-195, December, 1970.

Lynn, David B. The Father: His Role in Child Development. Monterey, California: Brooks/Cole, 1974.

MacDonald, A. P. "Internal-External Locus of Control: Parental Antecedents." Journal of Consulting and Clinical Psychology, 37:141-147, 1971.

Marlow, Dorothy. Textbook of Pediatric Nursing, Philadelphia: W. B. Saunders, 1969.

Mattsson, Ike. "Long Term Physical Illness in Childhood: A Challenge to Psychosocial Adaptation." Pediatrics, 50:801-809, November, 1972.

Mead, Margaret. Male and Female. New York: William Morrow and Company, 1949.

Mikkelson, Cynthia. "Cystic Fibrosis: A Family Challenge." Children Today, 7:22-26, July/August 1978.

Parsons, Talcott. "Social Structure and the Development of Personality." Psychiatry, 21:321-340, November, 1958.

Radin, Norma. "Father-Child Interaction and the Intellectual Functioning of Four Year Old Boys." Developmental Psychology, 6:353-361, 1972.

Read, Margaret. Children of the Fathers Growing Up Among the Ngoni of Malawi. New York: Holt, Rinehart, and Winston, 1968.

Rebelsky, Freda, and Cheryl Hanks. "Father's Verbal Interaction with Infants in the First Three Months of Life." Child Development, 42:63-68, March, 1971.

Sopchak, Andrew. "Parental Identification and Tendency Toward Disorder as Measured by the MMPI." Journal of Abnormal and Social Psychology, 47:159-165, 1952.

Spelke, E., P. Zelaza, J. Kagan, and M. Kotelchuck. "Father Interaction and Separation Protest." Developmental Psychology, 9:83-90, 1973.

Spradley, James P. The Ethnographic Interview. New York: Holt, Rinehart, and Winston, 1979.

Spradley, James P. and David McCurdy. The Cultural Experience: Ethnography in Complex Society. Chicago: Science Research Associates, 1972.

Steinhauer, Paul, David Mushin, and Quentin Rae-Grant. "Psychological Effects of Chronic Illness." Pediatric Clinics of North America, 21:825-829, November, 1974.

Travis, Georgia. Chronic Illness in Children: Its Impact on Child and Family. Stanford, California: Stanford University Press, 1976.

U.S. Bureau of the Census, Statistical Abstract of the United States: 1978 (99th Edition). Washington, D.C., 1978.

Weiner, Jerry M. "Reaction of the Family to the Fatal Illness of a Child." In Schoenbu-g, et al. (Eds.), Loss and Grief: Psychological Management in Medical Practice. New York: Columbia University Press, 1970, 87-100.

Wright, Benjamin and Shirley Tuska. "The Nature and Origin of Feeling Feminine." British Journal of Social Psychology, 5:140-149, 1966.

Wright, Logan. "Counseling with Parents of Chronically Ill Children." Postgraduate Medicine, 173-177, June 1970.