PARENTS' PERCEPTIONS OF NURSING CARE OF THEIR CHRONICALLY ILL CHILDREN

by

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STATEMENT BY AUTHOR

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APPROVAL BY THESIS DIRECTOR

This thesis has been approved on the date shown below:

Jan R. Atwood — 3-27-79

JAN R. ATWOOD
Associate Professor of Nursing

Date

To my husband

John

for all his

encouragement,

patience

and help.

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ABSTRACT

An inductive exploratory study was performed to (1) obtain information about how parents of chronically ill children who are not near death and hospitalized in a university health sciences center define nursing care and perceive the nursing care of their children; and (2) to obtain information from the parents about the kinds of nursing care parents think are needed but are not being provided. The theoretical sample of ten parents had chronically ill children who ranged in age from three to twelve years. Data were obtained in semi-structured private interviews.

Consistent with the initial steps of the grounded theory approach, analysis of the data yielded six categories (Right to Know, Environment, Nutrition, Attitude-Approach, Parent Concerns, Competency) and two subcategories of Competency (Parent and Staff Competency).

The findings of this study lend support for the categories in two previous inductive studies; i.e., the three emergent categories in the hypothesis of selective neglect, induced via grounded theory (Environmental, Nutritional, and Person-Centered); and all seven needs of grieving spouses in hospital settings which did not refer exclusively to dying. Clinical content in the findings may prompt pediatric nursing staff to provide a quality of care

which facilitates excellent relationships among parents, children, and nursing staff.

CHAPTER 1

INTRODUCTION

Medicine has made many rapid advancements in the past several decades, and has conquered many diseases. For those who work in medicine, it is evident that chronic illness is now a chief focus of attention.

Chronic illness is usually associated with adults. However, children also suffer from chronic illness which is increasing in the childhood years. Papers presented at the sixty-seventh Ross Conference on Pediatric Research (1975) provided an overview of the frequency of chronic illness in childhood. One of the papers contained a survey of pediatricians' examinations in the United States from 1963-1970. In this survey "one child in eight, ages 6-11 years, an estimated 3.1 million children" had one or more chronic conditions of the cardiovascular, neurologic, or musculoskeletal systems and some other physical abnormalities present, compared with "one adolescent in five, ages 12-17 years, an estimated 4.9 million adolescents" with such conditions and physical abnormalities (Schultz, 1975, p. 16).

Children with the disease processes of malignant tumors, leukemia, cystic fibrosis, and asthma are considered chronically ill. Because of the many advances in modern

medicine, such as sophisticated surgery, chemotherapy, and better radiotherapeutic medicine, the life expectancy of these children has greatly increased (Singher, 1974, p. 861). A child with cystic fibrosis can now live to the third decade of life. Ten years ago parents of a child with this disease would have been extremely lucky if the child reached the end of the first decade of life. Children with childhood cancers have had an increased survivorship in the past fifteen years, and children with sickle cell anemia can now survive to adulthood (Travis, 1976, pp. 370, 437).

Currently, a pediatric inpatient unit contains primarily two kinds of patients, i.e., children who are acutely ill and those who are chronically ill. The former have been injured due to an accident of some kind, have an infectious disease process that needs immediate treatment, or are in need of immediate surgery for appendicitis, hernias, and the like. The latter return periodically to the hospital to receive continuing or new treatment or they are being reevaluated through tests (Greene, 1975, p. 1710).

The investigator of this study has been a pediatric nurse for many years in hospital settings. During this time she has been curious about how parents perceive the nursing care of their children. Occasionally letters are received by the nursing staff and/or hospital administration from parents after their child has been discharged. In these letters parents thank the nursing staff for the care they

gave and the concern they had for their child. Other letters indicate how dissatisfied the parents were with the care. These letters present only a small sample of how parents feel. The staff never hear from the majority of parents.

Statement of Problem

Children with chronic illness are cared for and protected by their parents and/or guardians while they progress through the various stages of growth and development. The parents provide for the many needs of their children in the growing years. These needs are numerous and include nutritional, personal, social, spiritual, emotional, environmental, medical, and many others. Parents are able to carry out simple medical treatment required by their chronically ill child at home. However, when more complex treatments are needed hospitalization usually takes place.

In hospitals parents now have liberal visiting hours compared to when visiting was limited to a few hours on a Sunday afternoon (Aufhauser, 1967, p. 40). With liberal visiting hours some parents now stay twenty-four hours a day. During their visits parents become the observers of patient care. They watch the nursing staff perform their duties. Through this observation parents learn how to take care of their child. They also learn how the staff care for

their child and decide whether they want to take care of their child in the same manner.

The nursing staff are the main caretakers of the child in the hospital, especially during the time of an acute phase of the chronic illness. During the time of hospitalization, they render nursing care to the child which is designed to help him meet his needs in the activities of daily living and more (Rines and Montag, 1976, p. 57). Thus the nursing staff provide for some of the same needs of the child as his parents do at home.

In working with parents who have chronically ill children this investigator has found that these parents have set routines to care for their child's needs at home. They have set up these routines to fit in with their lifestyle. The parents

> . . . have a better knowledge of the disease, its eccentricities, the treatment and implications for daily routine than do the physicians and the allied health professionals with whom they are brought into contact. In short, it is the parents, and not the doctors or nurses, who become experts (Davis, 1975, p. 49).

Since the parents are the experts, they have established priorities of care in their daily routines of care for their child. When the child is hospitalized many of these home routines are set aside. What may be a priority of care for the mother at home may not be a priority of care for the nursing staff in the hospital. How then do parents perceive the nursing care of their children?

Statement of Purpose

The purpose of this study is to (1) obtain information about how parents of chronically ill children who are not near death and are hospitalized in a university health sciences center define nursing care and perceive the nursing care of their children; and (2) obtain information about the kinds of nursing care parents think are needed but are not being provided.

Definition of Terms

The following definitions are used in this study:

1. Parent is a blood mother or father, stepmother or stepfather, or foster mother or foster father, or a guardian appointed by a court of law.
2. Chronic illness is a disease with a prolonged course which is usually progressive and terminal. The disease has frequent exacerbations which require medical attention (Travis, 1976, p. 5).
3. Nursing care is the care given by the nursing staff in a hospital to help the chronically ill child meet his daily needs and become more independent.
4. Kinds of nursing care refers to the provision for meeting the personal, environmental, nutritional, spiritual, social, and emotional needs of the child by the nursing staff.

5. Hospitalized refers to a child who has been an in-patient on a hospital unit for forty-eight hours or more.
6. Selective neglect is the conscious or unconscious dereliction in at least one aspect of role performance to which the role performer attaches low priority (Atwood, 1975, p. 25).
8. Child refers to a person in the age range of 3 years to 12 years.

Theoretical Framework

Chronically ill children have parents who have formed role expectations of the nursing staff from the care their child has received previously in the hospital. How parents perceive the specific needs of their child being met in the hospital, may determine how they perceive the nursing care their child is receiving. Do they see that the nursing care provided by the nursing staff is helpful to their child and meeting the needs of their child? Or is there something else that the nursing staff could perform that would be more helpful to their child?

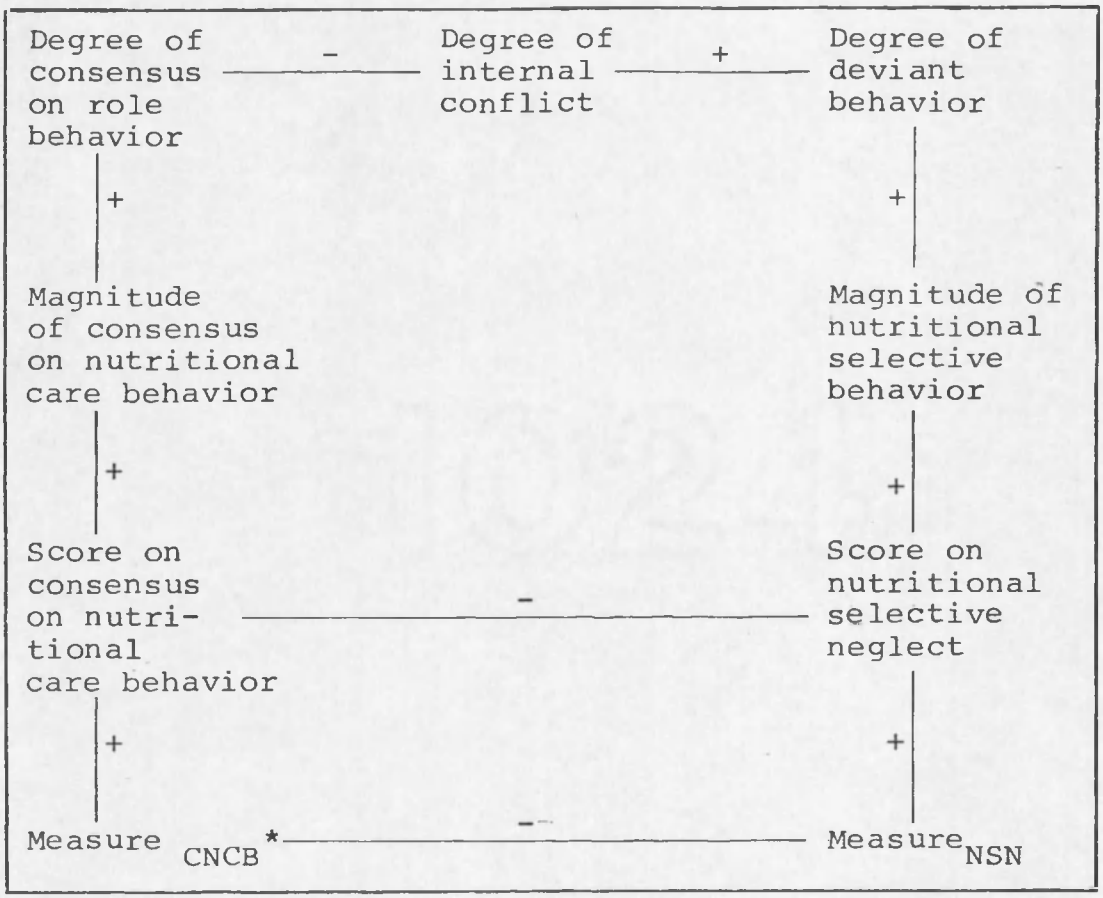
Atwood (1975) conducted a study on the perimortality care of oncology patients and their families. She obtained information on what aspects of nursing care were helpful and unhelpful to the oncology patient and his/her family around the time of death. Information was also obtained on what

other nursing care patients and families felt they needed but were not receiving.

In her study Atwood used a grounded theory methodology and generated the Hypothesis of Selective Neglect. "Selective neglect pertains to the failure to carry out an aspect of a role because it has much lower priority than other aspects" (Atwood, 1975, p. 28). Three categories of selective neglect emerged out of her study. These were environmental, person-centered, and nutritional selective neglect (Atwood, 1975, p. 30).

The model (Figure 1) for the Hypothesis of Selective Neglect is based on Gibb's Theory Paradigm (Atwood, 1975, p. 23). Atwood induced the substantive Selective Neglect model using the structure of the paradigm. The definitions of the constructs, axioms, concepts, postulates, and referentials are the following (Atwood, 1975, pp. 24, 25; 1978, p. 196). The constructs are:

> Role consensus--The degree to which role expectation and role performance coincide (Atwood, 1975, p. 24).
>
> Internal conflict--is a process which occurs cognitively within the individual. The process consists of consciously or unconsciously dealing with alternative, incompatable demands. The healthy organism attempts to resolve the inconsistency in order to survive or cope (Atwood, 1978, p. 196).
>
> Deviant behavior--The degree of behavioral response of another to the perceived selective behavior of an actor (Atwood, 1978, p. 196).



*CNCB = f(role expectation, role performance)

Figure 1. Theory Model for the Hypothesis of Selective Neglect According to Gibbs' Paradigm -- Revised theory model presented during the discussion of papers at the WICHE Communicating Nursing Research Conference 1977 (Atwood, 1977).

The axioms linking the constructs are:

> "The degree to which role expectation and role conception (role consensus) differ determine the amount of conflict (Atwood, 1978, p. 196).

The degree of internal conflict within the individual determines the amount of behavior that is demonstrated. Consistent with the paradigm, the concepts in the model, which are not united to each other are:

> Consensus on role specific care behavior--The degree to which the role-specific care effort made by the nursing team as perceived by a family member, conforms to the role-specific care expectations held by a family member. Three types of role-specific care behavior are nutritional, environmental, and person-centered.
>
> Role-specific selective neglect--The degree of behavioral response by a family member to the perceived omission and/or commission of role-specific behaviors by the nursing team. Three types of selective neglect are nutritional, environmental, and person-centered (Atwood, 1975, p. 25).

The postulates linking the constructs to the concepts are:

> The greater the degree of consensus on role behavior, the greater the magnitude of consensus on role-specific care behavior, three types of which are nutritional, environmental, and person-centered care behavior.
>
> The greater the degree of deviant behavior, the greater the magnitude of role-specific selective neglect, e.g., nutritional, environmental, and person-centered selective neglect (Atwood, 1975, p. 25).

The referentials given in the model are for Nutritional Selective Neglect. Referentials for Environmental and Person-Centered Selective Neglect are different.

Consensus on nutritional care behavior--A mathematical function (unspecified) of the difference between the family members' scores on the role expectation measure and the perceived role performance measure.

Nutritional selective neglect--The family member's score on the nutritional selective neglect measure (Atwood, 1975, p. 25).

The Hypothesis of Selective Neglect is consistent from role theory. All human beings have roles to perform in their lives and in their jobs. When there is a difference of opinion among individuals about the performance of a role then conflict can occur.

In the hospital environment, the nurse's role is to provide for the many needs of their patients. Thus, they are providing nursing care. When a child is frequently hospitalized, parents bring with them and develop further role expectations of the nursing staff through repeated observations. The nurse also has a conceived role of what she/he should be doing. This conceived role is the nurse's role conception. When there is a difference between what the parent expects (role expectation) and what the nurse provides (role performance) a conflict can develop. This conflict can be developed by the parents believing their child is receiving less-than-expected care, or the parents can be extremely pleased and believe their child is receiving better-than-expected care.

Three categories of Selective Neglect were developed from a study concerning the nursing care of adult

oncology patients around the time of death: Environmental, Nutritional, and Person-Centered. Do these same categories exist in pediatric nursing care when patients are not near death?

Literature Review

The literature provides very little documentation on how parents perceive the care their hospitalized child receives from anyone. Burton (1975) conducted a study in Northern Ireland with families of children with cystic fibrosis. The population included 53 separate families from all social classes, 97 parents and 58 children (Burton, 1975, p. 17). The study included reports on some of the reactions of parents to the medical staff who diagnosed their children as having cystic fibrosis.

The parents became hostile to the medical staff because they felt the children did not receive proper care when their child first became ill.

> Thirty-nine per cent of the mothers blamed their medical advisers for not recognizing the disease right away. Twenty-eight per cent of the mothers added that these experiences had radically altered their attitude to the medical profession, generally for the worse (Burton, 1975, p. 32).

Other parents stated that because of this experience with their physician it made them "More wary of unquestioningly accepting medical advice" (Burton, 1975, p. 33). As a result the parents became more self-confident, they were able to tell the doctors a lot more about the child, and

together they could find out what was wrong with the child. This experience made parents realize that physicians were just people and did not have the answer to all their questons (Burton, 1975, p. 34).

Comments regarding nursing care voiced by the mothers in the Burton study were both positive and negative; "It was great," "They left us alone and we played together," and "The majority of the nurses try to make you feel inferior and dependent on them" (Burton, 1975, p. 107). Burton found that mothers who have children with cystic fibrosis did most of their care because it was a role that was expected of them. Mothers seemed to have a very pronounced sense of responsibility for the care of their children. Fathers were less informed of the disease of their child and took less responsibility for child care (Burton, 1975, pp. 54, 62-63, 85).

Merrow and Johnson (1968) looked at perceptions of the mother's role with her hospitalized child. They interviewed 50 mothers staying with their hospitalized child and 50 registered nurses. They found that, "In most instances the mothers preferred to be responsible for more aspects of their child's care than the pediatric nurses realized (Merrow and Johnson, 1968, p. 156).

Roy (1968) studied the role cues nurses take from mothers to help maintain their mothering role to meet the needs of their hospitalized child. This study was performed

on a 30-bed pediatric unit of a private general hospital. Roy observed 14 brief encounters between mothers and nurses and recorded their interactions. Nurses seemed to help mothers with their mothering role in three ways. First, the nurse focused her attention on the mother's focus of attention. Second, the nurse communicated with the mother concerning the child's general condition, his treatment, or his activities. Finally, the nurse told the mother what she might do for the child (Roy, 1968, p. 20).

In a study by Jackson, Bradham, and Burwell (1978) performed on a 10-bed pediatric unit, thirty-one parents were asked whether they wanted to participate in their child's care. The majority of the parents wanted to participate and without the aid of the nurse. They all wanted to feed their children and the majority wanted to perform other nurturing activities such as bathing, staying during procedures and exams, changing diapers, giving medication, changing bed linen, and recording intake and output (Jackson et al., 1978, pp. 104-106).

Geis (1965) interviewed 26 mothers six weeks to one year after the death of their children, to determine the mothers' perceptions of nursing care given to their dying children. The mothers gave both positive and negative comments about the nurses. Of the former, one pertained to bringing in favorite toys and food, "Maybe the little things meant more to me than to him." Some statements regarding

satisfaction with nursing care were, "I have never seen nurses who were so good," "I just don't know what else they could have done," "The same nurses took care of Debbie. They were the ones who seemed partial to her" (Geis, 1965, pp. 105-107). Some of the negative comments were: "During Peter's 16 prior admissions the nurses were in his room much of the time. During his last admission they stayed away. You would have thought we had smallpox," "I questioned a med nurse. She went out and came back with a different medicine," "I didn't see much of the nurses, for Scott was in isolation" (Geis, 1965, pp. 105-107).

Mikkelson, Waechter, and Crittenden (1978, p. 22) interviewed families who had children with cystic fibrosis, "to learn how families cope with this devastating disease." Regarding nursing care, one parent said, "I know she's not going to get the individualized care she gets at home." Another parent stated, "But that nurse was too busy to remove the thermometer when Margie needed it. Her purpose for being in the hospital is to get rid of that mucous and here she had to stifle it for several minutes" (Mikkelson et al., 1978, p. 25). In this study the parents stated that ". . . hospitalization was a relief from the responsibility and fear of caring for a very sick child at home . . ." (Mikkelson et al., 1978, p. 25).

Hampe (1975) conducted a study which dealt with grieving spouses in a hospital setting. She interviewed 27

spouses before the deaths of their mates and identified eight eight needs of the spouse. The needs are:

1. The need to be with the dying person.
2. The need to be helpful to the dying person.
3. The need for assurance of the comfort of the dying.
4. The need to be informed of the mate's condition.
5. The need to be informed of the impending death.
6. The need for comfort and support of family members.
7. The need for acceptance, support, and comfort from health professionals.
8. The need to ventilate emotions.

These needs may have relevance to parents and their children.

In the studies reviewed, Geis's, Burton's, and Mikkelsen et al.'s were the only ones that quoted actual comments from parents on how they perceived the nursing care of their child. This investigator believes that further investigation is needed in this area of parent expectations and delivery of nursing care.

CHAPTER 2

METHODOLOGY

In this chapter, discussion centers on the design, setting, theoretical sampling and sample, data gathering procedures, and instruments of the study.

The Design

Consistent with the purpose of this study, an exploratory study was performed using the questions Atwood (1975) used in her interview schedule, to find out if the same categories of Selective Neglect emerge in pediatric nursing, in the care of the chronically ill child not near death, as they do in adult oncology nursing around the time of death. The process to obtain this information was a grounded theory approach. In this inductive method there was the simultaneous collection, coding, and analysis of the data collected from a sample of ten parents using the theoretical sampling method.

The emphasis in this study was on the emergent categories and their properties rather than the development of a theory. Categories are defined as "conceptual elements of a theory and can stand alone" (Glaser and Strauss, 1967, p. 36). A property is defined as a "conceptual aspect or element of a category" (Glaser and Strauss, 1967, p. 36).

It should be remembered that categories and properties are concepts indicated by the data. Once a category or property has been discovered, it is not discarded unless a better category is discovered. From the data that were collected, the investigator generated categories and their properties. The categories generated in this study will be compared to Atwood's categories and Hampe's eight needs of the grieving spouse.

The Setting

This study was conducted in the pediatric unit of a university health sciences center in a southwestern city. Acutely and chronically ill children ages three years through adolescence are treated on the unit. English-speaking parents of the latter form the population for this study. The patients on this unit come from the county in which the health sciences center is located plus small rural communities in the state and from the country of Mexico.

Theoretical Sampling and Sample

The data were collected through an approach consistent with the grounded method called theoretical sampling.

> Theoretical sampling is the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes his data and decides what data to collect next and where to find them in order to develop his theory as it emerges (Glaser and Strauss, 1967, p. 45).

In contrast to statistical sampling it is performed to

discover categories, their properties, and interrelationships rather than to document distributions among categories (Glaser and Strauss, 1967, p. 62). Once the discovery of a category or property is made, it makes no difference how many times the category reappears in the data. The aim of the investigator is the inclusiveness of the categories.

In theoretical sampling the investigator must decide when to stop collecting data. The process is fulfilled when theoretical saturation has taken place. "Saturation means no additional data are being found" (Glaser and Strauss, 1967, p. 61). In this study no new information was obtained in the tenth interview and the investigator believed saturation was reached. Data collection ceased with this interview.

Sample

The data for this study were obtained from parents of chronically ill children as the children were admitted to the pediatric unit. Parents of the children with the following chronic illnesses were eligible to be included in the study: (1) asthma, (2) celiac disease, (3) cerebral palsy, (4) congenital heart problems, (5) cystic fibrosis, (6) hemophilia, (7) Hodgkins disease, (8) hypertension, (9) juvenile rheumatoid arthritis, (10) juvenile diabetes melitus, (11) leukemia, (12) malignant tumors of all kinds,

(13) nephrotic syndrome, (14) neuro-muscular disorders, (15) seizure disorders. The above disease processes were chosen because all are long-term illnesses that have frequent exacerbations and remissions. Children having them are hospitalized more than once, usually during periods of exacerbation.

The investigator obtained the names and diagnoses from the charts and the nursing kardex on the unit. She then explained the purpose of the study to the parents. If they wished to participate in the study they were asked to read and sign the consent form (Appendix A). A time was then arranged for the interview to be held in a private office away from the pediatric unit.

The interviews were recorded on tape so the investigator could go over the data and code it at a later date. If the data had been collected only by note taking during the interview the researcher would have risked missing important information. After recording the interviews the interviews were transcribed and the tapes erased. The interviews were then coded and analyzed.

Human Subject Considerations

This study was conducted with the knowledge and approval of the Medical and Nursing Directors of the pediatric unit and the Ethical Review Committee of the University. Protection of human subjects was accomplished

orally and as indicated in the human subject consent form (Appendix A).

Data Gathering Procedures and Instruments

Identifying Data

Identifying data were obtained from the chart and/or the parents concerning the child (Appendix B). The identifying number is a number generated by the investigator to identify the parents of the chronically ill child and to maintain the anonymity of the parents. The date of birth and diagnosis of the child were obtained to determine that the child was in the eligible age range and had an eligible chronic illness. Duration of diagnosis was obtained to assess if this was a new diagnosis, making the child ineligible. Information on whether this was the first hospitalization provided inclusion of only children who had been previously hospitalized. Parent interviewed was designated male or female to help the investigator remember the gender of the parent.

Interview Instrument

An open-ended questionnaire was used in a semi-structured private interview. The questionnaire is composed of questions Atwood (1975) used in her study (Appendix C). The questions were intended to elicit information from the

parents regarding the nursing care their child was receiving in the hospital.

The investigator wished to establish face and content validity of the questionnaires to be used. The investigator believes that the tool used has face validity. Face validity is "based upon an examination of the nature of the instrument. The instrument measures what it looks like it's measuring" (Fox, 1970, p. 245). Nursing care of chronically ill children as perceived by their parents is the focus of this study. The content of the tool used focused on the nursing care of these children.

"Content validity refers to the extent to which the instrument samples the types of factors or situations under study. The content of the instrument must be closely related to that which is to be measured" (Treece and Treece, 1973, p. 183). A panel of eight nurses with clinical and research background judged that the Atwood questionnaire had content validity for the domain: nursing care of the terminally ill patient. For the purpose of this study a second panel of nurses with specialties in research, pediatric, and community-health nursing unanimously judged the content of the questionnaire to be an adequate sampling of the domain: nursing care of chronically ill children.

CHAPTER 3

PRESENTATION OF DATA AND DISCUSSION

This chapter includes characteristics of sample, the interviews, definitions of nursing care, nursing care needed, the categories and their development, and the comparison of categories.

Characteristics of Sample

The theoretical sample of the convenience type consisted of ten mothers from all classes of society who had chronically ill children in the age range of three years through twelve years. Two fathers who were present at the explanation of the study did not wish to be interviewed. The ten mothers were very willing to talk with the investigator about nursing care. Two other mothers approached refused. One mother was packing and getting her child ready to take home and had a tight schedule. The second mother was too upset about what a physician had told her concerning her child and was not emotionally ready to participate in a research study.

The investigator interviewed each mother after their child had been hospitalized for forty-eight hours on this admission. Appendix D contains the identifying number, age, diagnosis, duration, and times hospitalized of the sample.

As the appendix indicates the ten mothers had children with a total of twelve different diagnoses and three of the children had two diagnoses. The age range of the children was seven years to twelve years and ten months with a mean age of ten years and nine months. The average mean duration of illness was seven years and eight months indicating that the children had the disease process more than half their lifespan. Although some of the children had been hospitalized two to four times, over half of them had been hospitalized numerous times (greater than five).

Interviews

The semi-structured private interviews were conducted by this investigator. Although a private office had been arranged, seven of the ten interviews were conducted at the bedside at the request of the mothers because they did not wish to leave their children for various reasons. The child was the only other person in the room with the exception of one instance in which a patient who was an infant of three months was also present. One interview was replicated due to a mechanical problem with the tape recorder during the initial interview.

All interviews were conducted on the 7-3 and 3-11 shifts. The nursing staff on the unit had been informed that the investigator was conducting a study on how parents define nursing care. If the nursing staff entered the room

during the interview, the investigator would stop and continue after the staff left. This posed no problem with the nursing staff.

Definitions of Nursing Care

The first question in the interview was how parents defined nursing care. Four of the mothers had some difficulty with the question. They said they did not know how to answer it and pondered for a few moments. Some of the definitions are long and thought out and others are short and to the point. Table 1 presents the definitions. The investigator believed this question would set the mood for the rest of the interview by stimulating the parents to think about care performed by nursing staff rather than care provided by other health care providers.

Nursing Care Needed

In addition to identifying data, definitions of nursing care and categories of nursing care information were obtained from the parents about what aspects of nursing care they would have wanted for their child that was not being provided. Half of the mothers responded to the question by saying everything was done for their child that was necessary. However, five mothers shared some comments with the investigator. Table 2 contains comments from the mothers about care they would have wanted for their child while he/she was hospitalized.

Table 1. Definitions of Nursing Care

Identifying Number	Definition
01	"I think nursing care has to be meeting the physical needs of the child and of course it has to meet their medical needs at that time, but also the child's emotional needs and especially when it's a child, I think it involves more needs of the family as well."
02	"Nursing care is taking care of their patients, getting involved, doing their job."
03	"Nursing care is the best medical care my child can get. I expect tops from the nurses. They are very honest, answer questions, are relaxed."
04	"I think nursing care is the nurses coming in to help (my child) mainly with his vital statistics, also helping me take him to the bathroom because he is not able to go."
05	"Good nursing care takes an intuitive and a person that can read people well, that will respond to their needs as is needed. They are of great importance because they are the recording of what is happening, because the doctor sees them for a few minutes and it's important that they record even details that might be important in management of certain drugs."
06	"Nursing care is making sure that she has the medicines at the time the doctor says, putting the fluids into her, making sure her output is okay."
07	"It's someone looking after you, his health needs whatever it happens to be at the time. His health is important, whatever needs to be done by someone that knows what they're doing."
08	"Nursing care is the administration of medicine, the care and attention (my child) receives from the nursing staff."

Table 1.--Continued

Identifying Number	Definition
09	"Nursing care is to where he has to have special attention and special care for the problems that she had. They have to know what they are doing."
10	"They help me with things."

Table 2. Nursing Care Needed

1.	The showers in the children's rooms should have bath mats so children will not slip and fall.
2.	The windows which can be opened from the inside should have bars on them.
3.	Children should have a roommate approximately the same age.
4.	There should be a list of suggestions for parents about the use of the television and type of language used by parents.
5.	Older children should be interviewed regarding their likes, dislikes, and concerns.
6.	The playroom needs books and games for older children.
7.	There should be a list of nursing staff who are proficient in starting IV's.

Environment was identified as an important factor in statements one and two. Safety factors in the physical surroundings of the child were identified as problem areas. Parents voiced the need for bath mats when showers are taken to avoid falling and the need for bars on the windows so children would not fall out or throw their toys out, because some of the windows can be opened from the inside. This investigator later learned that certain windows had to open part way according to fire regulations. This needs to be communicated to parents in the future.

Emotional factors are considered important by parents in statements three, four, and five. Parents indicated that they want their child to have roommates that are approximately their child's age. Children in the same age range sharing a room may help make the hospitalization less traumatizing, new friendships can be developed, and support and comfort can be given to each other.

One mother had a bad experience with the parents of her child's roommate. There was disagreement over which television programs to watch and the roommate's mother did not use appropriate language at all times. Because the roommate's stay was only two days the mother did not wish to have her daughter moved. However, she thought parents should be careful of the language they use in the hospital.

Individualized care was identified by a parent in asking that children should be interviewed concerning their

likes, dislikes, and anxieties. Nursing histories are obtained from children or their parents by the nursing staff on the unit.

Play was identified as an important factor in hospitalization. One mother felt there were not enough books and games for older children in the playroom. She believed that those present were inadequate. This point was brought to the attention of the clinical nurse coordinator and the playlady.

Competency was identified as being what parents wanted in their child's care. Most chronically ill children need intravenous fluids when hospitalized. Veins that have been used numerous times become scarred and collapse, so when IV's are required it is a difficult procedure for the nurse to perform. Nurses who have great skill in starting IV's may have difficulty in performing the procedure. The procedure then becomes a source of trauma for the child. Informing parents and child that the nurse performing the procedure does have expertise in starting IV's may help to eliminate some of the anxiety of the situation.

Categories

Initial Analysis

Consistent with the grounded theory methodology, as each interview was obtained the investigator coded and analyzed the data to identify the categories and their

properties. The categories that emerged were Right to Know, Environmental, Competency, Attitude/Approach, Nutritional, Person-Centered, and Parental Involvement. Table 3 presents the categories, definitions, and properties which resulted from the initial analysis.

Reliability of Categories

Interrater reliability of the categories and their properties was estimated by a panel of experts. The panel consisted of three doctoral students who were research oriented but whose areas of expertise were not pediatric nursing but community, maternal-child, and psychiatric nursing. After the investigator had coded and analyzed the data, by random assignment each of the three experts was given one-third of the data.

The panel was asked if they would code the data in a similar manner as this investigator; i.e., whether or not they would use the same information to form similar groupings (categories and properties). They were asked to identify information in the transcriptions they thought was codable. Table 4 presents the per cent of agreement of codable information in the transcriptions by number, total agreement, and expert. It was expected that the investigator and the panel would have a 70% agreement on coding the data. The total agreement of codable information was 72% and the mean 69%. The mean for the experts was 70%.

Table 3. Categories, Definitions, and Properties of Initial Analysis

Categories	Definitions	Properties
1. Right to Know	Right to know pertains to open and honest communication between all members of the health team, parents, and child with regards to (1) the status and/or condition of the child, (2) explanation of tasks and/or procedures being performed, and (3) patient education of the disease process plus medication and procedures that may be needed at home.	1. Explanations 2. Communication
2. Environment	Environment pertains to those aspects of care which encompass the (1) atmosphere of the pediatric unit and hospital, (2) the immediate physical surroundings of the child wherever he may be on hospital property, and (3) persons with whom the child comes in contact with except for hospital personnel.	1. Atmosphere 2. Physical surroundings 3. Persons
3. Nutritional	Nutrition pertains to those aspects of care involving food served to the hospitalized child.	1. Food preparation 2. Palatability 3. Food preference 4. Serving size 5. Dietitian 6. Food selection

Table 3.--Continued Categories, Definitions, and Properties of Initial Analysis

Categories	Definitions	Properties
4. Attitude-Approach	Attitude-Approach pertains to the emotional feeling between the child, parent, and nursing staff.	1. Compassionate 2. Friendly 3. Trustful 4. Great 5. Mothering 6. Spoiling 7. Not mean 8. Gentle 9. Regimentated 10. Rushed 11. Sweet 12. Respectful of patient and relatives
5. Person-Centered	Person-Centered pertains to how parents view certain aspects of care.	1. Individualized 2. Staffing 3. Efficient use of time 4. Continuity of care 5. Advocate 6. Traumatic 7. Rest
6. Competency	Competency pertains to how parents perceive the expertise of the nursing staff performing any task, duty, or procedure.	1. Skill of personnel 2. Responsiveness to needs

Table 3.--Continued Categories, Definitions, and Properties of Initial Analysis

Categories	Definitions	Properties
7. Parent Involvement	Parent Involvement pertains to those aspects of care (1) provided by the parents to their child, and (2) the expertise of the parents regarding knowledge of the condition and child's care.	1. Care 2. Expertise and credibility of parents

Table 4. Per Cent of Agreement of Codable Data

Identifying Number	% of Agreement	Mean of Case Per Cent Agreement
01	31[a]/50[b] = 62%	69%
02	12/25 = 48%	
03	27/31 = 87%	
04	21/28 = 75%	
05	15/41 = 39%	
06	22/33 = 66%	
07	13/17 = 76%	
08	30/43 = 70%	
09	63/76 = 83%	
10	81/96 = 84%	
Total Agreement	316/440 = 72%	

[a]Number of pieces of codable information identified by experts.

[b]Number of pieces of codable information identified by investigator.

Experts	Identifying Number	% of Agreement	Mean
A	01, 02, 05	59[a]/116[b] = 51%	70%
B	03, 04, 09	111/135 = 82%	
C	06, 07, 08, 10	146/189 = 77%	

The experts were also asked to indicate whether or not they agreed that the data belonged in each of the properties of the categories coded by the investigator. Table 5 presents the interrater per cent of agreement of data contained in properties coded by the investigator. The mean per cent of agreement of the properties of the categories all met the 70% criteria: Person-Centered 90.7%, Parental Involvement 90%, Nutritional 92.8%, Attitude-Approach 88.6%, Environment 86.6%, Right to Know 90%, and Competency 81%. The overall mean is 88.5%.

Validity of Constructs

"Construct validity is the interplay between theory and the measurement of the constructs that make up the theory. A construct is a hypothelical definition that is used in a theory" (Treece and Treece, 1973, p. 184). Construct validity was estimated by the same panel and a 70% agreement was expected between the experts and the investigator.

The data given the experts consisted of the data as coded by the investigator in groups as shown in Table 5 but without labels. They were asked to label the properties and the categories. Table 6 presents the per cent of agreement of the category labels (constructs). All categories met the 70% criterion except the Person-Centered with zero agreement on the category label. The Parental

Table 5. Per Cent of Agreement of Data Contained in Properties

Properties	% of Agreement	Mean of Category
I. Person-Centered Category		
1.1 Individualized	$13^a/15^b$ = 86%	90.7%
1.2 Rest	9/9 = 100%	
1.3 Traumatic	5/6 = 83%	
1.4 Efficient use of time	6/6 = 100%	
1.5 Continuity of care	6/6 = 100%	
1.6 Staffing	12/12 = 100%	
1.7 Advocate	4/6 = 66%	
II. Parental Involvement		
2.1 Care	36/42 = 85%	90%
2.2 Expertise	23/24 = 95%	
III. Nutritional		
3.1 Food preparation	23/24 = 95%	92.8%
3.2 Palatability	26/27 = 96%	
3.3 Food preference	20/21 = 95%	
3.4 Food selection	15/21 = 71%	
3.5 Dietitian	9/9 = 100%	
3.6 Serving size	3/3 = 100%	
IV. Attitude-Approach		
4.1 Compassionate	19/21 = 90%	88.6%
4.2 Friendly	25/27 = 92%	
4.3 Trustful	14/18 = 77%	
4.4 Great	5/9 = 55%	
4.5 Mothering	6/6 = 100%	
4.6 Spoiling	6/6 = 100%	
4.7 Respectful of patient and relatives	3/6 = 50%	
4.8 Not mean	3/3 = 100%	
4.9 Gentle	3/3 = 100%	
4.10 Regimentated	12/12 = 100%	
4.11 Rushed	9/9 = 100%	
4.12 Sweet	3/3 = 100%	
V. Environment		
5.1 Atmosphere	34/36 = 94%	86.6%
5.2 Physical surroundings	40/51 = 78%	
5.3 Persons	48/54 = 88%	

Table 5.--Continued Per Cent of Agreement of Data Contained in Properties

Properties	% of Agreement	Mean of Category
VI. Right to Know		
6.1 Explanations	31/36 = 86%	90%
6.2 Communications	37/39 = 95%	
VII. Competency		
7.1 Skillful and/or technical personnel	42/54 = 77%	81%
7.2 Responsiveness to needs	51/60 = 80%	
Overall Mean		88.5%

[a]Number of pieces of data identified by experts agreeing with investigator.

[b]Number of pieces of data identified by investigator.

Table 6. Per Cent of Agreement of Category Labels (Construct Validity)

Category Labels	% of Agreement	Mean
I. Person-Centered	0%	78.6%
II. Parental Involvement	75%	
III. Nutritional	100%	
IV. Attitude-Approach	75%	
V. Environmental	100%	
VI. Right to Know	100%	
VII. Competency	100%	

Involvement category had 75% agreement, the Nutritional category had 100% agreement, the Attitude-Approach category had 75% agreement, and the Environmental, Right to Know, and Competency categories had 100% agreement. The overall mean of the categories is 78.6%.

Table 7 presents the per cent of agreement of the property labels. The Person-Centered property labels had 85% agreement, the Parental Involvement property labels had 75% agreement, the Nutritional property labels had 83% agreement, the Attitude-Approach property labels had 77% agreement, the Environment property labels had 75% agreement, the Right to Know property labels had 75% agreement, and the Competency property labels had 87.5% agreement. By category, all mean per cents of agreement for property labels met the criterion. The overall mean of the property labels is 79.6%. However, four property labels failed to meet the criterion. Under the Person-Centered category the property label "Efficient use of time" had a 50% agreement. Under the Attitude-Approach category the property labels "Great" had 50% agreement, "Respectful of patient and relatives" had zero agreement, and "Regimentated" had 50% agreement.

Final Analysis

After interrater reliability and construct validity had been estimated, refinement of the categories,

Table 7. Per Cent of Agreement of Property Labels (Construct Validity)

Properties	% of Agreement	Mean of Properties
I. Person-Centered Category		
A. Individualized	100%	85%
B. Rest	100%	
C. Traumatic	100%	
D. Efficient use of time	50%	
E. Continuity of care	75%	
F. Staffing	100%	
G. Advocate	75%	
II. Parental Involvement Category		
A. Care	75%	75%
B. Expertise	75%	
III. Nutritional Category		
A. Food preparation	75%	83%
B. Palatability	100%	
C. Food preference	75%	
D. Food selection	75%	
E. Dietitian	75%	
F. Serving size	100%	
IV. Attitude-Approach		
A. Compassionate	75%	77%
B. Friendly	100%	
C. Trustful	100%	
D. Great	50%	
E. Mothering	100%	
F. Spoiling	100%	
G. Respectful of patient and relatives	0%	
H. Not mean	75%	
I. Gentle	100%	
J. Regimentated	50%	
K. Rushed	100%	
L. Sweet	75%	
V. Environmental		
A. Atmosphere	75%	75%
B. Physical surroundings	75%	
C. Persons	75%	

Table 7.--Continued

Properties	% of Agreement	Mean of Properties
VI. Right to Know		
A. Explanations	75%	75%
B. Communications	75%	
VII. Competency		
A. Skillful and/or technical personnel	100%	87.5%
B. Responsiveness to needs	75%	
Mean 79.6%		

definitions, and their properties was accomplished. The investigator met with the panel of experts and discussed the categories. The Person-Centered category had zero per cent agreement and was relabelled Parent Concerns with 100% agreement. In the category Nutrition, the properties food selection and food preference were found to be almost identical and were combined into food preference. In the category Attitude-Approach the property respectful of patient and relatives had zero per cent agreement and was eliminated. In the category Environmental the property persons was relabelled human resources because the investigator was not satisfied with the previous label.

Further refinement was continued by the investigator. In the relabelled category of Parent Concerns, the property efficient use of time was eliminated because it did not meet the criterion. The property continuity of care was eliminated because it referred to other health care providers. In the Nutrition category, the property dietitian was eliminated as it referred to another health care provider. In the Attitude-Approach category, the properties great and regimentated were eliminated because they did not meet the criterion. The properties of the category Right to Know were eliminated as they are inherent in the definition of the category. The definitions of the categories Attitude-Approach and Environment were revised to clarify their meaning. The category Competency now

emerged as being composed of two sub-categories staff and parent competency, each with their own definitions and properties. Parent competency was the category labelled Parent Involvement. Table 8 presents the final categories, sub-categories, their definitions, and properties.

Development of Categories

The categories that emerged in this study were developed from the positive and negative comments of the parents in response to the interview instrument. The following discussion centers on how the categories and sub-categories were developed in keeping with the grounded theory method which includes search of existing literature as analysis occurs.

Category--Right to Know

The consumer movement in the United States has made the public more aware that they have rights. The consumer as a patient also has rights. Professional organizations uphold this concept. The National League for Nursing (1977) published a pamphlet which outlines what they believe are patients' rights and nurses have the responsibility to uphold. In 1974 The Association for the Care of Children in Hospitals published The Pediatric Bill of Rights which has eleven cannons covering a wide range of child's rights from access to competent health care, to information and treatment regarding V. D. and knowing which physician is

Table 8. Categories, Subcategories, Definitions, and Properties

Categories, Subcategories	Definitions	Properties
1. Right to Know	Right to know pertains to open and honest communication between all members of the nursing team, parents, and child with regards to (1) the status and/or condition of the child, (2) explanations of tasks and/or procedures being performed, and (3) patient education of the disease process plus medication and procedures that may be needed at home.	
2. Environment	Environment pertains to the milieu encompassing the hospitalized child.	1. Emotional atmosphere 2. Physical surroundings 3. Human Resources
3. Nutrition	Nutrition pertains to those aspects of care involving food and fluids served to the hospitalized child.	1. Food preparation 2. Palatability 3. Food preference 4. Serving size
4. Attitude-Approach	Attitude-Approach pertains to the characteristics of staff behavior toward the parents and child.	1. Compassionate 2. Friendly 3. Trustful 4. Mothering 5. Spoiling 6. Not mean 7. Gentle 8. Rushed 9. Sweet

Table 8.--Continued

Categories, Subcategories	Definitions	Properties
5. Parent Concerns	Parent Concerns pertains to those aspects of care about which the parents have an uneasy blended state of interest, apprehension, and uncertainty in the care of their child.	1. Individualized 2. Staffing 3. Rest 4. Traumatic 5. Advocate
6. Competency a. Staff	Staff competency pertains to how parents perceive the expertise of the nursing staff performing any task, duty, or procedure.	1. Skill of personnel 2. Responsiveness to needs
b. Parent	Parent competency pertains to those aspects of care that are (1) provided by the parents to their child, and (2) the expertise of the parents regarding knowledge of the condition and child's care.	1. Care 2. Expertise and credibility of parents

responsible for his care ("The Pediatric Bill of Rights," 1974, pp. 21, 22).

Right to know as defined in this study pertains to open and honest communication between all members of the nursing team, parents, and child with regards to (1) the status and/or the condition of the child, (2) explanations of tasks and/or procedures before being performed, and (3) patient education of the disease process plus medications and procedures that may be needed at home. The category was developed from the following comments of parents. "I do like to know when (my child) is taking drugs and I think I have the right to know the side effects, because I think that's important." "They tell her exactly when they are going to stick her, tell her exactly where they're going to wash her or what they are . . . ." "Everytime they take his blood pressure or temperature they never say. I've been quite concerned since you know, he had high blood pressure, so I am concerned about the numbers and they never say unless I ask them, but you know, they never volunteer to say, ..."

Category--Environment

The environment of the pediatric unit and the hospital emerged as an important aspect of care. Environment in this study pertains to the milieu encompassing the hospitalized child. The properties of this category include

emotional atmosphere, physical surroundings, and human resources. Some examples regarding the properties atmosphere and human resources are as one mother stated, "I think it's free, which is neat, because we can come anytime and like his relatives, his uncles and aunts have been able to come without, you know, being told you have to leave, no more than two persons in the room, which I think is really great." Another comment about the atmosphere is ". . . here its very cheerful, you have a nice playroom, and really this hospital is making the child, you know, pediatric corner, really nice and colorful." Comments regarding the immediate physical surrounding are: "She never wanted to go to the playroom, I guess she didn't feel like playing, but after she started getting better, that's all she wanted to do." "They take her to the cafeteria and things like that." And, ". . . he can go outside, you know, and of course at most hospitals when they are doing tests, they just don't let you go outside, and he can walk around the hospital." A comment regarding human resources is, "They admitted one little girl in here and it really upset my little girl and the other little girl was upset, and so I walked out to tell them and before I got my mouth open they said, "We're making arrangements" and it was taken care of. Just like that."

The playroom was referred to several times in the interviews and this is an important point. Play for the

child is his work. Through play the child learns, expresses fears, anxieties, and conflicts. Whether the child is ill or not he needs play to face the stressful situations of the hospital, everyday life, his illness, and it gives him the opportunity to reorganize his life (Petrillo and Sanger, 1972, p. 99). A hospital environment that is cheerful and colorful is important because it adds to the concept of play. Drab colors and poor lighting are not inducive to play (Steele, 1971, p. 57). Being able to move around the hospital and go outside are important factors that the parents identified. This is because fresh air, sunshine, and freedom of movement are hard to replicate in other ways (Steele, 1971, p. 67). Having family members around to visit provides support to the child and the child does not feel alone or deserted. Hampe (1975) in her study identified this as a need--the need for support and comfort of family members.

Category--Nutrition

Food is closely interwoven with the family, religious, ethnic, and social customs. "It provides satisfaction from stress" (Thompson, 1971, p. 197). Often ill children have decreased appetites and when hospitalized they may be put on therapeutic diets containing foods they are not accustomed to eating. Also drugs the child may receive may affect his appetite or cause side effects that

affect the appetite. Since food is linked with many customs and can be affected by many variables it is not surprising that a category of nutrition emerged.

Nutrition as defined in this study pertains to those aspects of care involving the foods and fluids served to the hospitalized child. This category has four properties. Comments regarding the property food preference are: ". . . now they can write out, you know, fill out their menus . . . ." "They want her to try new foods." "I did bring her food in--I brought her a hamburger and she did eat everything that I brought in, but the food here at the hospital, she didn't touch." "They have the same food every morning for breakfast . . . ." Examples of the property palatability of food are: "The hamburgers are tasteless and the green beans are waxy . . . ." "I've tasted some of it and found the vegetables and most of the meat very good." A child's comments regarding the food, "I don't like the food, it tastes lousy. I don't . . . they're too slow . . . the tray sits out there for a half hour and it gets cold." Food preparation was another property discussed. "The food he received? He didn't particularly like it. I think it's because his being from a Mexican-American family, you know, my food is a lot spicier than their's is . . . ." In the discussion of food the investigator asked the question "Do they serve the kind of food she's used to eating at home?" The reply from one mother was, "No, the name of the

food yes, but not the kind of preparation. I don't cook it that way--I don't fix it that way . . . ." Serving size of the food was commented on because one of the children received very small servings, "He got a small breakfast the other morning . . . ."

Category--Attitude-Approach

Attitude-Approach in this study pertains to the characteristics of staff behavior toward the child and the parents. This category has many properties and a few of them will be commented on. Examples of the property compassionate are: ". . . I think one can pick out nurses who you feel really want to sit down and listen, and are really concerned for that child . . . ." "He feels like people care whether he is happy or he's not." Statements in relation to the property friendly are: "I like all of them and they are really friendly to me, and maybe towards others . . . ." "Even these student nurses are nice." "Some of them is friendly, some is very nice and others it seems like its just hi and bye and well I don't have the time . . . ." The property trustful was developed from statements such as the following: "I feel very comfortable leaving at night, I know she's alright and I know that I would be notified at any time and I can call in during the night at anytime."

Category--Parent Concerns

The category parent concerns in this study pertains to those aspects of care that the parents have an uneasy blended state of interest, apprehension, and uncertainty in the care of their child. This category has several properties and the investigator considers staffing as one of the more interesting ones.

It is interesting how parents know when a pediatric unit is full and there is a shortage of nursing staff. Hospital units are not staffed for 100% occupancy, but usually for 70-85% occupancy. When occupancy goes over these figures help is needed and usually obtained from in-hospital resources or resources outside of the hospital. Sometimes extra nursing help is not possible and staff must do their best with what staff they have. Comments on staffing are: "There is only one thing, I think about nurses, I think the morning ones are too busy or may be they're not enough on the shift . . . ." "I don't know how many nurses there are by shift, but I got a feeling that it is something that has to be changed. I think they should put more in the morning . . . ." "The nursing system could be a little better. . . . if all the rooms are not full . . . two nurses, three nurses would be fine, but, when the rooms are full two or three nurses can't take care of them. They're running continually . . . ." At the time of these interviews the pediatric unit had 100% occupancy.

Individualized care brings out the fact that children have likes and dislikes and these need to be made known to the health team through a nursing history. Examples are: ". . . but I don't know whether he was interviewed, you know, by a nurse and asked you know, what things he likes to do, or what he needs to do while he is in . . . ." "They're just little things that really are not important . . . but I've watched and I've seen which ones are successful in getting him to cooperate during a treatment." The property of rest refers to a hospitalized child obtaining rest. "I'm finding that (my child's) biggest complaint is that he does not get enough rest and sleep. The treatments run rather late in the night and begin early in the morning and then with the other disturbances that come during that time he is not resting well." The property advocate is that parents not only are concerned about their own children but other hospitalized children as well. Examples are: "I not only feel that about her but I would any other child." "I'm afraid that (my child) or any other child will slip and fall . . . ." The property traumatic refers to the trauma of the child while he is hospitalized. The comment "But if they (nurses) make me go away then its traumatic for everyone including the nurses" expresses this point.

Category--Competency

This category is composed of two subcategories staff competency and parent competency. Staff competency as defined in this study refers to how parents perceive the expertise of the nursing staff performing any task, duty, or procedure. Its properties include skillful personnel and responsiveness to needs. The following statements from parents are examples of how the category was developed. One mother spoke of intravenous therapy, "He had two . . . the people most skillful should be doing it so that it should not be a thing where next time hospitalization becomes necessary that the child dreads going because of this trauma." Another parent had this to say about male nurses, "Even the male nurses are nice and they do a good job." Another positive comment is ". . . they gave medication to her to relieve the pain but they help her to be comfortable, to be turned on her right and left sides . . . ." Responsiveness to needs was identified in the following ways: "Every time I rang the buzzer they came in as fast as they could . . . ." "Some of the time she'd ring the bell, like it was all of twenty minutes and nobody answered . . . ." "Well, as far as her medication, my gosh, they're always very punctual and ah, with her baths and everything, that its just great to know that if I don't come in by eight o'clock that she will be bathed, even if I'm not here."

Parent competency in this study pertains to those aspects of care (1) provided by the parents to their child and (2) the expertise the parents have regarding knowledge of the condition of the child and his care. The properties of this category are care and expertise and credibility of the parents. Examples of this category are the following: "I gave (my child) her bath ever since she's been here." "There's only one thing, the kind of tape they use kind of breaks some of these kids out. . . . You can take a look at her neck there and I've been having a terrible time, it was a lot worse than that. And, I've been bathing her in warm water and lotioning her down, trying to get that cleared up." "I was afraid to touch her and by watching them, they really don't teach you, but just watching them do it . . . and now with (my child's) help we can do it." "There's things that are going to have to be done. Techniques, when they draw blood, he wants me here. He does not have to be held down. He'll hold his arm steady by himself but he wants me to hold the hand they're not working on." "The neonatologist taught me to gavage and just terribly intricate things you know, that most parents don't know . . . ."

In recent years the nursing literature (Aufhauser, 1967; Jackson and Bradham, 1978; Tetrick, 1978) has reported on studies that have shown parents wish to participate in the care of their children. Through this participation

there is a family support system for the child while he is hospitalized. In 1978 Senator Edward Kennedy, who has a son with cancer, in his address to the Association for the Care of Children in Hospitals noted that, "By assuring that parents participate in the care of their child--both in the hospital and after discharge--not only will the unnecessary psychological pain of illness be reduced but the direct costs of the actual medical care may also significantly be reduced as well" (Kennedy, 1978, p. 4). This is an important point to bring out with the escalating costs of hospital care today. However, when listening to the parents during the interviews, this investigator received the impression that parents want to participate but they also want the option of not participating as well. Parents need a break sometimes from the care they provide to their child for their own well-being and rest.

Comparison of Categories

Atwood's Study

Atwood (1975) in her grounded theory study of the perimortality care of oncology patients and their families generated the Hypothesis of Selective Neglect. Three categories of Selective Neglect emerged, Nutritional, Environmental, and Person-Centered. The definitions of the three categories are underdeveloped as emphasis was placed on generation of the hypothesis (Atwood, 1975, 1977).

However, definitions of the three categories can be considered to be: Nutritional Selective Neglect refers to those aspects of care involving feeding the patient. Environmental Selective Neglect refers to those aspects of care in the environment of the patient. Person-Centered Selective Neglect refers to those aspects of care involving individualized nursing care of the patient (Atwood, 1977, p. 347). See Table 9 for a comparison of Rath's and Atwood's Emergent elements.

The category of Nutrition in this current study is defined as those aspects of care involving food and fluids served to the hospitalized child. Atwood's category of Nutritional Selective Neglect is similar in that it is concerned with foods and fluids. In addition, data appear to contain two of the four properties identified in the current study, those of food preference and palatability. Even though her reports do not include analysis of properties, such labels from the current study are found in parentheses. Atwood derived her category of Nutritional Selective Neglect from data such as the following: "Cafeteria food is tasteless" and "The food is very, very good" (Atwood, 1975, p. 39) (palatability). "I wondered what she should have to eat. We've filled out the food charts. I've ordered things like milk, jello and custard. I only saw a tray once. . . . I was there from 10 a.m. to 3 p.m. today. No tray came in there. I gave her sips of water"

Table 9. Comparison of Rath's and Atwood's Emergent Elements

Rath		Atwood	
Categories	Properties	Categories	Content of Data
1. Environment	a. Emotional atmosphere b. Physical surroundings c. Human resources	1. Environmental	a. Data presented includes variables in the immediate environment of the patient.
2. Nutrition	a. Food preparation b. Palatibility c. Food preference d. Serving size	2. Nutritional	a. Data presented concerns feeding the patient.
3. Attitude-Approach	a. Compassionate b. Friendly c. Trustful d. Mothering e. Spoiling f. Gentle g. Rushed h. Sweet i. Not mean	3. Person-Centered	a. Data presented concerns behaviors of staff toward patients.
4. Right to Know			
5. Parent Concerns	a. Individualized b. Staffing c. Rest d. Traumatic e. Advocate		

Table 9.--Continued

Rath		Atwood	
Categories	Properties	Categories	Content of Data
6. Competency			
a. Staff	a. Skill of personnel b. Responsiveness to needs		
b. Parent	a. Care b. Expertise and credibility of parents		

(Atwood, 1975, p. 29) (food preference). "This time they didn't check on her. They just brought the tray in and set it. It seemed none of the nurses came in and checked if she wanted anything. I eventually asked her if she wanted us to feed her" (Atwood, 1975, p. 28). "Here the care and the food are the best! When I have my tray, they look at it to see if I've eaten anything. They ask me if I want anything else. If I do, they send right down to the cafeteria and get it for me. That's unheard of!" (Atwood, 1975, p. 30) (food preference).

The category Environment in this study is defined as the milieu encompassing the hospitalized child. Atwood's category of Environmental Selective Neglect is similar in that it is concerned with variables in the environment of the hospitalized patient. The properties of the category Environment in the present study are emotional atmosphere, physical surroundings and human resources. Atwood's data appear to contain all of these properties also. Her category was derived from data as the following: "There is too much noise. The TV's are on too much all over. There should be a specific hour to cut off TV. Period. There is a lot of noise in general. Buzzers buzzing, telephones ringing. A lot of noise from a lot of sources" (Atwood, 1975, p. 31) (atmosphere). "I've never seen a more thorough clean-up. They've gotten under the bed, each iron piece, both sides of the mattress. They must have pride

in their work" (Atwood, 1975, p. 39) (physical surroundings). "Even if more staff spoke Spanish, I would still stay because it keeps Dad happy" (Atwood, 1975, p. 40). "Whenever they have to tell her something, they tell me and I tell her. They let me stay. My mother is very afraid. And I am afraid, too" (Atwood, 1975, p. 40 (human resources).

There is no category in the present study that is labelled Person-Centered. However, in examining the data Atwood lists under the Person-Centered Category, the data fit three of the nine properties of the category Attitude-Approach of this study, i.e., friendly, gentle, and compassionate. Attitude-Approach is defined as the characteristics of staff behavior toward parents and child. Examples of Atwood's data are: "They're all pleasant--It's very noticeable. Wonderful." "The nurses were not rough." "The nurses showed friendliness--an interest in him" (gentle, friendly). "It's compassion that makes such difference. Compassion is inborn, you know." "They go in and ask how she is. 'Would you like to make your bed now?' or 'Would you like to take your shower?' In (place) they tell you. If the nurses weren't like they are, she wouldn't have stayed one day. She's afraid. The nurses are concerned. They ask how you are" (Atwood, 1975, pp. 32-33) (compassionate).

Summary

From the above discussion it appears that the Nutritional and Environmental categories of the two studies are very similar. Similar data were used to form the categories. In addition, the Person-Centered category of Atwood and the Attitude-Approach category of this study appear to be similar in content but not in label. The data used to form the Attitude-Approach category concern the behavior characteristics of the nursing staff, and the properties on the Attitude-Approach category are labels of the behaviors. Data used to form the Person-Centered category of Atwood reflect similar behavior characteristics of staff toward patients.

Hampe's Study

The categories that emerged in this study coincide with information obtained in another study that had been conducted with spouses of dying patients. Hampe (1975) used content analysis from semi-structured interviews and identified eight needs of spouses of dying patients. The Hampe needs of significant others (p. 15) were compared post hoc to the categories of the current study to assess the generalizability of the emergent categories, regardless of the patient's disease status. Seven of the Hampe needs are identified in the categories of this study. The need that was not identified was the need to be informed of the

impending death. Since none of these children were near death, one would not expect this need to appear. First, the need to be with the dying person (child) was identified in the human resources property of the Environment category. Parents stayed with their children in the hospital for various reasons. One parent said, ". . . if the parent can stay with them in the hospital it's much better to the point he will feel at ease." Second, the need to be helpful to the dying person (child) is identified in this study in the subcategory parent competency, parents giving care to their child. An example from parents is, ". . . I'd already given her her shower, and we had taken a walk." Third, the need for assurance of the comfort of the dying person (child) is identified in the responsiveness to needs property in the subcategory staff competency. An example from parents is, "Every time I rang the buzzer they came in as fast as they could . . . ." Fourth, the need to be informed of the mate's (child) condition is identified in the category Right to Know. For example, ". . . in fact, the doctor never told us that he ordered an EKG or ECHO and the reason we found out is he (male nurse) came in and told us . . . ." Fifth, the need for comfort and support of family members is identified in the human resources property of the Environment category. Comments supporting this conclusion include, "I've been here all the time, twenty-four hours a day" and ". . . his relatives, his uncles and aunts have

been able to come without, you know, being told you have to leave . . . which I think is really great." Sixth, the need for acceptance, support and comfort from health professionals is identified in the category Attitude-Approach. Examples are, ". . . they (nurses) have been able to be my friends and not take offense at my knowledge," and "I need to be aware of their feelings as much as they need to be aware of mine." The last need, the need to ventilate emotions was identified by the investigator. After the interviews several of the mothers vented their emotions to the investigator. They were willing to talk about nursing care and about other problems such as family and financial problems with which they were trying to cope. These conversations took place after formal termination of the interview. The tape recorder was shut off and the parents initiated the conversation which lasted up to forty-five minutes in one instance.

Limitations of the Study

The findings of this study are limited for the following reasons:

1. This study was conducted on one pediatric unit of a university health sciences center. If more than one unit or different hospitals had been used other categories may have emerged.

2. Parents of chronically ill children in the age range of three years through twelve years were interviewed. An older or younger age group may have generated other categories.
3. Only parents who spoke English were interviewed, as the investigator spoke only English. If parents who spoke other languages were interviewed other categories may have emerged.

CHAPTER 4

SUMMARY AND RECOMMENDATIONS

The purpose of this study was (1) to obtain information about how parents of chronically ill children who are not near death and hospitalized in a university health sciences center define nursing care and perceive the nursing care of their children, and (2) to obtain information about the kinds of nursing care parents think are needed but are not being provided. To obtain this information an exploratory study was performed using the initial steps of the grounded theory methodology. A theoretical sample of ten mothers was interviewed in semi-structured interviews which were recorded on tape. The information was analyzed for the parents' definitions of nursing care and what other kinds of nursing care parents would have wanted for their child. Also, the information was concurrently coded and analyzed to form properties and categories. After coding and analyzing the information the tapes were erased.

Six categories and two subcategories emerged in the study and they are: Environment, Right to Know, Nutrition, Attitude/Approach, Parent Concerns, and Competency. Competency is composed of two subcategories, staff and parent competency.

Some of the definitions of nursing care voiced by the parents were short and to the point and others long and involved. They contained aspects of the categories of Competency and Right to Know.

The information obtained from the parents regarding the kinds of nursing care they wanted for their child but was not provided had interesting responses. Parents expressed that they want competency according to parent standards in the care their child receives. In the environment parents identified problems in the areas of physical surroundings and human resources.

The categories of Environment, Nutrition, and Attitude-Approach that emerged in this study were compared to Atwood's (1975) three categories of Environmental, Nutritional, and Person-Centered Selective Neglect and were found to be similar. Hampe's (1975) needs of the grieving spouse were identified in the categories of this study. She identified eight needs and seven were contained in the categories. The need to be informed of the impending death was predictably not identified.

Recommendations

So far the emergent categories have been validated in adults and with the needs of significant others. The next step is for further studies to discover if the same

categories would emerge in other situations. Recommendations are:

1. Replicate the study with parents whose child has been discharged for twenty-four hours.
2. Replicate the study with parents who have a child who is acutely ill.
3. Replicate the study with parents who have infants in a nursery ICU.
4. Replicate the study with parents whose children are near death or have died.
5. Analyze the interviews for their interrelationships and generate a theory.
6. Have a person not associated with the health care system replicate the study.
7. Replicate the study by interviewing fathers only.

APPENDIX A

SUBJECT CONSENT FORM

TO: Parents of hospitalized children

FROM: Audrey Rath R.N., Graduate student

You are being asked to participate in a study of nursing care of hospitalized children. The purpose of this study is to obtain information about the nursing care children are receiving in the hospital for use by pediatric nurses to provide a better quality of care to children. You will be asked to answer a few questions concerning your opinions of what has been helpful or not helpful in the nursing care your child _____ has been receiving. You can answer all or part of the questions. This will be done through a tape recorded private interview lasting approximately thirty minutes, conducted by the investigator.

Your identity and the identity of your child will remain anonymous. All the information received will be coded into categories on a coding sheet. When this information has been analyzed, the coding sheets will be destroyed and the tapes will be erased. No names will be presented to the hospital staff or used in the research report.

There are no risks or discomforts involved by your participation in this study. You assume no costs in connection with the study. Your participation in this study is voluntary. You may withdraw at anytime without affecting the care of your child in any way. There will be no individual benefits received by you or your child during this study. The benefits anticipated from the study will accrue to society. The investigator will be happy to answer any questions you have pertaining to the study.

Parent's signature: _____

Child's signature: _____

Investigator's signature: _____

Witness signature: _____

Date: _____

APPENDIX B

IDENTIFYING DATA SHEET

1. Identifying number:

2. Date of birth:

3. Diagnosis:

4. How long has this child had this diagnosis?

5. Has this child been hospitalized before?

6. Approximately how many times has this child been hospitalized?

7. Parent interviewed:

APPENDIX C

INTERVIEW QUESTIONS

I am Audrey Rath, a graduate student in pediatric nursing conducting a study to help the pediatric nursing staff take better care of their patients. The nursing staff in pediatrics are interested in doing the best job they can to take care of your child. Could we talk for a few minutes about the nursing care your child _____ is receiving? All the information you will give me will remain anonymous.

While your child has been in the hospital he has been receiving nursing care.

1. As far as you are concerned, what is nursing care?

2. What kinds of nursing care have been most helpful to your child?

3. What kinds of nursing care have been least helpful to your child?

4. What other kinds of nursing care would you have wanted for your child?

Thank you for your help.

From Atwood (1975, p. 46).

APPENDIX D

NUMBER, AGE, DIAGNOSIS, DURATION, TIMES HOSPITALIZED[a]

Number	Age[b]	Diagnosis	Duration[c] of Illness	Times Hospitalized
01	12 years 7 months	Cystic fibrosis	Since birth	Numerous
02	10 years 5 months	Acute lymphoblastic leukemia	Eight months	Four
03	12 years 10 months	Cystic fibrosis and diabetes	Since birth	Numerous
04	11 years 8 months	Infantile spinal muscular atrophy	Nine years	Twice
05	7 years	Chronic lung and asthma	Since birth	Numerous
06	11 years 8 months	Dystonia musculorum deformans	Six years	Three
07	12 years 6 months	Abdominal adhesions and hypertension	Two years	Three
08	7 years 7 months	Ataxia telangiectasia	Five years	Numerous
09	12 years 3 months	Atrioventricular canal repair	Since birth	Numerous
10	11 years 5 months	Coxa Vera of left hip with leg length discrepancy	Since 4 months old	Numerous

[a]All interviewees were mothers and all children had been hospitalized previously.

[b]Mean age is 10 years and 9 months.

[c]Mean duration is 7 years and 8 months.

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