NURSING CARE OF AN INFANT WITH NEPHROGENIC DIABETES INSIPIDUS

BY

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CHAPTER I

INTRODUCTION

The major problem facing pediatrics today is the care of children with chronic disease (Wallace, 1962, p. 287). So, too, it is a major problem which confronts the pediatric nurse.

Whenever possible, the method of choice for the treatment of chronic disease in children is care administered by their mothers at home. In acute episodes of disease, facilities for care provided by a hospital may be necessary to promote the optimum well-being of the child and his family (Wohl, 1959, p. 621).

A continuous, intimate, mutually satisfying relationship with a warm and giving mother (biological mother or permanent mother substitute) is necessary to ensure the infant's optimum physical and psychological growth and development (Bowlby, 1953; Blake, 1963, p. 2; Erikson, 1963, pp. 247-74). Prolonged separation from his mother creates a crisis for the infant because it interrupts the continuity of a relationship which he needs for optimum growth (Bowlby, 1953; Freud and Burlingham, 1944; Spitz and Wolf, 1945, pp. 53-74).

Most infants can be aided in dealing with the crisis of illness and hospitalization by having their mothers remain with them and care for them in the hospital (Robertson, James; 1958). In most instances Pearson found that parents are better able to support their children during illness and convalescence than any member of the helping pro-

fessions (Pearson, 1941, pp. 716-29). The infant can also be aided by the provision of meticulous physical care which fosters bodily comfort and supports him both physically and emotionally in his fight against disease (Blake and Wright, 1963, p. 6).

Providing support to a child during illness is not an easy task for a mother (Erickson, 1965, p. 4). She faces a crisis when she learns that her infant is ill and must be hospitalized. She grieves and often feels angry, frightened, and markedly inadequate when she learns that her child is imperfect or chronically ill (Green and Durocher, 1964, p. 4). Most mothers need support to deal with this crisis when they visit their hospitalized infants. Hall and Bruce state, "The extent to which a mother is helped to realize her own strengths and to enjoy her infant because of what she can offer can significantly influence the child's development" (Hall and Bruce, 1964, p. 4).

By increasing the mother's knowledge of her child's problems, needs, and illness, the nurse can support the mother, decrease her fear, and increase her confidence and competence in administering care to her infant. "The known is less frightening than the unknown" (Blake and Wright, 1963, p. 29).

Assumptions

This study is based on two assumptions:

1. Continuity is essential in the relationships between nurse, mother, and infant to make hospitalization a constructive learning experience for all persons involved;

2. Care of a chronically ill infant can be improved when one professional nurse has the responsibility for establishing, continually evaluating, and redesigning plans of care for him. This responsibility entails purposefully planned activity with the infant's parents and all other members of the health team who are involved in the provision of care. To provide high quality care and to deal with problems presented by the child and/or his mother, the nurse should be available to the nursing staff for consultation services.

Hypothesis

This hypothesis will be tested: Nursing care purposefully planned to help Danny Smith, an infant hospitalized with nephrogenic diabetes insipidus, and his mother can protect Danny's potentials for optimum growth and development, lessen the number of subsequent hospitalizations and clinic visits, alter the medical treatment required, and sustain Mrs. Smith's self-esteem and involvement in her child's care.

Statement of the Problem

The purpose of this study is to identify and describe (1) the care given by the writer (a nurse) to an infant with a chronic disease, nephrogenic diabetes insipidus; and (2) the guidance provided to strengthen his mother's capacity to cope with his health problems.

The objective of the study is to answer these questions:

1. What care did Danny require during hospitalization?

2. What problems confront Mrs. Smith in the care of her infant born with nephrogenic diabetes insipidus?

3. How can a nurse help Mrs. Smith to improve her care of her infant and thereby prevent recurrent disruption of the mother-child relationship during hospitalization and loss of self-esteem for the mother?

Definition of Terms

For the purpose of this study, the following terms have been defined as:

Chronic illness is a pathological condition of life-long duration.

Constructive hospitalization is a hospitalization of an infant during which the infant gains in health and the mother attains increased competence and confidence in the care of her infant, as indicated by:

1. The infant's progress in physical growth and development (increase in height, weight, growth and development of motor and sensory potentials);

2. The infant's progress in psychosocial growth and development;

3. Limitation of the amount of hospitalization to the minimum requirement;

4. Evidence that the mother has acquired increased understanding of her infant's health problems, of the reasons for the special care that he requires, and has used the physician's advice concerning the prescribed treatment regimen and the nurse's guidance in the care of her baby;

5. Evidence that the mother has become less fearful of the hospital environment as demonstrated by increased capacity to care for her infant, to utilize the nurse's guidance, and to express her feelings, concerns and needs to persons who can help her;

6. Evidence that the mother is deriving more pleasure in caring for her child.

Coping is the process by which an individual attempts to accommodate to his problems in a healthy manner.

Development is the improvement of skill and functional capacity according to a complex but orderly process.

Growth is an increase in size according to a complex but orderly process.

Nursing care is thoughtfully planned activity in response to identified problems and needs. It requires:

1. Study of the infant's responses to his environment;
2. Understanding of his health problems and mode of adapting to them;
3. Evaluation of his physiological and psychological mechanisms of defence;
4. Understanding of the scientific principles underlying his disease and the medical treatment and nursing care that it requires;
5. Sensitivity to the influence which the family environment have had on him;
6. Sensitivity to the mother's problems and needs, awareness of her strengths and limitations in providing care to her infant;
7. Knowledge of the nurse's and mother's conceptions of their roles in the infant's care.

Nursing care includes:

1. The administration of physical care to the infant by his mother or nurse which includes bathing, inspection of his body, dressing, diapering, skin care, contact comfort, feeding and recording of food and fluid intake, recording of urine and stool output, taking and recording weight, height, vital signs;
2. Systematic study to evaluate and record the infant's

physiological, emotional, and behavioral responses to illness, treatment, physical care, stimulation; to plan ways to help him to adapt constructively to physical care which includes medicines, treatment, diagnostic tests, etc., as ordered by the physician; and to test the effects of care on him;

3. The provision of stimulation for the infant through spontaneous, purposeful interaction with him as a person, and through the use of a case of toys which includes: blocks, rubber doll, toy baby bottle, hammer and pounding board, string of wooden beads, clay, ball, paper cups, construction paper (white and colored), large crayons, toy dishes, syringe, tourniquet, plastic urine collector with tubing, tongue blades, cotton balls, bandaids, telephone, medicine cups;

4. Guidance of the mother regarding the infant's care: diet, maintenance of fluid balance, skin care, medications, stimulation and support required for optimum growth and development, knowledge required to understand the illness and the rationale for treatment and special bodily care;

5. The provision of an environment which encourages the mother to express herself freely about her problems in adapting to her role as a mother of a child with a congenital, chronic disease;

6. The coordination of the contributions made by all members of the health team into plans of care which change as required by the child and/or mother.

Psychosocial growth and development includes progress observed in these areas:

1. Capacity to become increasingly more intimately related to his mother and other significant persons;

2. Increased energy for play with inanimate objects and people;

3. Increase in capacity to express feelings;

4. Differentiation of feelings into those which demonstrate: growth in trust, pleasure, anger, sadness, pride in self, fear, anxiety;

5. Production and use of a wide variety of sounds and words;

6. Growth in capacity to use his body to feed himself, to

communicate his needs for stimulation and exercise, etc.

Nephrogenic diabetes insipidus is a rare chronic renal disease characterized by polyuria (large quantities of dilute but otherwise normal urine; specific gravity of urine less than 1.010) and polydipsia (unrelenting thirst). Dehydration, fever, vomiting, constipation, and failure to thrive are common consequences. In untreated infants, the serum levels of sodium and chloride are frequently elevated. The disease is present from birth. Its manifestations in early infancy are often overlooked.

The disease involves a disorder of the renal tubules, especially the distal tubules, which does not permit adequate reabsorption of water. In a healthy infant, the antidiuretic hormone produced by the posterior pituitary gland facilitates reabsorption of water. The child with nephrogenic diabetes insipidus produces this hormone in normal amounts but it is ineffective. In contrast to diabetes insipidus due to lack of antidiuretic hormone, hormone replacement therapy is ineffective. The specific pathogenesis is unknown; no biochemical or anatomical basis for the disease has been demonstrated. In some families it has been shown to be a heritable defect (X-linked dominant trait with variable expressivity in heterozygous females).

There is no specific therapy for the disease. The only established treatment is the maintenance of fluid and electrolyte balance by the ingestion of adequate amounts of water and the limitation of sodium intake to reduce the water requirements. Life expectancy is normal if dehydration is prevented. Hydrochlorthiazide (a drug which acts as a diuretic on the normal kidney) has been shown

to reduce the output of urine in children with nephrogenic diabetes insipidus. The mechanism of action of hydrochlorthiazide is unknown. (Stanbury et al., 1960, pp. 1274-94).

Review of Literature

Nephrogenic diabetes insipidus is described in most medical textbooks; Stanbury presents a thorough discussion of the disease and its treatment (Stanbury et al., 1960, pp. 1274-94). Most nursing textbooks omit this disease or mention it briefly.

The writer's search of the literature revealed that the nursing care of infants and children with this disease had not been studied and reported. There is also a sparcity of literature which presents studies of the help given by nurses to mothers of infants and children with chronic disease.

A few studies relating to chronic illness and to the hospitalization of infants and children are pertinent to this study. Bowlby and Robertson describe the three phases--protest, despair, and denial--through which a previously loved young child passes as he struggles to deal with separation from his mother (Bowlby, 1953; Robertson, 1958). Two distinct syndromes, each associated with a particular age group, have been described in infants separated from their mothers by hospitalization (Schaffer and Callender, 1959). Mahaffy concluded that the mother was better able to care for her hospitalized child if supported by a nurse (Mahaffy, 1964).

In writing about adaptation to chronic illness, Crate states that the role of the nurse is not to attempt to change the basic life

pattern of a person, but to support and guide him as he moves toward a way of life that helps him to accommodate to his illness (Crate, 1965). The importance of nursing care in the treatment of one infant who had failed to thrive as a manifestation of maternal deprivation is presented by Legeay (Legeay, 1965). The experience of a mother in caring for her hospitalized daughter are presented by Joyce (Mrs. James) Robertson (Robertson, 1956). Prugh studied the emotional reactions of children and their families to hospitalization (Prugh et al., 1953). The importance of the physician's role in counselling the parents of acutely and/or chronically ill children is discussed by several authors (Flesch, 1963; Glasser et al., 1961; Lewis, 1962; and Tisza, 1962).

Green and Durocher stress the importance of parent education by the doctor and nurse in the care of their chronically ill children (Green and Durocher, 1964). Moran found that preparation of parents by nurses was a significant factor in supporting their child's adjustment to an operation and hospitalization (Moran, 1963).

Hillsman writes of her experience in working with the families of children with phenylketonuria. She points out that the birth of a child with an inherited chronic disease threatens the parents' self-concepts and produces anxiety. These parents need continued support over a long period of time which includes answers to their questions. To provide this support the nurse needs to have interest in the parents and perceive them as worthwhile, important individuals. They require continued recognition of their accomplishments as well (Hillsman, 1966).

Methodology

Danny, an infant with nephrogenic diabetes insipidus and his mother (Mrs. Smith) were studied. Danny was eleven months old upon admission to the study. He and his mother were admitted to the study on the eleventh day of Danny's third admission to the pediatric service of the university medical center for re-evaluation of dehydration and failure to thrive secondary to nephrogenic diabetes insipidus. The writer continued to study Danny and Mrs. Smith in the pediatric outpatient department of the medical center for one year after their admission to the study.

Throughout the study the writer functioned as a participant observer of Danny, his mother, herself, and their interrelationships. She interacted with Danny and his mother in an attempt (1) to identify their problems in adjustment to nephrogenic diabetes insipidus and its treatment and to hospitalization; (2) to modify the hospital environment in the particular ways required by them for a constructive learning experience; and (3) to evaluate the effects of care in relation to the goals cited at the end of this chapter. In recording her observations and interactions, the writer attempted to record her own responses to Danny, his mother, and their requirements for help as fully as she was aware of them. The writer's instructors (nurse and physician) read all recorded data and assisted the writer in understanding the meaning of the observations and interactions which occurred. They assisted the writer in understanding Danny's medical problem, the principles used in the provision of care, in formulating nursing diagnoses and in planning and evaluating nursing care.

The writer arranged daily periods of study in accordance with the needs of the infant and his mother. These periods varied in length from one to eight hours, averaging three hours. In the mother's absence, the writer maintained the same period (4 to 7 p.m.: play period, supper, and bedtime) to provide a consistent pattern of care for Danny. Alterations in this time schedule were made to meet the needs created by medical procedures and Mrs. Smith's visits. Weekends were not included except on the occasions when Mrs. Smith visited. One four day interruption in the sequence occurred due to the writer's illness.

During the last eleven days of Danny's hospitalization, the writer was also a participant observer of one of Danny's roommates whom she had previously studied. During this time, the study periods were extended to provide time for individualized care to both children and for interviews with their mothers.

During periods of study with Danny, the writer provided physical care, play and relationship experiences. Whenever present Mrs. Smith was encouraged to care for her infant. When her behavior demonstrated a need for assistance, the nurse provided it. Hospital visiting hours were unrestricted. Parents were encouraged to visit. Rooming-in was not permitted because of inadequate hospital facilities.

The writer had no contact with Mrs. Smith at the initiation of the study. Distance, transportation facilities, economic and other factors limited the frequency of Mrs. Smith's visits. The writer initiated her contact with Mrs. Smith by letter. She wrote about Danny's condition, her interest in meeting her and in being of assistance to her. Upon reception of Mrs. Smith's answer, a second

letter (see Appendix, p. 82) was sent. Then a telephone call was made to plan a time when the writer could talk with Mrs. Smith on her next visit with Danny.

During a visit to the hospital the writer observed Mrs. Smith's care of Danny. She conducted a semi-structured interview with Mrs. Smith to learn about Danny's early life experiences and care and her concerns about Danny. She planned two subsequent visits, eight and four hours in length respectively. During these periods Mrs. Smith cared for Danny with the nurse's supervision. It was agreed by writer, physician, and Mrs. Smith that these visits be prerequisites for Danny's discharge. Between visits the nurse maintained contact with Mrs. Smith by making one or more telephone calls to her each week.

During the periods when Mrs. Smith cared for Danny and was interviewed by the writer, the writer provided support and specific instructions. Unfamiliar aspects of physical care which Danny required were demonstrated. Then Mrs. Smith performed these activities with the nurse's supervision. Instructions were given about the nature of Danny's chronic disease, the treatment he required, and the rationale for treatment. Guidance relating to the growth and development of young children was also provided. Interviews were limited to no more than one hour in length. The content of previous discussions was reviewed before proceeding to new material. To evaluate Mrs. Smith's progress in learning, the writer encouraged her to share her acquired knowledge with her. Repetition of information was given as necessary. Mrs. Smith was encouraged to ask questions and to write down questions which arose between interviews.

Initial teaching regarding Danny's low sodium diet was given by the dietitian; the writer was present when this instruction was given. Subsequent discussion and instruction regarding the diet was given by the writer. The dietitian served as a resource person for the writer.

The writer was also present for the interview between the mother and physician prior to Danny's discharge. Written instructions about Danny's needs were provided for Mrs. Smith. These were reviewed with her prior to discharge.

When Danny was discharged after fifty days of hospitalization, the writer worked with Danny and Mrs. Smith for eight weeks. She telephoned Mrs. Smith frequently to lend support by listening, by answering her questions and learning how she was dealing with her responsibilities. She was also present to provide guidance when Mrs. Smith brought Danny to the clinic two weeks and eight weeks after discharge.

During clinic visits the writer studied Danny and his mother and interviewed Mrs. Smith. She provided and observed Danny's use of play materials during each clinic visit. She was present when the physician interviewed Mrs. Smith and examined Danny. With the writer's help, Mrs. Smith assisted the physician during physical examination. Danny's height and weight were measured by the writer at each visit; laboratory studies of blood and urine were done periodically.

During the semi-structured interviews with Mrs. Smith, the writer obtained information about Danny's patterns of sleep, of behavior during meal or play periods, and of social relationships. In addition she talked with Mrs. Smith about the problems with which she

was confronted in the care of her children and in the family situation. Mrs. Smith was asked to record Danny's daily food and fluid intake (time, amount, substance) for the first two weeks after discharge. Thereafter she was asked to record the same information for one day each week. The writer reviewed these records with Mrs. Smith. She used them as a tool for continued guidance and as a basis for comparison of Danny's progress from one month to the next. Simultaneously the writer used measurements of weight, height, and other physical findings to help Mrs. Smith become aware of the relationship between food and fluid intake and Danny's rate of development.

Upon discharge, referral of the Smith family was made by telephone and letter (see Appendix, p. 83) to the local public health nurse to alert her to this family's need for continued health supervision. The public health nurse visited the Smith family weekly. Eighteen days after discharge the writer accompanied the public health nurse on a visit to the Smiths. Two and a half weeks later the writer made a second home visit unaccompanied by the public health nurse. Both visits were preceeded and followed by consultation with the public health nurse.

During prearranged home visits the writer studied Danny and his mother and other relatives in their familiar environment. She interviewed Mrs. Smith and offered additional guidance. Telephone numbers were given to Mrs. Smith and she was encouraged to call the public health nurse or the writer at any time questions or problems arose.

Over the writer's three month summer absence from the university, the public health nurse made weekly visits to the Smiths. Danny was

seen once in the university medical center's pediatric clinic and intermittently by a local pediatrician.

Upon return to the university, the writer worked with Danny and Mrs. Smith at monthly clinic visits for the remainder of the year of study. Two of these were cancelled due to complicating family situations. The writer called Mrs. Smith once or twice a month to plan clinic visits and to maintain contact when visits were cancelled.

The public health nurse shared her findings from work with the family with the writer by telephone. She shared them with the physician and writer when she accompanied the Smiths on the last clinic visit which ended the year of study. Then plans for Danny's care were made jointly by the physician, the public health nurse, Mrs. Smith, and the writer.

Throughout her experience with Danny and Mrs. Smith, the writer served as a member of the health team responsible for Danny's care. She conferred with the physician frequently during Danny's hospitalization, between and during clinic visits, and prior to and following each home visit. During Danny's hospitalization, she attended ward nursing conferences to discuss Danny's problems, needs, and the medical and nursing goals of care. Her purpose was to coordinate the various types of services which were being provided for the Smiths. Danny's pediatrician at the university medical center communicated his findings and recommendations to the local physician. At a later time the writer and public health nurse discussed their concerns and findings with the local physician.

All interviews, telephone conversations, and observational data were recorded as soon as possible after the periods of study. Notes were taken during interviews, telephone calls, and observations of Danny's play. Copies of letters of referral and the written instructions which were given to Mrs. Smith by the writer and dietitian were retained as sources of data.

Analysis of the Data

In caring for Danny, the writer sought answers to these questions:

1. What are Danny's physiological and psychosocial responses to disease, care by a person other than mother, and separation from his familiar home environment?

2. What are Danny's physiological and psychosocial changes throughout the course of his hospitalization? What were the possible causes of these?

3. What are Danny's strengths and limitations in coping with natural problems in growth and development and with those associated with his disease and the treatment he requires?

4. What elements of nursing care are used by the writer as she functions as a participant observer of Danny?

5. What does Mrs. Smith need to know to succeed in meeting Danny's needs for care and guidance at home?

In all contacts with Mrs. Smith, the writer sought to answer these questions:

1. How did Mrs. Smith care for Danny prior to his hospitalization?

2. What strengths and limitations does Mrs. Smith demonstrate in caring for Danny?

3. What problems does Mrs. Smith present in meeting Danny's needs?

4. What elements of nursing care are used to strengthen Mrs. Smith's resources to cope with each of her identified problems?

5. What changes occur in Mrs. Smith's care of Danny?

During all contacts with Danny and his mother after discharge, the writer sought to answer these questions:

1. What are Danny's physiological and psychosocial responses to his chronic disease and the treatment required?

2. How has Mrs. Smith cared for Danny since discharge or the previous clinic visit?

3. What changes have occurred in Danny?

4. What changes have occurred in Mrs. Smith?

5. What strengths and limitations does Mrs. Smith demonstrate in caring for Danny?

6. What problems does Mrs. Smith present in meeting Danny's needs?

7. What elements of nursing care are used to strengthen Mrs. Smith's resources to cope with each of her identified problems?

8. What changes have occurred in Mrs. Smith's care of Danny?

9. What methods has Mrs. Smith used in coping with the new natural developmental and/or health problems which have arisen?

Throughout her experience with Danny and Mrs. Smith during hospitalization and after discharge, the writer evaluated their progress according to the criteria which are cited subsequently. Danny's physical progress was evaluated after study of these recorded observations:

1. Weight and height (Growth charts used were prepared by H. C. Stuart and H. V. Meredith, Children's Medical Center, Boston; these are the standard growth charts

used on the pediatric service of the university medical center; see Appendix, p. 72);

2. Laboratory data: hemoglobin, serum sodium, specific gravity of urine, sodium content of urine (Normal values according to Watson and Lowrey, 1962);

3. Daily fluid intake (measured and recorded by hospital nursing staff and/or by mother);

4. Daily urine output (when measured for specific twenty-four hour urine tests);

5. Skin condition, especially of diaper area (as observed by hospital nursing staff, public health nurse, and/or mother);

6. Increased control of gross and fine motor movements (Normal values according to Watson and Lowrey, 1962 and Blake and Wright, 1963).

Criteria used to evaluate progress in psychosocial growth and development included the following (Watson and Lowrey, 1962, pp. 122-175; Blake and Wright, 1963, pp. 273-326, 415-54):

1. Growth in adaptive behavior (e.g., transfers object from one hand to the other, eyes follow moving object);

2. Growth in use of language (e.g., sounds and words used; action in response to verbal command or request);

3. Advances in personal-social behavior (e.g., spontaneous social smile, vocalization of wants or needs, feeds self);

4. Healthier responses to frustrations of hospital environment (e.g., care by someone other than mother, uncomfortable treatments, restrictions in activity);

5. A response of satisfaction to mother's return after an absence from the ward.

Mrs. Smith's progress in adaptation to her problems was evaluated with these criteria:

1. Increased skill and pleasure in administering physical care, stimulation, and comfort to Danny;

2. Understanding of Danny's problems and needs as indicated by her ability to explain his needs for food, fluid balance, and skin care;

3. Understanding of nephrogenic diabetes insipidus as a disease causing the above-stated problems;

4. Increased confidence in the writer and ease in using her as a helping person;

5. Ability to express and cope with her own feelings about her child's illness;

6. Increased skill in coping with new problems presented by the child.

CHAPTER II

DANNY, HIS PROBLEMS, AND HIS NEEDS

Initial Observations of Danny

Danny was a small thin child. His large blue eyes were his predominant facial feature. Curly blond locks of hair framed his tiny face. His skin was pale and dry. He looked chronically undernourished but not acutely ill. He looked more like a little old man than an infant. He was eleven months old and weighed twelve pounds four ounces.

When first observed, Danny was dressed in several diapers and a white undershirt. He was lying on his abdomen in his crib; his head and shoulders were raised, resting upon his elbows. Occasionally he extended one of his flexed knees or wiggled his toes. He made no sound. He did not play with the sock monkey, small plastic horse, or toy bar, all of which were within his reach. Intently his eyes moved from person to person, as if he felt that he had to protect himself. His expression never changed during the hour of observation. His lips curled neither up nor down.

A few excerpts from the initial observations of Danny describe his behavior more fully:

> Danny watched me as I entered the room and sat in a chair near the foot of his crib. During the entire period he intently scrutinized me and the other two children in the room.
>
> Mark, age five years, pushed a chair beside Danny's crib and climbed upon it to be on Danny's level. Danny

turned his head to look at Mark, but his expression did not change. Mark reached through the bars of the crib and touched Danny's foot. Mark gently moved the hanging toy which was strung across the crib, and touched Danny's curly head. Each of Mark's gentle movements were an attempt to elicit a playful response from Danny.

Danny lay still as he watched Mark closely. He must have wondered what this boy was going to do to him, but no change in his facial expression or his affect were evident.

Mark jumped off the chair noisily. He turned around and momentarily fingered the chair cushion. Then he directed his attention to the crank on the foot of Danny's bed. He turned it, slowly raising the head of Danny's bed. In response to this, Danny wiggled closer to the side of the bed to watch Mark. He wiggled and pulled himself forward rather than creeping. As Mark bent down to crank the bed up, Danny could no longer see him. He shifted his gaze momentarily to me. Then Danny straightened his body and rolled over with his bottle in his hand. He made a gurgling noise, lifted the bottle skillfully to his mouth, and drank some water. Then he released his grasp on the bottle, rolled over, resumed his initial position, and explored his surroundings with watchful eyes. He moved his left foot constantly, perhaps to release tension.

I put the cribside down, and sat down on a chair beside the crib with my hand resting on the bed. Danny watched me move toward him and wiggled around to face me. He spotted my ring and reached for it, first with one hand and then with both. He lightly fingered my ring and hand and looked into my face for an instant but my smile stimulated no emotional response that I could perceive. Danny submitted passively as I changed his wet diapers. He did not respond physically or emotionally to me or to diapering.

Then I picked Danny up and held him closely. Again he fingered my ring and hand. He required support as he sat on my lap. He complacently accepted care of his fingernails and hair. He showed interest in handling the scissors and comb, but submitted passively when I removed them.

I placed Danny on his crib. He reached for his bottle and sucked. Danny looked toward me but did not focus on me as I stood at the cribside momentarily and then walked away. His immobile facial expression and watchfulness continued.

Danny was slightly more active during meals but he did not resist being fed. His participation in self-feeding

was limited to holding his cup with assistance. He poured its contents half into his mouth and half down the front of his shirt, and occasionally handled his spoon or dish. His fluid intake was large; his intake of solid foods was less than his growth needs required.

After eating Danny fell asleep quickly in a posture which resembled the fetal position. He lay on his abdomen with his knees pulled up under him. His forehead rested face-downward on his hands. Before falling asleep, he did not cry; he was affectless and withdrawn.

After my first contact with Danny, I was motivated to take him as a study patient. I wanted to compare and contrast his behavior with that of a child with diabetes insipidus secondary to hypofunction of the posterior pituitary gland. As I sat observing Danny I was saddened by his despair in response to hospitalization, separation from home and family, and by the chronic character of his illness. I wondered when he had last seen his mother and how often she was able to come to visit him. I had not yet become aware of the problems and burdens which he presented to her.

Every patient is entitled to maximum physical comfort and help in coping with the frustrations and pain that he must bear during treatment for his medical problem. For an infant this includes appropriate clothing, diapers changed as often as necessary, food and fluids when hungry and thirsty, and the comfort of being loved and stimulated according to his readiness for learning. I longed to do this for Danny. I felt responsible for his welfare whenever I was with him, but as yet I felt no love for him as a person. I wanted to give to him because he needed it, but I had no feedback of responsiveness from him. In providing care to Danny, I moved slowly. I wanted to indicate to him that I was interested in him and did not intend to harm him. This plan also

provided Danny with a longer opportunity to become accustomed to another new person.

Danny's Health History

Danny's medical history told more of his story; it reflected chronic failure to thrive and recurrent hospitalizations. His weight at birth was six pounds thirteen and one half ounces. His length was twenty and one fourth inches. Mrs. Smith's pregnancy and delivery were uncomplicated. Danny was breast fed for five weeks after which he was switched to evaporated milk when his mother returned to work. Then he was cared for by a teenage baby-sitter. At the age of two months, he weighed eight pounds thirteen ounces and presented no apparent medical problems. One month later his weight was unchanged although he continued to eat well. Mrs. Smith reported that he always drank rapidly large quantities of milk and water. She introduced cereal into his diet at the age of two weeks. She added fruits at two months, and vegetables shortly thereafter. Danny ate well. Over the subsequent months he failed to gain weight.

At the age of four and one half months, Danny developed diarrhea, dehydration, and fever, and refused all solid foods. He was hospitalized locally and transferred to the university medical center for investigation of his failure to thrive. At this time he weighed eight pounds eight and one half ounces. He was markedly malnourished and showed five to ten percent dehydration. After diagnostic tests and evaluation of the findings, a diagnosis of nephrogenic diabetes insipidus was made.

After forty-one days of hospitalization, Danny was discharged to

his parents on this regimen: (1) low sodium diet; (2) maintenance of fluid intake at 1500 to 2000 milliliters daily; and (3) hydrochlorthiazide, five milligrams daily. After discharge, Danny was examined in the pediatric outpatient department at one to two week intervals. His progress was fair. His weight increased slowly, reaching fourteen pounds at the age of nine months.

At nine months of age Danny was rehospitalized at the medical center for eight days due to markedly elevated serum sodium levels and dehydration. After discharge he was again examined at two week intervals in the outpatient department. His weight increased to fourteen pounds four ounces and then began to decrease.

At the age of ten and one half months Danny was admitted to a local hospital with an upper respiratory infection and dehydration after an episode of vomiting. He was transferred to the medical center for treatment and for evaluation of his failure to thrive. Upon this, his third admission, Danny weighed twelve pounds. His height was twenty-eight and one fourth inches. Ten days later when I began to care for and study him, Danny weighed twelve pounds four ounces.

Danny's chronic failure to thrive is dramatically illustrated by comparing his height and weight measurements over a period of time with those of other healthy children (See Growth Chart in Appendix, p. 72). One method of presenting such data is as a percentile comparing normal growth patterns. It is important to know that a child is consistently maintaining a given channel (in height and weight) compared with other children of his sex and age.

Watson and Lowrey state that:

> The progress of growth (height and weight) is predictable for a given child once his approximate percentile position or channel is established. Deviation from his channel is more noteworthy than the actual percentile relationship (Watson and Lowrey, pp. 56-7).

Danny's height over the first eleven months of his life dropped from just above the fiftieth percentile at birth to just below the third percentile at eleven months of age. His weight at birth was just below the twenty-fifth percentile. It had dropped below the third percentile by the time Danny reached two months of age. Thereafter Danny's weight curve vacillated sharply while remaining below the third percentile. At the time of his admission to the study, Danny's weight was markedly below the third percentile and showed a sharp drop during the preceeding six week period.

Danny's Nursing Diagnosis

Having observed Danny for two days and acquired knowledge of his medical problems and the treatment required, I made this nursing diagnosis: Danny is suffering from loss of his mother. He has innumerable contacts with hospital personnel, but insufficient opportunity to become emotionally involved with one person. His complacent acceptance of physical care stems from his reaction to loss of his mother and her care. He is responding to separation from her with distrust and despair.

Danny also suffers from constant, unrelenting thirst; frequent voiding; and skin irritation secondary to constantly wet diapers. His knees are reddened from rubbing them on the bedding. He has minimal energy for physical activity. He has failed to thrive and become de-

hydrated. He conserves his energy by maintaining a relatively stationary position in bed, by few large muscular movements, and by passive observation of ongoing activities. He does not have energy for active play by himself. He maintains a protective vigil throughout the hours when is is awake.

Danny needs large quantities of fluids to maintain his fluid and electrolyte balance. He needs sufficient quantities of solid foods to promote growth. Foods and fluids have to be low in sodium content to decrease additional fluid loss. He is interested in self-feeding and seems eager to try to eat finger foods and foods which can be chewed. His physical abilities are commensurate with those of a six to nine month old child. His small physical size and failure to thrive are caused in part by relationship loss during frequent hospitalizations.

A condensed nursing diagnosis was placed on the kardex. It read:

1. Despair from separation from his mother;
2. Constant thirst, frequent voiding, and skin irritation due to nephrogenic diabetes insipidus.

During the next few weeks, I searched for evidence to support the above nursing diagnosis and validated it. At a later time, findings from study of Danny's mother were added to the nursing diagnosis and to the kardex. In response to my observations and nursing diagnosis and the medical evaluation and orders, I formulated a plan of care for Danny. This was modified as Danny made progress toward health and as new problems arose (see Appendix, pp. 73-75).

Progress During Hospitalization

Observational Data

Danny spent twenty-seven per cent of his first year of life hospitalized at the university medical center (this figure does not include admissions to the local hospital). Danny's progress during his third hospitalization was evident in his physical and psychosocial growth and development and in his positive physiological response to the treatment of his disease.

The development of a meaningful relationship with Danny, as the nurse carried out maternal functions during his mother's absence, was a fundamental requirement for his progress. The most important person in an infant's life is his mother. When hospitalized and away from his mother and her care, he looses what is most vital to him. A baby may react to these circumstances in a number of defensive ways.

Danny's reaction to the loss of his mother was withdrawal and passive acceptance of the physical care which he received. He accepted what was given, asked for no more, and retreated into inactivity, silence, and a sleeping posture resembling the fetal position. He kept protective contact with his hospital world with his eyes, but made no attempt to gain contact with people by physical or vocal activity. He accepted what he received, but did not deplete his strength in crying for more. Robertson and Blake describe this response to maternal deprivation as the phase of despair (Robertson, 1958; Blake, 1965). The child suffers intensely with deep mourning and increasing hopelessness as he longs for his mother. This response to maternal deprivation is unhealthy (Bowlby, 1953, pp. 11-74). Of this type of reaction to

separation Bowlby writes:

> [The child in despair is] listless, quiet, unhappy, and unresponsive to a smile or a coo....The emotional tone is one of apprehension and sadness. The child withdraws himself from all that is around him, there is no attempt to contact a stranger and no brightening if a stranger contacts him. Lack of sleep is common and lack of appetite is universal. Weight is lost and the child easily catches infection. There is a sharp drop in general development.
>
> In what conditions, it may be asked, does this develop? In general, it is characteristic of infants who have had a happy relationship with their mothers up till six or nine months and are then suddenly separated from them without an adequate substitute being provided. (Bowlby, 1953, pp. 23-4).

Danny's response to hospitalization indicated that he had known a loving mother, one with whom he had begun to form a significant trusting relationship. This was Danny's greatest strength. The rapidity with which he was able to respond to me reaffirmed this hypothesis. Later this hypothesis was reaffirmed again when I observed the warm responsiveness which was exchanged between Danny and his mother when she visited.

Blake and Wright state that "the infant's first step in overcoming separation anxiety is to acquire the concept that his mother exists in substance even though he cannot see her at the moment" (Blake and Wright, 1963, p. 319). My goal was to help Danny to cope with his feelings about separation from his mother. My knowledge of the possible consequences of separation of an infant from his mother, the length of Danny's separation from his mother, and of his present despair in response to separation heightened my interest in Danny and his mother. I designed a plan of care for Danny. I provided five daily periods of intensive care in an attempt to help Danny regain trust and take steps

in mastering separation anxiety. I contacted Mrs. Smith by letter and telephone to encourage her to maintain contact with Danny through more frequent visiting and communication with me when she was unable to visit.

As hospitalization progressed and Danny and I became more intimately related with one another, Danny's whole appearance changed. I was both delighted and amazed by the changes as they occurred. His physical activity became abundant; his energy and strength increased markedly. His eyes sparkled. He sat with more stability and minimal support. He actively assumed a position on his hands and knees and began to creep backwards. He was able to stand for short periods with support. He began to take unsteady steps with assistance. Vocalizations became frequent and he delighted in imitating sounds. His vocabulary consisted of numerous sounds, including "M-m-m-m-" and "Da-da-da" but no distinct words. His face, no longer immobile, began to express both pleasure and displeasure. The following excerpts from data collected during play periods are characteristic of his progress in physical and psychosocial growth and development and in his relationship with me:

> Seventeenth Day of Hospitalization.--Returning after being absent over the weekend, I found Danny in the jumper chair in the playroom. I approached him slowly and silently, squatted down beside him, and smiled. He looked up at me and made clucking sounds which indicated pleasure. He had never before made these sounds with me. I spoke to him and made some clucking sounds which Danny imitated. Then I held out my arms toward him and offered to pick him up. In response he reached toward me with his arms but he did not smile. I untied the harness that restrained him, picked him up, gave him a gentle hug, and carried him to his room to change his soaked diapers.
>
> Eighteenth Day.--After being with Danny for half an hour as he played with the case of toys, I put his crib

side up. He looked up from his play and watched me as I picked up the highchair and prepared to carry it to the playroom to use for supper. As I reached the door of his room, Danny burst into tears for the first time since I had begun to care for him. I turned, told him gently that I'd be right back, and proceeded with my task. A few moments later when I returned, Danny was still crying. I walked toward his bed, lowered the side, and spoke his name. I stood there a few moments waiting to see if he could reach out to me. Tears ran down his face. He needed more comfort than words could give him. I picked him up, held him closely against my shoulder and rubbed his back gently as we walked around the room. Gradually his crying ceased and I took him to the playroom for supper.

Twentieth Day.--Danny was standing in the jumper chair reaching for toys which he had dropped onto the floor of the playroom. His sock covered legs were firm and straight. His feet were steady in new white shoes placed widely apart. The blue shirt he wore enhanced his sparkling blue eyes. He stood straight. His arms reached outward and downward as he tried to regain the toys. His whole body stretched for the toys, but he could not reach them. Up he popped; then immediately he reached down again. Danny was actively involved in his task; his body was in vibrant motion. Happy, playful sounds emanated from his lips.

In a minute or two, Danny became aware of me as I quietly approached him. Danny turned and looked up at me. His eyes sparkled and his lips curled into an open smile. I knelt down to be closer to him as I spoke. He tried to turn to face me but the jumper chair restricted his movement. His arms reached out toward me. I reached out for him, untied the harness which restrained him, and lifted him into my arms. It was a joyous moment for both of us!

When I placed the open case of toys on Danny's bed, he watched with intent curiosity. Then, sitting unsteadily, he reached forward toward the toys and flopped over into his usual prone position. He held his head high as he peered into the case. Supported on one arm, he reached immediately into the case with his right arm. He hauled out a bag of clay and dropped it onto the bed. He found the toy baby bottle, eyed it with curious familiarity, popped the nipple into his mouth, flopped over onto his back and sucked and chewed it. Then he carefully explored its tactile properties with his hands and mouth. He rolled onto his abdomen, grasped his own bottle, rolled onto his back and took a drink of water. For several minutes he alternately played with the toy bottle and his own. He

chewed, sucked, and felt as if he were comparing their properties. When he tired of this, he flopped over and peered into the case to find another toy.

Twenty-fourth Day.--After a weekend separation from Danny, I found him playing with a telephone. He looked up, smiled, and returned to his active play.

Five minutes later when I returned, Danny was crying. I spoke softly to him as I lowered the cribside to reassure him that I had come to care for him. When he lifted his head to look at me, he did not smile. There were tears on his cheeks; his eyes were sad. After he looked at me, he lowered his forehead onto his hands and retreated into the fetal position in which he had slept during the early days of his hospitalization. (He had abandoned this posture soon after I began to care for him.) Several times he repeated this same action as I stood at his bedside. It seemed as if he were trying to reassure himself that I was not going to leave him.

Then Danny rolled over, looked at me and whimpered. I talked to him while changing his soaked diapers. Then I picked him up, held him on my lap, and gave him a cup of water which he drank eagerly. As I held him during the next half hour, his whimpering slowly ceased and he began to finger the toys which I offered. When comforted by physical closeness, I moved him to his bed and offered him the case of toys. Quickly he involved himself in play as I sat and observed at his bedside.

Thirtieth Day.--Danny watched me intently when I entered his room after a four day absence. He was lying on his back, still wearing the harness he had worn when sitting in the jumper chair earlier. His diapers were soaked; his bottle lay on the floor beside his crib; he had no toys. He rolled onto his tummy and watched me with wide eyes as I washed my hands. Momentarily he smiled, but it quickly faded into his intent gaze. When I talked with him as I lowered the cribside, he watched suspiciously and submitted passively as I picked him up. His expression did not change as he studied my face and hands with his eyes and hands. I thought he was asking, "Are you really you? Where have you been? Are you really going to stay?" His behavior was sharply reminiscent of our earliest experiences together.

Thirty-first Day.--Today Danny's response to me was markedly different from that observed yesterday. He played languidly with the telephone and blocks when I observed him

in the playroom. Danny looked up as I walked toward him, smiled, and said, "Hello, Danny." Then he grinned as he bounced himself into a standing position and reached toward me with open arms as I squatted beside him. He bounced as I untied his harness, and squealed with delight as I lifted him into my arms.

Thirty-fourth Day.--Danny watched with curiosity as I placed him beside the tub of water. Eagerly he crawled toward it and grabbed the edge of the tub as if he were trying to crawl into it. When I helped him into the tub, he smiled delightedly.

Danny held the edge of the tub firmly for balance. Whenever he released his grasp, he slipped, became frightened, and grabbed for the edge. When he tried to turn over onto his tummy, he found the tub too small and contented himself with sitting.

While in the tub, he moved his legs constantly, splashed, and enjoyed the moving water on his body. With his free hand he grabbed the floating boat, and explored its properties with his mouth.

Danny moved his legs and hands and splashed vigorously. Occasionally when his face got splattered, he looked up in surprise, rubbed the water from his eyes, and splashed again. When the water sprayed onto the floor, Danny's facial expression and vocalization echoed his delight. Cries of protest broke forth as the play period drew to a close.

Thirty-ninth Day.--On this day when Danny was restrained in his crib for a twenty-four hour urine collection, he played quietly with the toys which were strung across his bed. When he saw me, he smiled with delight and giggled. Then I released his restraints and sat him up to drink water from a cup.

While with him, Danny played, giggled, and conversed with me in his sing-song way. The moment I turned away from him, he fretted and cried. When another child's parents asked me questions, he sobbed with anger. His eyes were sad and tired. When the questions were answered, I talked and sang to him as I carressed his forehead. When his sobs diminished, he watched my lips and listened. Then his tears ceased to flow and he fingered other toys which I had given him.

Seated on my lap during supper, he needed frequent bubbling as he nibbled food and consumed quantities

of Lonolac and water. When supper was over, I cuddled him in my arms for a short while before tucking and restraining him into bed for the night. He fell asleep quickly as I sat at his bedside.

Interpretation of Data

As Danny's relationship with me deepened, his strength, physical activity, responsiveness to me, and ability to play expanded. Danny expressed more pleasure in his play and during meals. He reached out to me as I approached; the first faint smile broadened into a grin; his sad eyes began to twinkle; his thin arms reached out manifesting his need to be held; silence became replaced with happy sounds.

As Danny became more attached to me, I became more emotionally involved with him. My intellectual interest in him expanded into an emotionally important relationship with a special little boy. My responses to him became increasingly more spontaneous. I enjoyed playing with and feeding him, and watching him at play and as he struggled to learn to feed himself. I missed him and was concerned about his well-being when a four day illness necessitated separation from Danny. During that period, Miss Blake cared for Danny during the time when I had planned to care for him. It reassured me to know that Danny would be cared for by a familiar person who knew his patterns of need for care. While separated from Danny, I became acutely aware of the feelings that Mrs. Smith must have had to bear throughout the period of Danny's hospitalization. I became eager for her to visit Danny and to meet her. I was not satisfied with communication with her by letter. Therefore, I decided to telephone her so that I might have more personal communication with her.

As Danny's trust in me grew, he became able to express his anger and disappointment. He discovered that expression of feeling did not deprive him of the loving, giving relationship that he needed to maintain with me. Danny heartily disliked having to wait to play with the case of toys while his diapers were being changed. He whimpered, squirmed, and kicked constantly while being diapered. When free of my restraining hands, he grabbed for the handle of the toy case and for its contents.

Danny grew increasingly more able to express his displeasure each time he re-experienced separation from me and from his mother. If not already asleep when I left after supper, Danny cried. The day after each of his mother's visits, he regressed; his activity and appetite decreased and his face looked sadder. Re-establishment of his relationship with his mother became easier and more rapid on each visit.

Physical examination of his ears, throat and eyes brought cries of protest. Injections and the painful removal of adhesive tape from his body evoked screams. The application of the urine collectors and restraints for twenty-four hour urine collections aroused feelings of frustration and anger. The frequency of Danny's protests mounted. When frustration was more than he could bear, he resorted to withdrawal and sleep.

Chest and ankle restraints and lower body covering to prevent removal of the urine collector from his penis gave Danny more freedom than wrist restraints. This facilitated play with toys strung across his bed, but his enthusiasm for play was limited during these periods.

Danny was able to play for short periods when I remained with him. Thereafter the imposed limitations were more than he could tolerate. His toys and bottle rolled out of reach even when tied in place. It was difficult for him to get air up from his stomach when lying on his back, and his physical discomfort mounted. When stress became more than he could bear, Danny sobbed until comforted or until he fell asleep from exhaustion. He ate poorly when restrained for urine collection. He burst into tears of fury whenever I left him to help another child or adult.

Play periods and meals in the highchair relieved some of the stress which restraints imposed upon Danny. Urine collection could be maintained and a larger variety of play experiences provided. Danny ate better when sitting up in the highchair and when given freedom to play before meals.

My joy in caring for Danny increased as he became more able to express both pleasure and displeasure. His tears were not an annoyance to me; they were a signal of an unfulfilled need. I was acutely aware of the painful stress which restraints imposed and comforted Danny by holding him on my lap for longer periods. I also made it possible for Danny to play and eat in the highchair. I was greatly relieved when the urine collections ended.

As I grew to appreciate Danny as a person, the scope of my concern broadened to include his mother (see Chapter III). I began to realize how much Mrs. Smith must miss her son. I wanted Danny to go home. My conviction that a child should be with his mother--the most important person to him at this stage of his development--was

reinforced by my observation of their relationship with each other. With increased awareness of my own feelings, I became able to encourage Mrs. Smith to care for and comfort Danny when she visited. I was able to support Mrs. Smith rather than replace her. Anticipation of Danny's discharge became easier to bear when I discovered how much this child and his mother needed each other.

Danny's weight gain and the maintenance of his fluid and electrolyte balance were evidence of steady physiological progress and emotional growth. During hospitalization, Danny's weight progressed from twelve to sixteen pounds. It remained below the third percentile but showed a marked progression toward his predicted percentile position. His height remained at a position just below the third percentile. (See Growth Chart in Appendix, p. 72.) This weight gain reflected improved fluid balance and increased intake of solid food. It was probably also a response to growth in his relationship with me, and to Danny's participation in self-feeding. The alteration of his diet to include some junior and finger foods facilitated participation in self-feeding.

The laboratory chemical determinations of Danny's serum sodium level provided descriptive data about Danny's fluid and electrolyte balance. Danny's serum sodium level remained within normal limits when adequate fluid intake was maintained. Twenty-four urine tests for volume and sodium content and corresponding serum sodium determinations indicated that Danny's daily fluid output averaged 2500 milliliters. To maintain adequate hydration, his fluid intake had to exceed this amount. Deviations below this quantity were reflected by elevations of the serum sodium level, increased thirst, and decreased intake of

solid food.

A healthy infant of Danny's weight (about seven kilograms) requires about 1000 milliliters of fluid per day. The urine volume of a healthy seven kilogram infant averages 500 milliliters per day and has a specific gravity of 1.010. It could fluctuate between 150 milliliters of concentrated urine with a specific gravity greater than 1.010 and 2500 milliliters of dilute urine with a specific gravity of 1.002.

Comparative urine tests for volume and sodium content revealed that hydrochlorthiazide appeared to have minimal effect in decreasing Danny's urinary output. Therefore, this medication was discontinued. When Danny's health status was re-evaluated three months later, this conclusion seemed inaccurate. Therefore hydrochlorthiazide was again added to the plan of treatment with diminution of Danny's water requirement.

Danny made marked progress during this period of hospitalization. To insure continued progress, Mrs. Smith was encouraged to spend longer periods in the hospital so that she would have help in learning how to care for Danny before he was discharged.

CHAPTER III

PREPARATION OF MRS. SMITH FOR DANNY'S CARE AT HOME

Mrs. Smith's Early Experiences with Danny

Mrs. Smith and I did not meet until the thirty-sixth day of Danny's hospitalization. Information, which was gleaned from later study, is presented first to provide chronological clarity.

Mrs. Smith was twenty years old when Danny, her second child and first son, was born. From birth Danny ate and drank well. This was undoubtedly helpful in promoting a mutually enjoyed post-natal mother-child relationship. The rapidity with which Danny drank and the large quantity of milk, water, and cereal which he consumed were subjects for his mother's boasting. When Danny failed to gain weight, Mrs. Smith expressed her concern to a number of physicians until she found one who recognized that Danny had a health problem. When Danny became suddenly ill at the age of four and one half months, Mrs. Smith became frightened. It was necessary for her to call several local physicians and the hospital before finding a doctor who would see her son that night. She said that she felt relieved when she was told that Danny was sick and needed hospitalization.

During the first two periods of hospitalization, Mrs. Smith's visits to the hospital were infrequent and she had less help than she needed. During the first hospitalization, Mrs. Smith wondered if Danny "would be all right." When she related this to me, I surmised that she

had been fearful lest he might die, but she did not verbally express this. Prior to Danny's first discharge from the hospital, Mrs. Smith had one period of instruction with a dietitian to learn about her son's low soidum diet requirement. The physicians explained his disease and treatment to her. No referral was made to the local public health nurse at that time. During Danny's second period of hospitalization Mrs. Smith reported that all instructions for the care of her son were given to her by physicians.

During the first weeks of Danny's third hospitalization, distance, winter weather, transportation, economic problems, and perhaps also fear of the hospital environment made only a single visit possible for Mrs. Smith.

Danny as a Source of Information

The second source of information regarding the problems confronting Mrs. Smith was Danny himself. Through the provision of nursing care to Danny, I identified the problems imposed upon by his disease, its treatment, and hospitalization. These aspects of my work with Danny were described in Chapter II.

Mrs. Smith Is Studied Directly

To learn what problems confronted Mrs. Smith, direct study of her was essential. My major goal was to identify Mrs. Smith's strengths and weaknesses, concerns, and her perceptions of Danny's problems and needs.

Mrs. Smith's failure to visit distressed me. My increasing delight in Danny's improvement and developing trust was my only solace.

When I received this message written in large, awkward but legible script, there was a glimmer of hope and my discouragement diminished: "We would be very glad to have your assistance in helping us with Danny. We will be there on Sunday. We should be there sometime in the late morning."

When Mrs. Smith did not arrive on the planned date, hope dwindled again until she arrived a week later. After my first experience with her, my favorable impression of her encouraged me again.

Mrs. Smith was a youthful, fair-complected woman of medium build. Her curly blond hair was shoulder length and unkempt. She wore a clean but poorly-fitting print blouse, gray wool skirt, white ankle socks, and unpolished loafers. Her blue eyes sparkled and she smiled as she watched her son bounce with excitement on her lap. Initial interaction with Mrs. Smith began this way: "I'm Miss Aradine, the nurse who has been caring for Danny. I'm so glad you could come to see Danny and that I could be here to meet you." Mrs. Smith smiled in response to me and said, "It's so good to see him. He looks so much better. And thank you for writing about him. I started to answer the second letter but never got it mailed to you...."

As Mrs. Smith held Danny on her lap as we talked, she watched his movements as he played with a toy telephone and paper cups. He looked up at her frequently as if he wanted her approval. His eyes sparkled. He walked with eager but unsteady steps as she held his hands firmly. Numerous times she commented with amazement upon the changes that had transpired in his growth, development, and health since she had seen him three weeks earlier. She seemed happy and at ease with Danny and

with me.

In this initial informal interview with Mrs. Smith, another major goal was to find answers to these questions:

1. What concerns and problems has Mrs. Smith had at home in caring for Danny?
2. How does Mrs. Smith think I can be of most help to her in caring for Danny?
3. What is Mrs. Smith's concept of Danny's medical problem?
4. What help has she had in the past in learning about Danny's problem and the care he requires?

Mrs. Smith's Nursing Diagnosis

As Mrs. Smith responded to my questions, I began to formulate impressions of her strengths and weaknesses. I made this nursing diagnosis: Mrs. Smith is an enthusiastic and receptive mother of a one-year-old boy and two-year-old girl. She has sketchy knowledge of Danny's needs and little understanding of the nature of his medical problem. She is able to tell me that Danny's disease involves his kidneys and that he should have little salt and large quantities of water. However, she has little comprehension of the amounts of salt and water which Danny receives and/or needs. She associates his failure to gain weight with his loss of water. She believes that in passing large quantities of urine, Danny "washes from his body the good things that he needs to grow." Her major concerns center around his dietary needs and the preparation of his food. She asked, "How much should Danny eat? What meats can he have? Does he have to have Lonolac? What has he been eating here?" Her questions reflect

motivation to learn what Danny should eat, but as yet she is not ready to delve into the reasons why he needs a special diet.

Mrs. Smith is dismayed that Danny has to be hospitalized for every minor illness. Her questions indicate that she wants to learn how to prevent it: "What should I do if Danny starts to get a cold or the flu? Does he have to go to the hospital every time?"

Mrs. Smith watches Danny's activities closely and asks about the things he is becoming able to do, e.g., sit, stand, walk: "Is he behind (in growth and development)?" Her concern about his development is present but less prominent than those previously mentioned. She has minimal knowledge of growth and development.

An addition was made to the condensed nursing diagnosis and placed on the kardex:

3. Danny's mother has little knowledge of his health problems and physical and developmental needs; she is eager to learn.

The Helping Relationship with Mrs. Smith

After Mrs. Smith explored the above questions with me, I asked her if I might begin to help her by explaining Danny's basic problem. I included the following main points in approximately these words:

1. Danny has a disease called nephrogenic diabetes insipidus.

2. His kidneys are not able to keep as much water as his body needs.

3. He needs large amounts of water. When he does not get enough water he becomes sick and dehydrated (that means dry).

4. His salt intake is closely associated with how much water he needs. Because salt increases his need for

water, Danny should have very little salt.

Mrs. Smith listened closely but asked no questions when I explained that Danny's disease and requirements were hard to understand. I assured her that I could help her best if she could spend several days taking care of Danny in the hospital and asking questions when they arose. I told her that I was eager to help her in any ways I could. She seemed desirous of help but needed to arrange for the care of her older child and find transportation.

During the visit Mrs. Smith expressed joy in being reunited with Danny, sadness upon leaving him, and gratitude for the assistance which I offered. Her overt behavior did not demonstrate grief about Danny's illness or fear the hospital environment. Her concern about Danny's numerous hospitalizations suggested that her adequacy as a mother was threatened. I postulated that Danny's imperfection had produced grief that she had been unable to face. Mrs. Smith's visit was encouraging. I no longer felt only that she needed help; I now desired to help her.

During the next two weeks, Mrs. Smith spent two non-consecutive days caring for Danny. She fed, bathed, and clothed Danny with confidence. She diapered him only when his diapers became soaking wet. She offered him drinks by filling his bottle whenever he emptied it but was careless about keeping his bottle within his reach. She learned to record accurately his fluid intake and asked, "Would it help if I recorded Danny's food and fluids at home?" Her desire to learn and succeed was evident.

The hospital dietitian instructed Mrs. Smith in the selection

and preparation of low sodium foods. She wrote out low sodium diet information for Mrs. Smith (see Appendix, pp. 76-79). Mrs. Smith's questions during this interview centered upon what foods she could give Danny and how to prepare them. Mrs. Smith understood that she should not add salt to Danny's foods, but she had minimal comprehension of sodium as a component of foods. She equated high salt content with all fats because she knew that Danny could not have butter unless it was unsalted. Mrs. Smith seemed bewildered by Danny's dietary restrictions. She was certain that she would have to prepare all his foods separately. Mrs. Smith wanted to use as many packaged mixes as possible; the dietitian cautioned her against doing so because they often contained large amounts of sodium. Mrs. Smith reread the dietary instruction sheets over the week between her visits. On her next visit, I reviewed the low sodium diet instructions with her. She seemed less bewildered and expressed the need "to learn by doing it."

Helping Mrs. Smith to learn the care that her son required included discussing Danny's chronic disease, the treatment it required, and the rationale behind the treatment. I expanded the four points previously listed in this way; the wording is approximately that used during the interviews. I did not discuss the function of the anti-diuretic hormone in order to limit the details which Mrs. Smith had to learn.

> The human body must maintain a balance between its various components to function correctly. Two important parts of the body which must be balanced are its sodium (salt) and water; these are very closely related in the chemistry of the body's function. Both are received from the food and fluids which we take into our bodies; excesses of both are discarded by the kidneys.
>
> The kidney is the part of the body responsible for

the maintenance of the body's balance between salt and water. Danny's basic problem, nephrogenic diabetes insipidus, centers in the inability of his kidneys to retain water; they are able to keep some water but not nearly the amount which his body needs. Therefore he needs to drink large quantities of water to supply his body's needs. He voids frequently because much of his fluid intake cannot be reabsorbed and is discarded.

The human body requires specific amounts of both sodium and water. Water and sodium are found in the cells and blood of the body. Cells are the units of structure and function of which the body is composed. Sodium is always found dissolved in water. (The analogy of dissolving salt in a glass of water helped to illustrate this point.) If more sodium is eaten than is needed, the kidneys discard it. The body cannot store sodium as it does sugar and fat. The body excretes additional water when it discards excess sodium. Danny needs water in sufficient amounts to balance the sodium and water that he loses. Therefore, the more salt Danny eats, the more water he needs.

The water needed to excrete the waste products of the body comes from the water contained in the body's fluids (including blood) and cells. The water in the body fluids and cells comes from the food and fluids which are eaten. When there is a large quantity of sodium to be discarded, a great deal of water is required. If the blood does not contain enough water, the body must use some of the water contained in other body fluids and within the cells. In so doing the cells do not have sufficient water to meet their needs and become dry or dehydrated. (Helpful analogies were dry skin and chapped lips.) When Danny's fluid intake is less than the urinary output, his body becomes dehydrated. To replace this loss, Danny needs to drink increased amounts of water. The amount of water Danny drinks must exceed the amount he loses daily as urine. Thirst is the best indicator of Danny's fluid need. (Danny's great thirst after periods of lessened fluid intake was descriptive of this.) As Danny gets older it will be easier for you to know when he is thirsty because he will be able to tell you this and get himself water to drink.

When Danny has a cold, fever, diarrhea, or vomiting, his body needs even greater quantities of water to replace that which is being lost and to fight the illness. He is unable to obtain this needed water when he vomits. All babies become sick when this occurs, but Danny becomes sick more rapidly because of his greater need for water

> and his inability to preserve the water in his body. It is important to contact your local doctor as soon as you realize that Danny is ill.
>
> Hydrochlorthiazide, the medication you were giving Danny, helps some children with this problem to retain larger amounts of water. As it does not seem to be helping Danny, it has been discontinued.

Mrs. Smith was eager to learn. She listened intently and interrupted me to ask questions when she did not understand what I said. She asked me to wait until she lighted her cigarette before continuing our discussion. At each interview Mrs. Smith was given the opportunity to explain Danny's problem and needs in her own words. She eagerly commented, "Now let me try to explain it to you." With repetition, her understanding increased. Her confusion between diabetes mellitus and nephrogenic diabetes insipidus decreased. Mrs. Smith became able to explain Danny's problem in this way:

> The name of his disease is "water diabetes." Danny needs lots of water. He should not have salt because it makes him need more water. His kidneys don't hold his water. He gets sick when he doesn't get enough water. When he gets a cold he needs more water than usual and I should call the doctor right away. When he drinks lots of water he doesn't have as much room for food so he doesn't gain weight as well.

Between visits Mrs. Smith initiated discussions of Danny's dietary and fluid needs with several family members and friends. She informed them that Danny could not eat certain foods. She told them what foods Danny was permitted to eat and what foods were restricted. Mrs. Smith suggested that these foods not be served to the children. Mrs. Smith recognized the importance of keeping a bottle of water within Danny's reach until he was old enough to ask for a drink. She brought several extra bottles for water with her on the day he was

discharged.

Mrs. Smith's enthusiasm and increased understanding of her son's problems and needs were encouraging. I became increasingly interested in Mrs. Smith as well as in Danny. My desire to help her grew. I believed that she was capable of caring for Danny at home with further knowledge and encouragement. When Danny was discharged, I gave Mrs. Smith a written list of his needs and the plan of care which she had been learning. I contacted the local public health nurse and asked her to assist Mrs. Smith (see Appendix, pp. 83-86). I made plans with Mrs. Smith to be present on subsequent clinic visits and to telephone her frequently to answer questions and offer encouragement.

CHAPTER IV

THE FIRST EIGHT WEEKS AFTER DISCHARGE

Danny's Progress

Danny's initial progress after discharge was hampered by an upper respiratory infection and otitis media. When he returned to the clinic two weeks after discharge he was lethargic and irritable. He showed no interest in any activities. His color was pasty; his eyes no longer sparkled. His weight (fifteen and one half pounds) had decreased one half pound. Purulent discharge obstructed his nasal passages. His fluid and food intake were low. His slightly elevated rectal temperature and markedly elevated serum sodium indicated that he was mildly dehydrated. His perineal area was red and irritated.

Danny's upper respiratory infection gradually subsided in response to treatment with saline nose drops and penicillen. Two months after discharge Danny showed definite physical progress. He was constantly active. His eyes sparkled, and his curly blond hair was shiny. His weight (eighteen pounds six ounces) had increased to a level proportionate to his present height (twenty-eight and one half inches) although both remained below the third percentile for his chronological age. Clinical observations and laboratory data confirmed that he was adequately hydrated. His nose and ears showed no signs of continued infection. His skin, including the perineal area, was without irritation. Mrs. Smith reported that Danny had eaten well over the

past few weeks and had maintained or exceeded the minimum fluid requirement.

In psychosocial growth and development Danny had also progressed. By the end of his hospitalization he had begun to creep backwards on his hands and knees and walk short distances with uncertain, wide-based steps when well-supported by an adult. He sat and stood without support. He was participating in self-feeding. His vocabulary consisted of numerous sounds including "m-m-m-m" and "da-da-da" but no distinct words.

When a home visit was made a week later, Danny's activity had increased. Excerpts from the recorded data demonstrate his progress:

> Danny sat in his highchair in the tiny living room. His white tee-shirt was streaked with breakfast foods. His face was smeared with toast. His hair was filled with toast crumbs. His eyes sparkled when he smiled. He chewed a piece of toast, played with it, smeared it across his tray and face, dropped pieces of it onto the floor, and carried on a constant conversation of jargon with himself while doing so.

Danny had learned to creep in a forward direction and stood steadily with support. He cruised and walked with increased steadiness when supported. He had learned to sit down by bending his knees and letting his buttocks drop with a gentle thud; he had not yet learned to pull himself up into a standing position.

Eight weeks after discharge Danny was an active boy as he explored the clinic waiting room:

> On hands and knees Danny scooted rapidly from one corner of the waiting room to another. He crawled under tables and chairs and into corners to explore their properties with hands, eyes, and ears. Frequently he returned to the middle of the room, lifted his bottle, took a drink, and dropped it to the floor and then continued to explore. His eyes sparkled with interest. His shoes were scuffed and the knees of his red playsuit were well-worn.

Danny crept rapidly with well co-ordinated movements. He walked rapidly with support, lifting his widely-spread feet high. He was not yet able to walk alone. He had learned to pull himself into a standing position. He vocalized numerous sounds and explored new ones. He achieved a vocabulary of at least five distinct words: mama, dada, bye-bye, hi, and nigh(t)-nigh(t).

During the early weeks of hospitalization, Danny submitted to care and physical examination with little protest. Slowly he had begun to voice his displeasure whenever he was restrained, his ears or throat examined, urine collectors attached or removed, or medications given by injection. During the first clinic visit he was irritable and cried throughout the physical examination. During the second clinic visit, crying and struggling were limited to examination of eyes, ears, and throat for which he was restrained.

Danny's participation in self-feeding increased gradually. Mrs. Smith gave Danny fluids by cup during and between meals; she retained his bottle as a source of fluids Danny could easily obtain during play periods and during the night. Danny learned to manage the cup without spilling except when increased thirst caused him to drink rapidly. He communicated his thirst by crying. He took a new interest in the water faucet and came to watch whenever he heard water running. He fed himself finger foods, played with a spoon during meals, and experimented using a spoon to put food into his mouth. His appetite improved as more finger foods were included.

Sibling rivalry presented an additional stress for Mrs. Smith when Danny returned home. Danny cried for his mother whenever Susie

approached. Susie regressed to wetting, wanted a bottle, snatched Danny's bottle, and demanded attention. Occasionally Susie treated her brother roughly by hugging him tightly. Gradually the degree of rivalry decreased. The public health nurse and I worked with Mrs. Smith to help her to grow in understanding of these aspects of behavior; this however will not be discussed in this paper.

Mrs. Smith's Progress

During the first eight weeks after Danny's discharge, I worked with Mrs. Smith through clinic visits, home visits, and telephone calls. I gradually transferred the helping relationship to the public health nurse in preparation for my coming absence. Through my interviews with Mrs. Smith and Danny, I became increasingly aware of Mrs. Smith's strengths, weaknesses, abilities, understandings, and misunderstandings about Danny's care and needs.

Danny's homecoming after his seven week absence required adjustment by all family members. Mrs. Smith had cared for Danny in the hospital on two occasions prior to his discharge. Now it was necessary for Mrs. Smith to transfer her learning to her own home. Here Danny's care was her responsibility. The support of professional people was less readily available although the public health nurse and I maintained contact with Mrs. Smith by telephone, home visits and clinic visits.

Maintaining a balance between Danny's food and fluid intake and his sodium and water intake continued to be the area in which Mrs. Smith needed the most assistance. For the first two days Mrs. Smith faithfully recorded Danny's food and fluid intake. She recorded his fluid

and food intake sequentially, but rarely recorded the times at which the food and fluids were given. The amounts and the content of Danny's fluid intake were described as follows: "8 oz. water, 8 oz. milk, 4 oz. juice." It was necessary for me to clarify that "milk" meant Lonolac formula and that "juice" meant orange juice. My observations and those of the public health nurse verified that Mrs. Smith recorded the amounts of fluids accurately. Mrs. Smith recorded Danny's intake of solid foods less accurately; e.g., "1 spoon meat, 1 dish cereal, 1 egg." She rarely recorded the exact amount or the specific food that Danny ate.

After keeping a record of Danny's intake for a few days, Mrs. Smith omitted this recording because it seemed to be too much of an effort. She felt Danny was "doing okay" (in spite of his upper respiratory infection) and receiving sufficient fluids. At the first clinic visit Mrs. Smith learned that she could not make this assumption. She resumed her recording of Danny's food and fluid intake for several days. Then she became spasmodic in recording his intake. Toward the end of the eight weeks, Mrs. Smith began to maintain a record of Danny's fluid intake, but she did not record his food intake.

As her recordings became more frequent, Mrs. Smith became increasingly aware of the large quantity of fluid Danny consumed. By the end of this eight week period she had become aware that Danny drank more water in the morning. She noticed that he did not awaken for drinks at night, and that he ate poorly when he was thirsty. She grew to understand that whimpering during meals, some crying at other times, and interest in running water was often Danny's way of communicating

his need for water.

Mrs. Smith found the low sodium diet difficult to follow. Initially she followed rigidly the written instructions for Danny's low sodium diet which were given to her by the dietitian (see Appendix, pp. 76-79). She prepared all Danny's foods separately. Mrs. Smith ennumerated what Danny ate, but asked few questions about his diet restructions. She used Lonolac, low-sodium bread, and a small variety of the cereals, fruits, proteins and vegetables which he was allowed. She frequently asked if she could use prepared, packaged foods. It was necessary to remind her frequently that most packaged foods were prepared with extra salt and therefore were not permitted on Danny's diet. She did not use dietetic foods because of their expense and her confusion between dietetic foods prepared without salt and those prepared without sugar.

Mrs. Smith was instructed to prepare and use saline nose drops to treat Danny's upper respiratory infection. This use of salt confused her: "Why can he have salt this way if he can't eat it?"

As the weeks passed and her experience with Danny's diet and eating habits increased, Mrs. Smith became less rigid in following the diet format. If Danny refused his meat, Mrs. Smith substituted an egg. If he did not eat well at lunch, she gave him more food at supper. She began to give Danny fruit juice, an extra glass of Lonolac or some Kool-aid instead of water to drink between meals. Mrs. Smith introduced more table foods. She prepared Danny's meal with that prepared for the other members of the family, seasoning theirs after cooking. Her questions became more specific and more numerous: e.g., "Danny doesn't

like meat; what should I do? He won't eat mashed vegetables any more; how do I get him to eat them? How much sodium is there in a hot dog? Can he have hot dogs and bologna once in awhile?"

The preparation and use of foods were the most prominent areas of discussion with Mrs. Smith. During the second home visit I observed her prepare lunch for Danny and her family and feed Danny. This offered me an excellent opportunity to observe her skills and problems and to offer helpful suggestions to her as questions arose. Encouraging her to use more finger foods (e.g., pieces of meat, vegetables, fruit he could pick up) was one such item of help. I obtained evidence to prove that she had used this suggestion on the second clinic visit: "Danny just loves pieces of string beans when he can pick them up with his fingers. He wouldn't eat the mashed ones."

Mrs. Smith showed that she had learned to observe the developmental milestones which I had anticipated for her: "He can stand by himself; he has learned to say 'hi'; he always comes to see what's going on when I turn on the water faucet."

Mrs. Smith's perception of Danny's state of health or illness grew slowly. In talking with her by telephone during the first two weeks, she said: "Danny is doing okay." In reality, he was not. Her observations of his upper respiratory infection symptoms were limited to: "His nose still is running" or "He has a cough" or "He didn't eat today." She had difficulty making additional observations, e.g., fever, fatigue. Over this eight week period I noted little change in Mrs. Smith's ability to observe. However, her skill in preparation and administration of Danny's nose drops increased. She understood their

purpose and results. Thereafter she administered them regularly rather than spasmodically.

The core of the nursing support which I gave during this eight week period was the maintenance of a helping relationship with Mrs. Smith. Frequent visits and telephone calls facilitated communication. Interviews and observations enabled me to provide information and added instruction as Mrs. Smith indicated need for it. I reviewed Danny's basic problem and needs with Mrs. Smith at clinic visits. As yet Mrs. Smith did not have intellectual comprehension of Danny's problem, but her recognition of his needs and of the ways in which she could meet them grew significantly.

The public health nurse visited the Smiths weekly. The frequency of her visits, the maintenance of telephone contact between the public health nurse and me and the home visit I made with the public health nurse helped Mrs. Smith to perceive this nurse as a helpful person. Gradually the public health nurse developed a helping relationship with Mrs. Smith. As this relationship grew I decreased the frequency of my contacts with Mrs. Smith to prepare her for my absence over the summer months.

My own emotional response to Danny and Mrs. Smith fluctuated with the progress they made. I was discouraged by Danny's upper respiratory infection during the first weeks after his discharge. Six weeks later his improved health encouraged me. My knowledge of the multiple concerns facing the Smith family at home was limited. This restricted my understanding of the demands and burdens Mrs. Smith bore. The two home visits helped me to envision more clearly some of the problems confront-

ing her. I became especially aware of the limited space for play and work that their small home provided. Mrs. Smith had limited space to store and prepare food for two differing dietary regimens for her family. The toddlers had a small area for play and were constantly underfoot which undoubtedly increased Mrs. Smith's tension. Mrs. Smith's increasing recognition of Danny's progress in growth and development and her attempt to follow Danny's dietary restrictions were encouraging. Her unsystematic recording of Danny's food and fluid intake annoyed me. I had to remind myself constantly that the pressures of the home environment and Mrs. Smith's limited education had not given her an orientation toward systematic recording. The most encouraging aspect of Mrs. Smith's behavior was her desire to learn and to follow the plan of care established for Danny. This was reflected in Danny's physical and psychosocial progress. Mrs. Smith's ability to utilize the help the public health nurse and I offered also reflected her desire to learn and succeed. Mrs. Smith showed increased joy in Danny as a person and in his increasing abilities. This bolstered my interest in Mrs. Smith as well as in Danny.

CHAPTER V

FLUCTUATIONS IN PROGRESS DURING THE SUMMER

Danny's Progress

During the summer, Danny and Mrs. Smith made progress with the public health nurse's frequent supervisory visits. Danny had one examination at the university medical center pediatric clinic and one by his local physician. The only illness Danny had during the summer was scarlet fever at age fifteen months. This did not require hospitalization. His serum electrolytes remained in balance. His hydration was adequate. Hydrochlorthiazide was reinstated with resultant effective limitation of water loss.

Danny's physical and psychosocial development progressed. He used his fingers and a spoon and fed himself without assistance. Cruising became a familiar and stable means of locomotion; he did not walk alone. He learned to climb with agility upon various pieces of furniture.

Danny's physical growth was reflected in an increase in height which was consistent with his growth curve. However, his weight decreased one pound. His weight curve dropped while his height curve demonstrated progress.

Mrs. Smith's Progress

Mrs. Smith understood Danny's need for fluids and consistently supplied his daily requirement. However, the public health nurse noted that Mrs. Smith gave Danny several cups of Kool-aid daily. She observed

that family meals were often poorly balanced and without fresh fruits and vegetables. Mrs. Smith continued to have difficulty in understanding Danny's daily need to have a balance between his intake of fluid and food.

Although progress fluctuated during the summer, I was encouraged because Danny had not been hospitalized for five months. This was the longest period he had had a sustained relationship with his mother. Upon my return to the university, I was eager to continue my study of Danny and Mrs. Smith.

CHAPTER VI

PROGRESS DURING THE LAST FIVE MONTHS

Throughout the last five months of the study there were many opportunities to help Mrs. Smith during clinic visits and intermediate telephone calls. I administered immunizations and penicillen intramuscularly to treat otitis media when it was ordered. I coordinated the health team's plan of care for Danny. During this period, progress was observed except when concurrent family crises occurred.

Danny's Progress

Danny's growth chart depicts fluctuations in physical progress. His height increased at a steady rate, maintaining a smooth growth pattern just below the third percentile. His weight luctuated sharply in response to the balance achieved between his food and fluid intakes. At the age of twenty-three months Danny weighed twenty-two pounds four ounces. He remained below the third percentile for his age and sex but had reached a level nearer to his predicted channel.

Throughout this period of study Danny's hydration was maintained which indicated an adequate daily fluid intake. His skin remained in good condition. Serum electrolytes remained within normal limits. The stability of his electrolyte levels was in marked contrast to the fluctuations observed during Danny's first year of life. Clinical observations and Mrs. Smith's twenty-four hour recordings of Danny's fluid intake furnished data to support the assumption based on

clinical observations that adequate levels of hydration were being maintained.

Danny showed steady progress in gross motor activity. At the age of eighteen months he cruised with agility and climbed adeptly. However, creeping remained his fastest and easiest means of locomotion. One month later he was beginning to take three or four hesitant steps alone before reverting to more familiar means of locomotion. He had learned to move from sitting to standing without using an anchor to pull himself up. At the age of twenty-two months he walked steadily alone and this became his major means of locomotion.

Danny's psychosocial growth reflected movement toward the attainment of autonomy. Danny fed himself. At age twenty-two months he was fully weaned from the bottle. He managed a cup well and asked for drinks by using the word "milk" and by crying when tired and irritable.

Danny's vocabulary increased considerably. His speech was distinct and he practiced constantly. He progressed from the use of single words to the use of three word sentences by the age of twenty-two months: "Where's my sock? (I) Get my sock. Here's my shoe. Take it (stethescope) away." At age twenty-three months, he talked briefly with me over the telephone: "Hi! What's your name? Bye."

Danny was apprehensive when he arrived for clinic visits. He remained silent until after all painful procedures and the physical examination were completed; thereafter he played and chattered. During the physical examination he cried and kicked with increasing vigor when his eyes, ears, and throat were examined. At the age of

twenty-two months, he began to indicate his displeasure by pushing the stethescope away from his chest with both hands as he said: "Take it away." His response to injections was vigorous, healthy vocal and physical protest.

Mrs. Smith began toilet training during this five month period but did not maintain her efforts consistently. At age twenty-two months Danny began to say, "Go potty," to indicate his need to void. However, he was only occasionally successful in voiding or passing stool on the toilet.

Mrs. Smith's Progress

Danny's physical and psychosocial progress were indices of his mother's progress. The physical care which Mrs. Smith gave reflected her growing abilities and perceptions of Danny's needs. Hourly diaper changes and large daily wash loads were burdensome. Mrs. Smith experimented until she found a way to fold diapers which increased their absorbancy, limited their bulkiness, and thereby decreased her work load.

Mrs. Smith understood Danny's need for fluids and met it adequately. When I suggested that several cups of Kool-aid daily might limit his appetite at mealtimes, Mrs. Smith replaced it with water. However she did not observe any variation in Danny's appetite.

Mrs. Smith's comprehension of Danny's need for a low sodium diet and the interrelationship between sodium, water, and nutrient intake remained inadequate. Over the summer she substituted milk for Lonolac which increased Danny's sodium intake. When she became able to

tell Danny's physician and me what she had done, it was medically approved. When no immediate detrimental results were noted in Danny's growth during the clinic visit when Danny was nineteen months old, Mrs. Smith again liberalized his sodium intake considerably without consulting any health team member. She gave Danny table foods including those to which salt had been added. Occasionally she added a "pinch of salt" when cooking Danny's food. As a result, Danny's fluid needs increased; his appetite decreased. Concurrent stresses occurred in the family when Mr. Smith was hospitalized and then had to change his place of employment. These stresses limited Mrs. Smith's perception of Danny's changing needs.

When Danny returned to the clinic at the age of twenty-two months, Mrs. Smith said: "He drinks so much but he doesn't eat very well. He was doing all right until he got a cold two weeks ago." Mrs. Smith did not recognize any interrelationship between Danny's lack of progress and the changes which she had made in his diet. She had not noticed that some foods made Danny more thirsty than others. Mrs. Smith recorded Danny's food and fluid intake for one or several days prior to clinic visits when I suggested that she do so. She did not record his food or fluids for her own information. Her records of Danny's fluid and food intake remained unspecific in amount and kind of food: "1 piece toast, apple, 3 heaping tablespoons corn, 2 serving spoons meatloaf, 1 cookie." Occasionally she provided additional information when recording his intake: "he takes no bottle" and "he crews on pieces of meat but doesn't eat them."

As we talked about the changes which Mrs. Smith had made in Danny's diet, Mrs. Smith discussed some of her problems and concerns. With more help in understanding Danny's need for a low sodium diet and with encouragement, Mrs. Smith again became able to meet Danny's dietary requirements. Furthermore, for the first time she was able to see the relationship between the intake of salty foods and Danny's increased requirement for water. She said, "You know, this week I noticed that Danny drank lots more water the day he had bologna for lunch. If he eats food like that with more salt in it, when will I see his water needs go up? Will it go up right away, later that day, or the next day?" This statement indicated that Mrs. Smith was making progress in understanding Danny's chronic problems and in the acquisition of observational skills.

Mrs. Smith also grew increasingly observant of signs and symptoms of illness and of the need to seek medical care. She learned how and when to prepare and administer saline nose drops to treat upper respiratory infections when they occurred. During the last month of the study, Danny's sister became sick. To prevent Danny from becoming ill, Mrs. Smith promptly asked her mother to care for Danny at his grandparents' home until Susie was well.

During the clinic visit which occurred eleven months after I began to study Danny and his mother, Mrs. Smith expressed openly to me for the first time her grief over Danny's imperfection. She wept with discouragement because Danny had failed to progress and blurted forth: "You think I'm not a good mother and I'm doing the best I can." Seventeen months after the diagnosis was made, she was able to get

relief from crying. Two weeks later Mrs. Smith felt encouraged but expressed few feelings as she talked about her past experiences with Danny. At that time Danny's physical progress reflected his mother's use of more instruction about his dietary requirements. She asked more questions and freely interrupted me or the physician when we repeated our description of Danny's disease and the rationale underlying his treatment. After listening attentively to the fact that the disease could be familial, she interjected: "Does that mean it's harder on girls than on boys?" Mrs. Smith's questions reflected her growing interest in learning why Danny required special care.

The study period ended two weeks after the last clinic visit. At this time the public health nurse reported with discouragement that Mrs. Smith was again feeding Danny an unrestricted diet. Danny's fluid intake remained adequate. Mrs. Smith had also failed to make an appointment with the local physician for Danny's continued immunizations.

Feelings of discouragement arose when I reviewed my work with Mrs. Smith, Danny, and the public health nurse with my instructors. With help I became aware of the magnitude of Mrs. Smith's daily problems. Only on one occasion had she expressed feelings of grief, anger, or disappointment to any member of the health team. Yet the daily burdens that Mrs. Smith bore in caring for Danny were great. Mrs. Smith had demonstrated that she understood Danny's dietary restrictions enough to follow them accurately. I wondered if her wide fluctuations in facing Danny's need for dietary restrictions stemmed from conflicting feelings: love for her child, grief over his imper-

fection, resentment of constant direction from others without the reception of concern for her burdens and for her as a person as well as a mother of a chronically ill child.

With help I gained awareness that I had failed to communicate to Mrs. Smith my interest in her as an individual. I had not centered my concern on the problems which Danny created for her. Furthermore I had failed to recognize other problems which she had. This self-awareness saddened me, but with help I learned that it paved the way for behavior change. As a result, I made adjustments in the plan of care for the Smiths after completion of the study. I searched for ways in which I could help Mrs. Smith to acquire the courage to dare to disclose to members of the health team the legitimate resentment she must feel at times. I wanted her to know that she could telephone us when she felt "fed-up," discouraged, or needful of personal support from others. These observations and the alterations in the plan of care for Danny and Mrs. Smith were discussed with her and the public health nurse and communicated to the public health nurse by letter as well (see Appendix, pp. 87-88).

The most dramatic proof of Mrs. Smith's progress in the assumption of responsibility for Danny's care came from contrasting the length of hospitalizations for Danny before and during the study period. Danny spent twenty-seven percent of his first year of life in a hospital. Every upper respiratory and gastrointestinal infection which Danny had had disrupted the mother-child relationship while he was hospitalized. Re-hospitalization was unnecessary during the study period. His mother was able to provide care at home with the help of the health team.

This was true even during those periods when Danny had scarlet fever, otitis media, and several bouts of upper respiratory infection.

CHAPTER VII

SUMMARY, CONCLUSIONS, AND AREAS FOR FURTHER RESEARCH

Summary

Danny Smith was a small, scrawny, despaired child at the age of eleven months. He was hospitalized for twenty-seven percent of his first year of life. During the study period, Danny grew to be a small but well-proportioned, active, and happy twenty-three month old boy. Additional separations from his mother for hospital re-admissions were unnecessary during the study period. Mrs. Smith's feelings of fear and inadequacy diminished as she acquired understanding of Danny's disease and his requirements for care. She learned to recognize his problems and needs and to respond appropriately to them. Her enjoyment and pleasure in providing care to her children increased considerably. During the study of Danny and his mother, nursing diagnoses and plans of care were made, evaluated, and modified when changes proved necessary.

Conclusions

After analysis of the data collected during the study of Danny and his mother, these conclusions which support the proposed hypothesis were drawn:

1. The major element of nursing care which contributed to the progress evident in two members of the Smith family was the supportive relationships established with them. Through the relationship established with

Danny, the nurse (a participant observer) acted as an extension of his mother as she provided daily periods of nursing care during hospitalization. Through this activity, he became less helpless and regained trust in himself and others. The knowledge of and interest in Danny and his health problem which was gained from study and care of him prepared and motivated the nurse to learn ways in which she could become helpful to his mother. The establishment and maintenance of a helping relationship with Mrs. Smith gave her the support, anticipatory guidance and knowledge which she needed to care for Danny. As a consequence, re-hospitalization and frequent clinic visits became unnecessary. This outcome of the study protected Danny's potentials for physical and psychosocial growth and development. It also contributed to the restoration of Mrs. Smith's self-esteem.

2. Systematic study of all children and their parents should be initiated by hospital nurses during their first admission to the hospital. Plans of care should be made with parents as well as with all other members of the health team. Every effort should be made to sustain parents' active involvement in the care of their children.

3. Filmed records of Danny's progress would have been an effective way to validate the findings of this study.

4. Tape recordings of interviews and periods of instruction with Mrs. Smith would have been helpful in the collection and analysis of data. They would have helped the nurse's instructors to identify Mrs. Smith's problems more quickly and those which were preventing the nurse from attaining her goals.

Areas for Further Research

The hypothesis proposed for the study of Danny and his mother was reformulated at the completion of this study: Nursing care purposefully planned to help a chronically ill child and his mother on his first admission to the hospital can protect the child's potentials for optimum growth and development, lessen the number of subsequent hospitalizations and clinic visits, alter the medical

treatment required, and sustain his mother's self-esteem and involvement in her child's care.

Extension of study to groups of children with nephrogenic diabetes insipidus and other chronic diseases and their mothers is needed to supply data to support or disprove the proposed hypothesis. Answers to these questions are needed:

1. What problems are presented by children with nephrogenic diabetes insipidus (or another chronic disease)? What problems are presented by their mothers?

2. Are there problems which are common to all children in the study group? Were these problems presented by Danny?

3. Are there problems which are common to all mothers in the study group? Were these problems presented by Mrs. Smith?

4. How do the children in the study group cope with the problems they present?

5. How do the mothers in the study group cope with the problems presented by their chronically ill child?

6. What elements of nursing care were valuable in helping the subjects of study? Were the elements of nursing care used in the care of Danny and his mother valuable in the care of other subjects of study?

7. What modifications in the provision of nursing care were necessary? What rationale supported the use of these modifications?

8. What additional problems were identified? What elements of nursing care were used to meet these problems?

9. Does the data collected from the study group support the hypothesis proposed? In what ways does it disprove the hypothesis? What additional hypotheses can be proposed?

This study provoked additional questions relating to the nursing care of children with chronic illness and their mothers in the hospital

and/or in the home. Such questions suggest potential areas for further study:

1. How can professional nurses in hospitals, clinics, and public health nursing services coordinate their efforts to provide improved services to families with chronically ill children? What functions does each member of the health team perform in the care of chronically ill children and their mothers? What problems are encountered in working together? How can these be resolved?

2. Can the nursing care of children hospitalized with chronic disease be organized to utilize the case method of assignment? Can it include home visits before, during, and/or after hospitalization? Can it include clinic visits by the professional nurse assigned to the family? What advantages and disadvantages to patient, family, nursing service, and medical team are evident? What problems arise? What suggestions can be made to solve these problems?

3. How do children of differing ages react to the handicaps presented by chronic disease? How do they cope with their handicap? How do their parents cope with the child and his problems and needs? What care can the professional nurse provide to children and parents to support healthy adaptation to their problems?

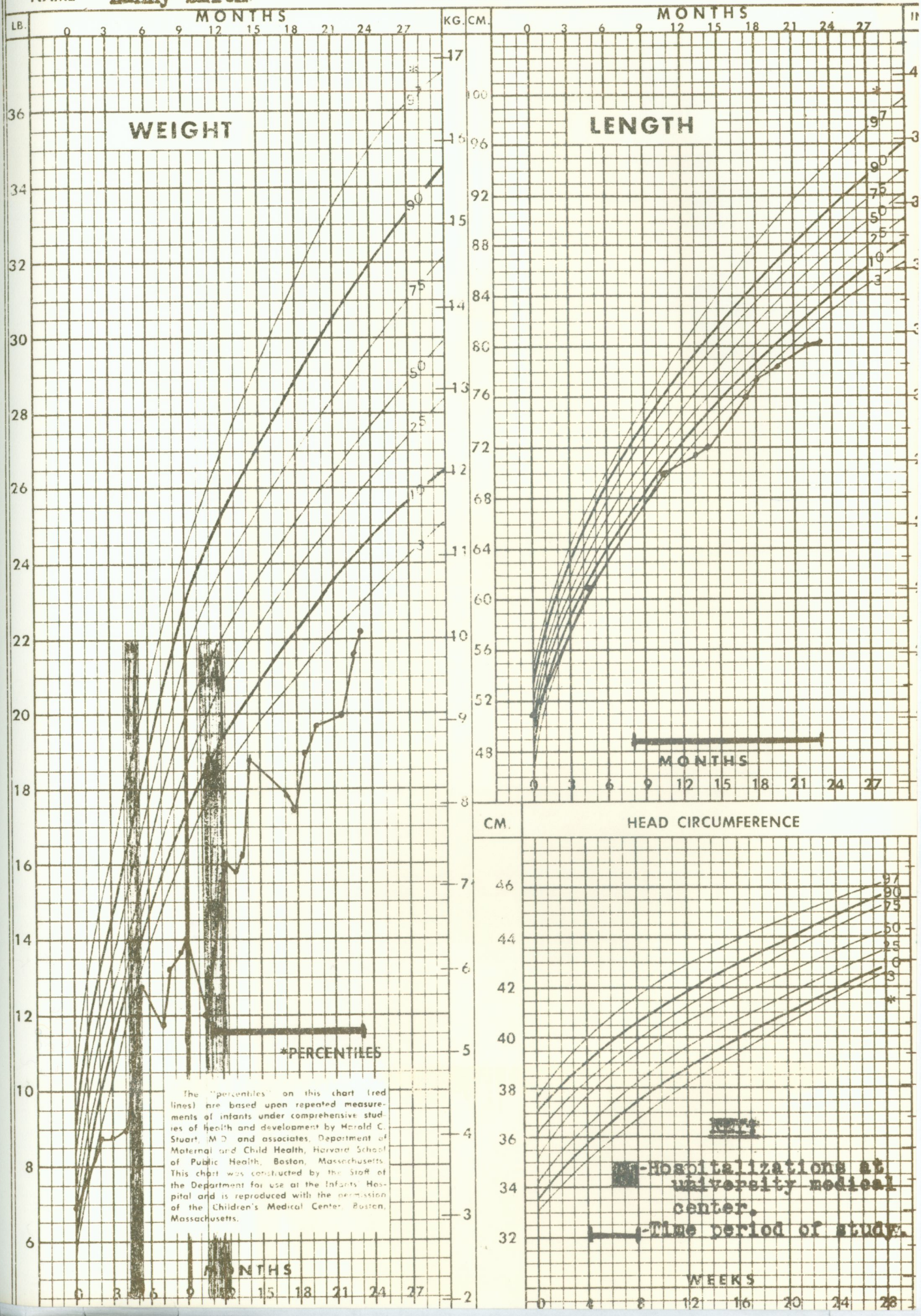
4. How can clinical nursing experience for undergraduate students of pediatric nursing be planned to include study of families with chronically ill children? How can such experiences be provided as in-service education for graduate nurses employed for service in pediatric wards?

5. How can the professional nurse communicate more effectively with members of the health team to provide comprehensive health care for the healthy, the chronically ill, and the acutely ill child and his family?

A P P E N D I X

INFANT BOYS

NAME Danny Smith BIRTH DATE NO.



THE CHILDREN'S MEDICAL CENTER, BOSTON - ANTHROPOMETRIC CHART

THE PLAN OF CARE FOR DANNY

This plan of nursing care was formulated for Danny after study of Danny, his health history, and progress notes, medical texts and doctor's orders:

1. Spend time daily caring for Danny, feeding him, and playing with him in order to establish a relationship with him in which he can learn that I am a providing and protecting person. In so doing Danny will regain trust in people and in his mother.

2. Provide Danny with a daily minimum fluid intake of 2000 ml. Danny drinks readily if offered water in a cup at frequent intervals between meals. He should always have access to his bottle of water because his thirst is the best index of his fluid needs.

3. Encourage Danny to eat low sodium solid foods by providing him with fluids throughout the day and night. He should receive enough fluids between meals so that he is able to eat at meal times. Encouraging Danny to participate in self-feeding increases his interest in meals. He enjoys junior and finger foods and uses a cup. Providing an extra spoon for Danny to manipulate during meals encourages his participation in feeding himself. He enjoys eating with the other children in the playroom.

4. Perineal skin irritation can be decreased and/or prevented by changing Danny's diapers at least every hour and by washing, drying and applying oil to his perineal area when his diapers are changed.

5. Covering Danny's knees with soft materials such as long socks and flannel pajamas decreases and/or prevents skin irritation caused by rubbing on the bedding. Keeping Danny off his knees for part of the day by allowing him to sit in the jumper or high-chair also helps.

6. Administer medications as ordered: Hydrochlorthiazide 2.5 mg. bid (8 a.m. and 8 p.m.).

7. Providing play activities for Danny in his crib with the use of the case of toys and play periods in the playroom promote his physical and psychosocial development.

8. Contact Mrs. Smith by letter and telephone to keep her informed of Danny's progress and to encourage her to visit. Develop a helping relationship with her through which I can assist her to recognize Danny's needs and problems, offer her support in providing care to Danny, and instruct her in order that she may understand his disease and the rationale of treatment.

9. Contact the local public health nurse by telephone and letter to secure her assistance in working with Danny and Mrs. Smith when Danny is discharged.

10. Continue to provide nursing care and encouragement to Danny and Mrs. Smith through telephone calls and clinic visits after Danny is discharged from the hospital.

As new data was obtained, these additions and/or alterations were made in the plan of care:

2. Provide Danny with a daily minimum fluid intake of 2500 ml. ... Bubble Danny frequently after he takes a drink to help him manage the air he swallows when he drinks rapidly. Awaken Danny during the night to offer him fluids; this may help to abate his seemingly unrelenting thirst when he awakens in the morning.

6. Hydrochlorthiazide was discontinued.

During the collection of twenty-four hour urine specimens, these additions were made to the plan of care:

11. When Danny is restrained he has difficulty obtaining adequate fluids. Fastening his bottle so that it cannot roll out of his reach, offering him fluids with a cup frequently, releasing his restraints and allowing him to sit up to drink from a cup, and bubbling him frequently after he drinks are helpful to Danny.

12. When a child eats or drinks while lying down, he may choke, vomit, and/or aspirate part of his food. Feeding Danny in the highchair prevents this hazard while allowing the urine collection to continue.

13. Restraints severely limit Danny's play activities. Supervised periods of play while seated in the highchair permit Danny a wider variety of play activities and facilitate urine collection. This also helps

Danny to release some of the tension that is generated when he is restrained. Suspending toys from a toy bar across his bed helps to prevent them from rolling out of Danny's reach.

14. Accurate data can be collected only when urine specimens are collected correctly. It is necessary to check Danny's position and the urine collection equipment frequently to assure complete collection of the specimen and the maximum possible comfort for Danny. Accuracy in recording both time and amount is important.

15. Restraining Danny with a harness around his chest leaves his hands free to play. Restraining his ankles gently prevents his feet from becoming entangled with the drainage tubing. A sheet or blanket tucked over his lower body helps to prevent Danny from removing the urine collector from his penis.

LOW SODIUM DIET

(300 mg. sodium)

Foods to Include	Modification	Foods to Avoid
1. MILK AND/OR CREAM: Lonolac - 3 to 4 cups/day (Later modified to Similac 60/40 - 3 to 4 cups/day)	Dietetic low sodium cheese may be substituted for part of milk.	Additional milk either for drinking or cooking. All other cheeses. Ice cream & sherbet. Sour cream Buttermilk Dried cream products
2. MEAT, POULTRY, FISH: Not over 6 oz. per day; 1 serving 1/4 cup = 1 serving	Do not add salt in preparation. Use only salt free fats and spices in cooking. Lemon juice adds a very pleasing flavor to cooked fish. <u>Choose from the following</u>: Fresh or frozen beef, veal, pork, lamb, mutton, fowl. Fresh fish. Fish specially canned without salt (must be labeled "no salt added").	All cured meats such as corned beef, dried beef, bacon, ham and salt pork. All sausages, sausage products and processed cold meats. Hot dogs. All pickled and smoked meats and fish. All regular <u>canned</u> fish, meat and meat products (including chickens and turkey). Commercially frozen fish.
3. WHOLE EGGS: Not over 1 per day Egg yolks as desired	Do not add salt or high sodium foods in preparation. Yolks can be used in cooking--use 2 egg yolks	

Foods to Include	Modification	Foods to Avoid
(one whole egg = 60 mgm sodium; one egg yolk = 5 mgm sodium)	in place of one whole egg.	
4. FRUITS AND VEGETABLES: (at least 5 servings per day) Choose: a. At least 1 citrus fruit or other good source of Vitamin C such as tomatoes, melons, strawberries (approx. 2 mg sodium per serving) b. At least 1 yellow or green vegetable (1/2 cup vegetable averages 9 mg sodium) c. Other fruits as desired (1/2 cup fruit averages 2 mg sodium) d. Potatoes (1/2 cup = 1 mg sodium)	Add no salt at table or in cooking. Do not use salted fats or salted salad dressings in preparing fruits and vegetables. Use only fresh or frozen vegetables or vegetables canned with no added salt (must be labeled "no salt added"). Most fruits (except frozen apples) are very low in sodium content and can be used as desired. Canned fruits and baby fruits can be used.	Beets, beet greens, celery stalks, kale, mustard greens and spinach. All canned vegetables. All soups unless they are specially prepared and labeled "no salt added." Commercially frozen lima beans and peas. Sauerkraut and hominy. Frozen apples. Commercial fruit preserves which may have preservatives added. Commercially pickled fruits.
5. BREAD AND CEREAL: (at least 3 servings per day)	Use special bread made without salt. Special sodium free baking powder can be used to make baked foods. Choose from following breakfast cereals: oatmeal, Ralstons, Maltex, Pettijohns, Wheatena, wheat germ,	Regularly baked breads, rolls, etc. All crackers except plain unsalted matzoths. Any baked foods made with regular baking powder, baking soda, self-rising flour, or

Foods to Include	Modification	Foods to Avoid
	puffed wheat, puffed rice, shredded wheat, cream of wheat, sugar coated cereals.	a prepared mix.
		All baby cereals.
	Macaroni, spaghetti, rice, barley.	All cereals except those listed.
	Flour, cornstarch, tapioca can be used as desired as long as no restricted food is added to them.	Prepared pudding mixes.
6. FATS: (salt free fats contain less than 1 mg sodium per serving)	Choose from following: Salt free butter Lard Vegetable fats such as Crisco Vegetable oils such as Mazola Specially prepared salt free mayonnaise or French dressing.	Regular butter. Regular margarine. Peanut butter. Regular mayonnaise and mayonnaise-base spreads. Regular French dressing. Bacon fat and other meat drippings.
7. OTHER:	Plain gelatin and chocolate can be used as desired. Within consideration of total sodium intake per day, the following may be occasionally included: Coke = 2 mg sodium per 6 oz. bottle 7-Up and gingerale = 18 mg sodium per 8 oz. bottle Pepsi = 35 mg sodium per 8 oz. bottle 1 Zwieback = 63 mg sodium	Potato chips. Salted popcorn, nuts, seeds, etc. Pretzels. Most soft candies. Brown sugar. Corn syrup. Molasses.

Foods to Include	Modification	Foods to Avoid
	1/2 cup pudding (made with Lonolac) = 50 mg sodium 1/2 cup jello = 50 mg sodium 1/2 cup or 1 Dixie Ice Cream = 30 mg sodium 5 vanilla wafers = 50 mg sodium 2 graham crackers = 130 mg sodium 3 macaroons = 7 mg sodium 5 animal crackers = 60 mg sodium.	

SEQUENCE OF EVENTS DURING HOSPITALIZATION

Day	Events
*1.	Danny admitted to university medical center for third hospitalization.
11.	Nurse began her study of Danny.
*15.	Parents visited briefly; nurse not present at the time of their visit.
20.	First letter to Mrs. Smith.
26.	Mrs. Smith's reply to first letter received.
26-29.	Nurse absent due to illness; instructor substituted for her.
*30.	Parents planned to visit Danny but were unable to do so.
32.	Second letter to Mrs. Smith.
33.	Nurse presented nursing staff conference on the care of children with diabetes insipidus using Danny as one example.
*36.	Parents visited Danny; nurse met parents for first time.
39.	First twenty-four hour urine collection.
40-50.	Nurse simultaneously studied another child in same room.
40.	Second twenty-four hour urine collection.
41.	Hydrochlorthiazide discontinued.
42.	Third twenty-four hour urine collection.
*43.	Danny's first birthday. Mrs. Smith spent the day at hospital, caring for Danny and discussing his needs with nurse and dietitian.
*44.	Fourth twenty-four hour urine collection.
48.	Fifth twenty-four hour urine collection.
49.	Sixth twenty-four hour urine collection. Referral made to public health nurse.
*50.	Mrs. Smith cared for Danny at hospital; discussed his needs with nurse and pediatrician. Danny discharged at 3 p.m.

*indicates Saturday or Sunday.

SEQUENCE OF EVENTS AFTER DISCHARGE

TIME AFTER DISCHARGE: Months	Days	EVENTS:
1.	*1.	Discharge
	2-14.	Daily telephone calls to Mrs. Smith (except weekends).
	*15.	First return visit to pediatric clinic.
	19.	Nurse's first home visit to Smith's, accompanied by public health nurse.
	22-30.	Nurse's vacation.
2.	34.	Second home visit by nurse.
	*57.	Second visit to pediatric clinic.
3 -- 5.	--	Nurse's summer absence.
5.	--	Third clinic visit.
6.	--	Fourth clinic visit.
7.	--	Fifth clinic visit.
11.	--	Sixth and seventh clinic visits, twelve days apart.
12.	--	End of study; telephone report from public health nurse.

*indicates Saturday or Sunday.

SECOND LETTER TO DANNY'S MOTHER

Dear Mrs. Smith:

Since you were unable to visit Danny over the weekend, I thought you would appreciate knowing that he is progressing well at this time. He has gained weight and now weighs fifteen pounds. His appetite is improved; he eats well and is attempting to feed himself. His physical strength has increased since his illness. He now plays actively and enjoys being in the playroom for part of the morning and afternoon. He stands when in the jumper and is beginning to take steps when assisted by an adult. Danny has found that it is more comfortable and easier to travel when on his hands and knees (than on his tummy); he is beginning to try to creep.

Danny has become happier as he has felt stronger. Of course, he misses you very much. I have tried to help him by being with him part of each day, and will continue to work with him during the remainder of his hospitalization. I do not know how long the doctors feel it will be necessary for him to remain in the hospital.

The medical problems of his disease, diabetes insipidus, have not changed. He continues to need a large intake of water each day. He also continues to need to eat only those foods which contain small amounts of salt and to drink Lonolac instead of milk. You are already familiar with these needs.

Since I have been unable to talk with you directly, I have been searching for other ways in which I could also assist you. Perhaps I could be of more help to you when you do come to visit Danny if you would write to me some of the concerns and questions which you have about Danny and his care. If so, I have enclosed a stamped envelope for your use. May I also inquire if you have had the assistance of a public health nurse? If so, what is her name, and is she still in contact with you?

I am looking forward to meeting you. Please let me know when you plan to come to visit Danny and I shall try to be available at the hospital. Meanwhile, feel free to ask my assistance in any ways you need it.

Most sincerely,

Carolyn R. Aradine, R.N.

LETTER OF REFERRAL TO PUBLIC HEALTH NURSE
(Initial Referral)

Dear Mrs. _____:

Danny is a one year old white male who has been hospitalized at the university medical center three times for dehydration and failure to thrive, secondary to Nephrogenic Diabetes Insipidus.

Danny will be discharged from his third admission within the next few days. I would very much appreciate your assistance with this child and his family. I have worked with them through the course of Danny's present hospitalization and will continue to follow him on subsequent clinic visits. He will be followed by the pediatric renal clinic here. Danny is a delightful child; his parents are receptive to help and eager to learn more about Danny's medical problem, his needs, and his care. They would benefit greatly from your support and assistance. Would you please visit them as early as possible after Danny's arrival home. I would also very much appreciate your keeping in touch with me regarding his progress and/or problems. (I can be reached by mail at _____; or by phone: _____)

Danny is the second child (one sister, Suzie--age two) of
Mr. and Mrs. Smith
_____
_____
phone: _____

Danny was born _____; birth weight six pounds thirteen and one half ounces. The pregnancy and delivery were uncomplicated. Danny was breast fed for five weeks and then switched to bottle feedings of evaporated milk when Mrs. Smith returned to work. (She is no longer employed and will be caring for Danny herself now.) His course was unremarkable until three months of age at which time he was noted to be gaining weight very slowly, although he ate well. At the age of four and one half months he was hospitalized in a local hospital with dehydration and diarrhea and fever. He was then transferred to the medical center for evaluation of his dehydration and failure to thrive. At this time he was hospitalized for forty-one days. He was diagnosed to have nephrogenic diabetes insipidus.

Following discharge he was followed at one to two week intervals in pediatric clinic. At the age of nine months he was readmitted for one week with a markedly elevated serum sodium level. Following this discharge he was again followed at two week intervals here. At the age of ten and one half months he suffered an upper respiratory infection, vomiting, and dehydration and was again admitted to a local hospital. He was transferred to the medical center for re-evaluation of his dehydration and failure to thrive. At this time Danny weighed twelve pounds; his greatest weight to that time had been fourteen pounds four

ounces one month earlier.

During the course of his present hospitalization, Danny has progressed gradually to a weight between fifteen and sixteen pounds. He is being discharged on the same regimen he has been following during his hospitalization. Before giving you the details of his care, let me explain briefly his medical problem upon which the care is based.

Danny has nephrogenic diabetes insipidus which is characterized by polydipsia (unrelenting thirst) and polyuria (large quantities of dilute but otherwise normal urine). His basic problem is the inability to retain water; the distal tubules of his kidneys are unable to reabsorb water in response to the posterior pituitary's anti-diuretic hormone which normally acts at this site to facilitate water reabsorption. Danny has no pituitary defect; the anti-diuretic hormone is present, but for an unknown reason the cells of his distal kidney tubules are unable to respond to it. (In contrast to diabetes insipidus due to hypofunction of the pituitary, Danny cannot be assisted by replacement therapy with pitressin.)

Nephrogenic diabetes insipidus has its onset shortly after birth and is a chronic medical problem. In some families it is a heritable defect; this has not been proven in Danny's family.

Danny's major medical problem centers around the maintenance of his fluid and electrolyte balance. He requires a daily minimum fluid intake of about 2500 milliliters. He voids frequently in moderate quantities and has a daily output of about 2500 milliliters. He is receiving a low sodium diet to prevent the loss of additional water with the excretion of excess sodium from his body. The inadequate intake of fluids; loss of fluids in illness, vomiting, diarrhea, etc; and refusal to eat or drink lead Danny quickly into dehydration and metabolic inbalance; for these reasons he needs careful management and observation.

Danny's care requires the following specifics:

1. Low sodium diet: 300 milligrams sodium; Lonolac formula as a substitute for milk. Diet has been arranged in food groups.
2. Fluid intake of at least 2500 milliliters (eighty four ounces) daily, distributed throughout the night as well as daytime.
3. Skin care as required and frequent diaper changes.
4. No special medications.
5. Close follow-up by pediatric clinic here.

Much of my work with this child has been concerned with developing a relationship with his parents and helping them to understand Danny's medical problem as the need to maintain his body in balance. They understand that his defect involves his kidneys, but I have not

discussed it as a lack of response to the hormone; I did not want to introduce another confusing variable into the discussion. Both parents are interested and eager to learn; they are responding well to assistance. Mrs. Smith spent two days here caring for Danny with my assistance and discussing his needs with me. Over the time I have worked with them they have, I believe, made strides forward in understanding Danny's problem and needs. They will continue to grow in understanding with assistance and support.

Their major need at the moment centers in understanding and becoming comfortable in following Danny's low sodium diet. Mrs. Smith understands Danny's fluid needs; she will need assistance in his dietary needs. One of her areas of special confusion lies in equating fat with high sodium content; this I have reminded her is not true except for butter. She has been given in written form a diet to follow, based on food groups. I hope that she will also come to learn relative sodium content of various foods and these have been included on the list. Food which children tend to especially like have been included. As Danny is now beginning to become interested in self-feeding, finger foods, and able to gradually be switched to table foods, I have begun to discuss this with her. Your helpful hints to her will be appreciated.

Mrs. Smith's other two major concerns include recognizing coming illness in Danny and preventing dehydration and hospitalization. She has discussed this with me and I have instructed her to contact her local physician whenever Danny is becoming ill and to give him no medications except upon the physician's orders. Their other concern is to help Danny's grandparents to recognize that Danny does have this defect, and does need special care. Both parents express concern that they be able to help the grandparents realize that Danny has these needs, and that it is not just a daughter-in-law's differing opinions about child rearing.

This family and child are delightful to be associated with. I have thoroughly enjoyed working with them, and will continue to be in contact with them by phone when Danny is first discharged, and will talk with them when he returns for clinic visits. Your assistance with them will be deeply appreciated by both the family and by me. If I can be of any further assistance to you with this family, do not hesitate to call upon me. I would appreciate your keeping in touch with me, and if you would be interested, I would very much like to join you in making a home visit to this family.

I plan to phone you early next week; if there are any other questions you have about the Smiths, please feel free to ask me.

Many thanks for your assistance, and good luck. I hope that you will enjoy working with them as much as I do.

Most sincerely,

Carolyn Aradine, R.N.
Graduate student in
pediatric nursing

LETTER OF REFERRAL TO PUBLIC HEALTH NURSE
(Final Re-evaluation and Plans for Continued Care)

Dear Mrs. _____:

Thank you for your phone call regarding the Smith family. It must be extremely frustrating and discouraging for you to visit them so faithfully and see such fluctuations in progress. Since you called I've been thinking and re-evaluating in an attempt to get some new insights into ways in which I can help you and we can help the Smiths.

The magnitude of the daily problem this mother faces is more than I can imagine. I wonder how she must feel to get up every morning to face two active demanding toddlers underfoot, Danny's continuous thirst, hourly diaper changes, a load of wash, Danny's medicine twice a day, food that must be selected and prepared uniquely for Danny, special formula milk, and so much more I don't even know about. This is no easy task for her. Nor would it be for me if I had to face this each day.

Mrs. Smith has rarely expressed any feelings of anger, disappointment, or grief to any of us. Yet how much she must feel about the burdens Danny poses for her. She loves him; this we know. But she must also be upset with him at times for imposing such an enormous burden upon her! I'm wondering how we can help Mrs. Smith acquire the courage to dare to disclose to us the perfectly legitimate feelings of resentment she must feel sometimes. I truly can't see how she does all she does seven days a week without some periods when she feels she can't deal with all the responsibilities before her. I'm wondering how we can help her to know that she can call us when she feels "fed up," discouraged, or needful or someone being interested in her as well as in Danny. Do you think this might charge her batteries and strengthen her to face her steady diet of burdens? If she felt free enough to explode with us once in awhile she might become increasingly more able to meet Danny's dietary needs. Then she'd have the pleasures and rewards of seeing Danny thrive at a faster rate.

Danny <u>has</u> made progress. His electrolyte balance has been maintained throughout his second year of life. This is in sharp contrast to the fluctuations of the previous year. His hydration has been maintained. He has grown and he has gained weight. He has learned to walk, to talk, to feed himself, to ask for drinks when thirsty. His trust in his mother has been regained and he is striving to become more of a person in his own right.

Mrs. Smith has shown great progress in adjusting to her problems. She has learned about Danny's fluid needs and maintained this consistently. She sees with delighted eyes his progressing abilities.

She has learned enough to keep Danny out of the hospital (when sick and when well) since last March--nearly a year now. This is dramatic evidence of her ability to learn from all of us. But her job and ours is not over. Danny's problem is a lifelong one and that isn't easy to face as you know so well. It is one his family will need help and support with for some time. The path ahead will have its mountain peaks and valleys, as it has in the past (and so will our feelings). But I firmly believe that this family can and will meet the tasks ahead if we can maintain our trust in them and not grow too disappointed when Mrs. Smith gets overwhelmed and can't do all she has been able to do before.

As we agreed, we all need to help Mrs. Smith be consistent about Danny's diet restrictions. We need to appreciate the magnitude of the problem they face and the feelings it engenders. I believe we need to permit and assist Mrs. Smith to express her concerns, problems, and feelings no matter what they may be.

Let's talk about this further if it seems to you a helpful path to take. You can reach me by phone, or, we could meet together here to talk about it.

I am most appreciative of your help and interest in the Smiths. You have done much to make possible the progress we have seen. Please keep me informed about this family's situation. I feel certain that more progress will occur.

Very sincerely,

Carolyn R. Aradine, R.N.
Graduate student in pediatric nursing.

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