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The effect of instructional nursing intervention on mothers of children with spina bifida with myelomeningocele

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THE EFFECT OF INSTRUCTIONAL NURSING INTERVENTION ON MOTHERS OF CHILDREN WITH SPINA BIFIDA WITH MYELOMENINGOCELE

by

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DISSERTATION

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THE EFFECT OF INSTRUCTIONAL NURSING INTERVENTION ON MOTHERS OF CHILDREN WITH SPINA BIFIDA WITH MYELOMENINGOCELE

ABSTRACT

Patricia Dotson Scearse

Problems relating to the care of myelomeningocele children have recently emerged. Prior to 1960, ninety per cent of the children died before the age of one year. Present treatment methods make it possible for approximately seventy per cent of the infants born with myelomeningocele to survive past one year of age. The physiological problems of the myelomeningocele child are related to the location of the defect and amount of spinal cord tissue which is involved in the lesion. Classifications of spina bifida were defined and described, and physiological problems of the child including hydrocephalus, urinary and gastro-intestinal abnormalities and absence of lower extremity innervation were discussed.

Mothers of children with spina bifida with myelomeningocele composed the sample for this quasi-experimental study. The purposes of the study were: (1) to obtain information concerning the parents of children with myelomeningocele which related to unmet needs and unsolved problems of the parents and other family members; and, (2) to systematically investigate the effect of instructional nursing intervention conducted by a professional nurse in the homes of the parents.

A family information survey form was completed by the investigator on all families participating in the study. Data was collected concerning the following factors: (1) socio-economic status; (2) educational background of parents; (3) race; (4) maternal age at birth of child; (5) obstetrical history; (6) marital status; (7) causes of stress for parents during the intial period after birth; and, (8) unmet needs and unsolved problems encountered by parents of myelomeningocele.

A conceptual framework was developed from selected crisis intervention concepts and presented in an open systems model. Elements of the model were supported by literature review and observations of the investigator in clinics, hospitals and homes of participating parents. The model described the unique experiences of the parents of myelomeningocele children. The experience of the parents following the birth of the child was identified as a critical period in the lives of the parents. In a critical period the ability to cope with the problems encountered may permanently influence future behaviors and adaptations. A teaching protocol was constructed from information obtained from parents of older myelomeningocele children during a previous exploratory study. A synchronized audio-tape teaching tool consisting of a 22½ minute audio and 55 color slides was developed and tested. The purpose of the audio-visual tool was to provide a set for the experimental families and to define the parameters of the teaching protocol.

The twenty families composing the sample were assigned to the experimental and control groups by the investigator on the basis of the age, sex, and degree of disability of the myelomeningocele child.

The pretest and posttesting of the experimental and control groups and the teaching sessions presented to the experimental group were all conducted in the homes of the participating families. The testing instruments included the Tennessee Self-Concept Scale by William H. Fitts, The Elias Family Adjustment Test, and a multiple choice test on aspects of myelomeningocele constructed and tested by the investigator. The degree of disability of the myelomeningocele child was assessed by an adaptation of the Scherzer-Gardner Rating Scale.

Nonparametric statistical methods were used to test the ordinal data obtained. Analysis of pretest data indicated the experimental and control groups were similar on the five study variables at the time the study began. Significant correlations between the following variables were found utilizing Spearman Rho Rank Order Correlations:

(1) High degree of disability of the myelomeningocele child and high level of self-concept of the mother.

(2) High degree of disability of the myelomeningocele child and high level of understanding of the mother of the child's condition.

(3) High self-concept of the mother and high level of understanding of the mother.

Implications of these correlations were explored.

Hypotheses were tested utilizing the Kolmogorov-Smirnov two-sample test for small samples and the Wilcoxon Sign Test for Differences Between Related Samples. Significant differences were found

between pretest and posttest scores of understanding of the mother and the self-criticism subscale of the Tennessee Self-Concept Scale. The results indicated that the understanding of the mothers of myelomeningocele children increased significantly following the teaching sessions and that the defensiveness of the mothers, as measured by the self-criticism subscale, was significantly decreased. The implications of the study for clinical nursing practice and for further research were discussed.

To Vicki

my fondest hope is that someday she

will dedicate a dissertation of her own

ACKNOWLEDGEMENTS

My introduction to the families of children with myelomeningocele and to the problems which provided the basis of this study was through a Spina Bifida Parents' Group originated and fostered by two former instructors at the University of California, San Francisco: Janice E. Hitchcock and Brenda Roberts. I would like to recognize their efforts with this group and also their part in interesting me in the problems associated with the birth of a child with myelomeningocele.

I wish to thank the parents who participated in this study and those parents who served as subjects in the exploratory study which preceeded this investigation. The complete cooperation I received from them added much to the authenticity of the study.

The cooperation received from the medical staffs at the four cooperating medical institutions is sincerely appreciated. I particularly wish to thank: Dr. Sanford Sherman, M.D., Childrens' Hospital, Oakland; Dr. Roderick Smith, M.D., Chief, Department of Neurosurgery, The Permanente Medical Group, Redwood City; Dr. Elmer E. Specht, M.D., Assistant Professor, Division of Ambulatory and Community Medicine, University of California Medical Center, San Francisco; and Dr. Harold M. Sterling, M.D., Professor, Department of Physical Medicine and Rehabilitation and Pediatrics, University of California, Davis, and Director, Birth Defects Clinic, Sacramento Medical Center. The efforts of these individuals in assisting me

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Assistance with the early formulation of the research design and the plans to develop and test the research instruments was obtained from Professor Marlene Kramer, School of Nursing, University of California. To Dr. Kramer and the many other faculty members and clinical specialists who participated in reviewing and editing the research instruments, I am indebted.

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CHAPTER I

INTRODUCTION AND THE PROBLEM OF SPINA BIFIDA

INTRODUCTION

> Well, when you first get the news, it's a shocker all right. At first you don't believe it...you think they have made a mistake or that they had the wrong baby or something and that they'll come back and tell you that everything is all right...but it doesn't happen that way. In fact, every time they come back they have something worse to tell you. Then it starts to dawn that it is all true and I thought, "Oh, my God, why me? Why us?" And I just wanted to scream out that it wasn't true and I didn't think I could stand thinking about it.[1]

The woman speaking in the above quotation was responding to a nurse researcher who had asked a question regarding the mother's initial reactions to the news that her baby had been born with a birth defect. The defect is known as spina bifida with myelomeningocele.

Spina bifida with myelomeningocele is among the most common major congenital malformations known to medical science. Out of every one thousand live births, approximately two infants will demonstrate some form of spina bifida. Until a few years ago spina bifida with myelomeningocele was considered to be virtually incompatible with life. Aggressive medical and surgical management of infants born with myelomeningocele has resulted in lowering the

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[1]Quotation from interview with mother of spina bifida child, January, 1972.

mortality rate from 90 per cent to less than 30 per cent in under a decade. The surviving children demonstrate varying degrees of paraplegia and manifest complete or partial urinary and rectal incontinence. Seventy to 80 per cent of the surviving children require surgical treatment for hydrocephalus. Some of the surviving children are mentally retarded regardless of the quality of treatment received.

Each year children with myelomeningocele defects comprise an increasingly larger percentage of the total number of children who receive care at major rehabilitation centers, orthopaedic facilities, schools for the physically handicapped and at residence care facilities. The spina bifida population now exceeds the number of survivors of the thalidomide-induced limb deformity population (Swinyard, Shahani, 1966). It has been projected that at current incidence and survival rates, the total number of children chronically handicapped by myelomeningocele birth defects will soon exceed the number of permanently incapacitated patients effected at the peak of the poliomyelitis epidemic of 1947-1958 (Lightowler, 1971).

The impact of spina bifida on the quality of life of the surviving children and their families has received scant attention in the literature. This dearth of information concerning the effects of the child on family life and structure may be attributed to the fact that successful medical management of the birth defect and reduction of the mortality rate has been accomplished in a relatively short period of time. Studies have shown that parents who have had one infant with myelomeningocele experience a higher risk for giving birth to myelomeningocele infants in future pregnancies (Hare and others, 1966; Lorber, 1971; Austin, Lindgren, 1972). Little

information is available, however, concerning the reactions of parents to the increased risk, preferences of parents as to future pregnancies, or the nature of the information presented to parents relative to the increased risk. One study of 107 mothers of spina bifida children indicated less than 50 per cent understood the increased risk to further pregnancies (Walker, Thomas, Russell, 1971). Increased numbers of children with myelomeningocele who need long range medical management and supervision have been reported (Hide, Semple, 1970; Bensman, Long, Merrill, Horrobin, Easton, Lai, 1971), but little attention has been given to the needs and problems of the parents and family members who are responsible for the daily requirements of the child.

Because of the dearth of information concerning the unique problems and unmet needs of families who are providing day to day care of children with spina bifida, the following factors need to be studied: (1) The emotional factors involved in parenting such a child; (2) The total impact on family life and family structure of parenting a spina bifida infant; (3) The kinds of help and professional services needed; and, (4) The efficacy of specific types of teaching and counseling by professional persons. When such information is available, programs can be designed which will respond efficiently and effectively to the needs of families of children with myelomeningocele.

PROBLEM DELINEATION AND PROBLEM STATEMENT

Problem Delineation

In the Fall of 1971, the author conducted an exploratory study. The goals of the study were two-fold: (1) to gather information concerning coping patterns and mechanisms demonstrated by parents of children with myelomeningocele; and, (2) to determine what, if any, problem areas existed in the coping patterns of parents of children with myelomeningocele. An interview schedule was designed and tested which emphasized the concerns, needs and problems of the parents in the initial period following the birth of the infant and the changes which had occurred in the life style of the family since the birth of the affected child (Scearse, 1971).

"I don't mind talking to you about Jennie," commented one mother during the exploratory interviews. "I still spend hours when I should be working or at night when I'm trying to sleep going over and over it all again in my mind. I guess it's not healthy, but I do it." "I don't think of the future," stated another mother, "I don't want to know what she's going to be like in five or ten years. I want to know did I do right."

In another interview, a mother commented, "Of course, who knows what causes all the infections? I remember I had to 'milk' his shunt 10 times every hour when he was awake and then put this big lamp on his back. It took three or four weeks for the skin to grow over where he didn't have any. I didn't ever know if I was doing the right thing--I still don't but he's alive. I was very frightened I wasn't going to be able to handle it all; but, day by

day, you learn...; but every time he would cry at night I would think 'shunt' and wonder if I had done something wrong."

A father interviewed voiced content with their decision but also offered some insight into the problems of other parents when he said, "I can understand why they prepare you for the worst, but at the time I thought they were kind of cold... They said right off that the chances of the baby living were something like 70/30 or whatever, if they didn't operate, and if they did operate there was a chance of paralysis for the rest of his life with no bladder or bowel control. It was a hard decision. The main thing at the time seemed to be to save the baby's life, so we O.K.'d the operation... he's coming along so good we are sure we were right, but what if he hadn't...?"

One mother of a child with low disability said emotionally, "He [the doctor] was very - very - well, he told me these babies usually die at birth - oh, he just - I was more upset by what he had to say than the fact something was wrong with her... I still just can't stand that doctor..." Another mother commented concerning the physician who had given her the news concerning the infant, "I told him to get out and never come back unless my husband was with me. . . I was never so angry as I was at him--and still am in fact. I'd walk a city block to avoid seeing him face-to-face."

These quotations are examples of the behaviors noted in the exploratory study. Content analysis of the tape recorded interviews at the conclusion of the study provided support for the premise that patterns of behavior were apparent in the families interviewed.

These patterns were indicative of maladaptation and unsuccessful resolution of the basic problems arising from the birth of the infant with myelomeningocele.

Behaviors that were consistently observed in the interviewed families included: (1) preoccupation with the past; (2) reworking of previous decisions concerning care and treatment of the child; (3) denial of information concerning myelomeningocele that had previously been presented; (4) difficulty in meeting the needs of today and planning for the future; and, (5) easily evoked anger, specifically directed toward an individual concerned with the early treatment regimen of the infant or, diffused to the point where the parents reported being "angry at the whole way it was handled". The behavior patterns observed in the families studied differed from the functional "chronic sorrow" reported by authors in the field of parental adjustment to the chronically handicapped child (Olshansky, 1962).

The findings of the preliminary investigation suggested that many problem areas existed in the coping patterns of the parents of children with myelomeningocele, and that many such parents had failed to achieve a successful adaptation. A research study was then designed to investigate the effects of professional nursing intervention on the understanding and adaptation of mothers of children with myelomeningocele.

Problem Statement

What are the effects of instructional nursing intervention on the understanding, self-concept and adaptation of mothers of children born with spina bifida with myelomeningocele?

Purpose of the Study

The purpose of the study was to determine whether professional nursing intervention in the form of instructional sessions conducted in the privacy of the clients' homes would positively effect the understandings, self-concepts, and adaptations of mothers of children with the clinical diagnosis of spina bifida with myelomeningocele. There were two major objectives:

1. To obtain information concerning the parents of children with myelomeningocele related to unmet needs and unresolved problems.

2. To systematically investigate the relationship between instructional nursing intervention conducted by a professional nurse and the understanding, self-concept, and adaptation of mothers of children with myelomeningocele.

The first objective was met through analysis of a preliminary interview administered to each family participating in the study. The second objective of the study was investigated by means of a quasi-experimental research design. The data collected can be used as a scientific basis for the planned discharge programs for other families of myelomeningocele infants. When many similar studies investigating the results of planned nursing intervention with parents of other chronically handicapped children are available, the results

of the studies may provide a theoretical basis for the formulation of a theory of nursing intervention in families of chronically ill children.

THE NATURE OF SPINA BIFIDA WITH MYELOMENINGOCELE

Definitions and Classifications of Spina Bifida

Spina Bifida literally means cleft spine. Stedman (1972) defined it as "...a limited defect in the spinal column, consisting of absence of the vertebral arches, through which spinal membranes, with or without spinal cord tissue, may protrude." In practice, no standardized terminology exists, although many classification systems have been proposed (Smith, 1965; Swinyard and Shahani, 1966; American Academy of Orthopaedic Surgeons, 1972). The need for definitive terminology was cited by Smith in his 1965 monograph when he stated that it was necessary to differentiate between a "clinical syndrome" and a "pathological state" of the defect. He suggested that much of the confusion stemming from present usage of terms concerning spina bifida arose from the attempt to make clinical diagnostic terminology conform to pathological distinctions. Smith (1965) was the first to present a formal classification system for the defect. Although the system has not been widely adopted, it has served as the basis for many adaptations of classifications.

A review of related research on spina bifida by the author revealed discrepancies in the reported incidence rates, survival rates, and the severity of the chronic disabilities. Since the discrepancies may be a function of the differences in the system of

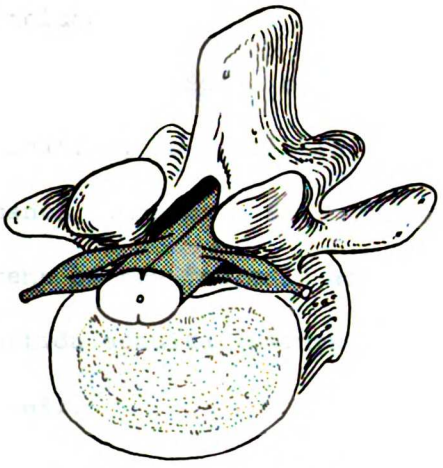
classification employed by the researcher, it is essential that studies of spina bifida make explicit the classification used by the researcher.

Three major systems of classification of spina bifida defects are summarized in Table 1.1, and the various spina bifida defects are illustrated in Figure 1.1. Smith's definition of spina bifida occulta listed in column one, states that there may or may not be changes in the overlying skin and pathological changes in the spinal cord. In Bunch, Cass and Bensman's classification, spina bifida occulta has no external evidence of the underlying pathology that can be detected at birth. The definition of spina bifida occulta, under closed defects, states that there may be a minor surface lesion such as a hairy patch or dimpling, but may not be an open lesion. Examples of such discrepancies are found throughout the various classification systems. Lipomas are listed under meningoceles in the Bunch, Cass and Bensman system, but in closed defects along with spina bifida occulta under another system. The importance of the discrepancies becomes apparent when results of research studies on spina bifida populations are examined. Comparisons of the results of studies on the incidence, effectiveness of various treatment methods, and mortality and survival rates are meaningless unless the investigator reporting the studies makes clear the system of classification upon which the study is based.

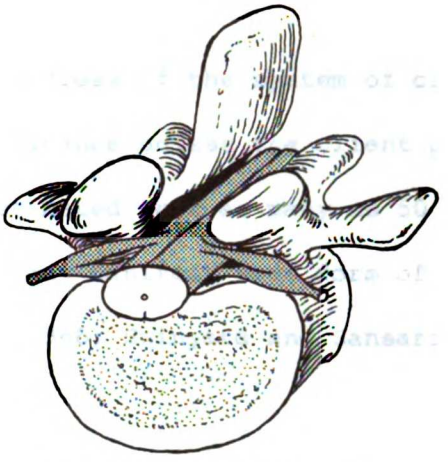
TABLE 1.1

SYSTEMS OF CLASSIFICATION OF SPINA BIFIDA DEFECTS IN CURRENT USE

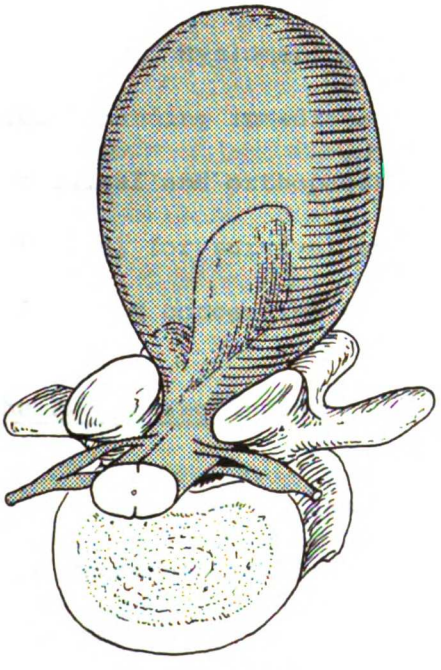
Smith, 1965; Menelaus, 1971	Bunch, Cass, Bensman, 1972	American Academy of Orthopaedic Surgeons, 1970
Spina Bifida Occulta: The unfused condition of vertebral arches without cystic distention of the meninges; there may or may not be changes in the overlying skin, neurological signs, or pathological changes in the spinal cord.	Spina Bifida Occulta: The unfused condition of vertebral arches in which there is no evidence of the underlying defect. Often is unrecognized until later life.	Closed Defects, including Spina Bifida Occulta and intraspinal tumors such as lipomas, angiomas, dermoids. May occur with minor signs at site of defect, such as a patch of hair or "dimpling".
Meningocele: The unfused condition of vertebral arches with cystic distention of the meninges, but absence of myelodysplasia of the spinal cord, and absence of neurological signs. Parts of the cord or nerve roots may or may not be present in the sac of meninges, but if so, they conduct impulses normally.	Meningocele: The unfused condition of vertebral arches with a fluid-filled sac or attenuated meninges present at site. Defect is in both paraspinal muscles and in the bony canal. Nerve roots may adhere to inner wall of sac. Neural elements displaced, but appear (to inspection) normal. Includes lipomas, dermoids, osteomas.	Open Defects, including Meningocele: Unfused vertebrae underlie an open lesion in which no neural elements are exposed to inspection.
Myelomeningocele: The unfused condition of vertebral arches with cystic distention of the meninges and associated with myelodysplasia of the spinal cord and neurological signs. Within this group all pathological structures of the cord may be included.	Myelomeningocele: The unfused condition of vertebral arches with an unepithelialized sac at the site. The dome of the sac consists of dysplastic spinal cord from which spinal nerves radiate into wall of sac. Wide variations from absence of cord to dysplastic cord occur.	Open Defects, including Myelomeningocele: Unfused vertebrae underlie an open lesion of exposed and visable neural elements in a distended or undistended sac.



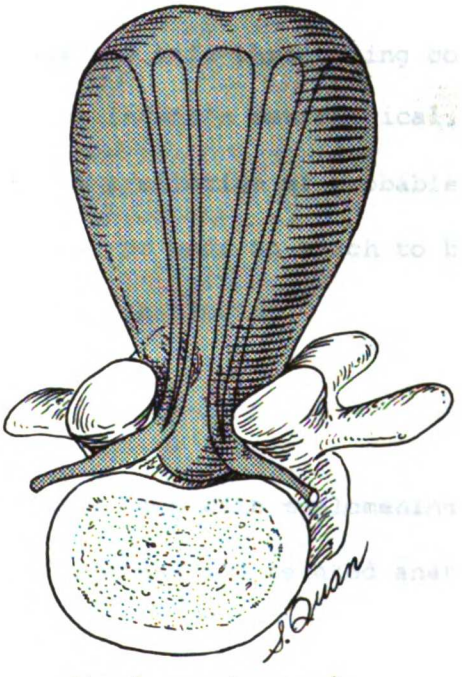
Normal Vertebra
and Spinal Cord



Spina Bifida Occulta



Meningocele



Myelomeningocele

Figure 1.1. Normal Vertebra and Spinal Cord and Various Spina Bifida Defects.

There are several issues on which authors agree. These include:

1. Spina bifida occulta, regardless of the system of classification, is of little clinical significance unless the client presents symptoms. Some authors have estimated that as many as 50 per cent of the "normal" adult population may manifest some form of spina bifida occulta (Swinyard and Shahani, 1966; Swinyard and Sansari, 1969).

2. True meningoceles with cystic distention of the meninges with a fluid filled sac or a condition of attenuated meninges in which nerve impulses are conducted normally, are very rare (Doran and Guthkelch, 1961; Smith, 1965).

3. Myelomeningocele is a serious and life-threatening condition demanding immediate assessment of the infant's neurological, urological and orthopaedic involvement. A prediction of probable potential for survival and development must be made on which to base a decision concerning the treatment regimen instituted.

The Presenting Infant

The defects demonstrated by infants born with myelomeningocele represent several major physiologic systems and related anatomical components.

The local lesion. A bluish-white or translucent sac protrudes from an incompletely formed vertebra(e). The defect may occur anywhere along the vertebral column, but the most common site is the lumbar-sacral area (Dadell-Ribera, Swinyard, Greenspan, Deaver, 1964; Swinyard and Shahani, 1966). Elements of the dysplastic spinal cord

usually adhere to the inner lining of the sac. The sac may be flat without distension at birth, but will soon fill with cerebral spinal fluid.

The skin. Normal skin is usually present around the base or "neck" of the sac, but it is thin and "...at the summit of the mass [the lesion] is devoid of skin" (Smith, 1965). The skin may slough off, but evidence of epithelial growth is soon seen and the lesion may eventually heal over completely. An untreated myelomeningocele may finally resolve into a thick, scarred area.

The skull. The head size at birth ranges from normal to grossly enlarged. Bones forming the fontanelles are frequently more widely spread than normal and the fontanelles may bulge if intercranial pressure is high. It is estimated that between 70 and 90 per cent of myelomeningocele infants will develop progressive hydrocephalus (Eckstein, 1972; Lorber, 1971; Bensman, Long, Merrill, Horrobin, Easton, Lai, 1971). The relationship between the size of the skull and the amount of hydrocephalus is not a direct one. Hydrocephalus can progress without an apparent increase in cranial size. Many physicians advocate that routine ventriculography (Lorber, 1961; Ransohoff, Mathews, 1969) be used in conjunction with the clinical indicator of head circumference as diagnostic measures of the amount of hydrocephalus present.

The urinary tract. Abnormalities of the urinary tract range from neurogenic bladder at birth (Bunch, Cass, Bensman, Long, 1972) to developmental abnormalities of the upper urinary tract. These upper urinary tract abnormalities result from bladder distention,

continual increased pressure in the bladder, ureters, and kidneys and eventual destruction of urinary tract tissue. After the age of two years, urinary tract infections and urinary tract failure are the cause of an increasing proportion of deaths of children with myelomeningocele. After five years of age, they are the major cause of death (Smith, 1965; Morales, 1969).

The lower extremities. Weil (1972) states there is a "... predictable correlation of the degree of lower extremity deformity with the level of the lesion" along the vertebral column. Nearly every infant with myelomeningocele will have some orthopaedic complications. Both flaccid and spastic paralysis are common. Deformities may result from muscle imbalance or from contractures due to intra and extra uteral posturing. Some indication of the range of orthopaedic defects demonstrated by children with myelomeningocele can be assessed on the basis of Lorber's (1971) report of 134 children. Forty-nine per cent of the children Lorber studied were chairbound or could ambulate only with maximum amounts of orthopaedic appliances. Eighteen per cent walked with the aid of crutches, and thirty-three per cent walked without aid or with minimum amounts of orthopaedic appliances. This information is presented in Table 1.2.

Sharrard (1972) has estimated that if the ability to walk more than twenty-five yards independently with or without help of bracing is used as a criterion, 75 per cent of the surviving children with myelomeningocele should be able to walk, regardless of the level of paralysis. This assumes optimum therapeutic and rehabilitative management from the day of birth.

TABLE 1.2

LOCOMOTION OF SURVIVING MYELOMENINGOCELE CHILDREN

Mobility Functioning	Number	Per Cent
Normal extremities, walks without aid	17	13
Walks with limp, no aid	15	11
Waddle walk with sticks	12	9
Walks with calipers and/or crutches	24	18
Walks with extreme caliperage, uses wheelchair	10	7
Walks very little with chestband and wheeled trunk	15	11
Chairbound	41	31
Total Sample	134	100

The lower gastro-intestinal tract. The majority of myelomeningocele patients will have a neuropathic bowel. Approximately 50 per cent will have rectal incontinence as judged by "social criteria" used in a recent study (Eckstein, 1972). Attempts to correlate rectal function in the individual child with the level of the lesion or the degree of limb paralysis have been unsuccessful.

History of the Treatment of Myelomeningocele and the Change in Prognosis

Although the birth defect now known as spina bifida has been known to physicians for more than 2000 years (Swinyard and Shahani, 1966), the clinical literature prior to the seventeenth century was essentially descriptive in nature and devoid of treatment methods or care considerations. Surgical treatment for the condition was

first attempted in the 1600's by a physician named Tulpius (Ingraham, 1943). Sporadic attempts at treatment were recorded in the literature during the following two centuries, but the focus of interest in myelomeningocele continued to center around enhancing medical knowledge concerning the pathology and physiology of the defect.

During the nineteenth century, interest increased in attempting to find successful surgical treatment methods for the back lesion and the orthopaedic problems. By the mid-1800's the condition was occurring frequently enough to prompt the Clinical Society of London to appoint a committee to investigate the treatment and survival rates of spina bifida cases. In 1885 this committee published its report on eighty-three cases of myelomeningocele and forty-two related conditions. Treatment methods employed at that time included aspiration, excision, ligation and injection of sclerosing solutions. The committee recommendations strongly advised against all treatment procedures other than injection, preferably with Dr. Morton's iodoglycerine solution (Doran and Guthkelch, 1961). It was the expressed opinion of the committee members that any other treatment method increased the chances of infection and caused further damage to neural tissue included in the sac.

After publication of the Clinical Society committee report in 1885, attempts at surgical correction were all but abandoned. Around 1900, with the institution of aseptic technique, surgery on the lesion on the back and aspiration of the hydrocephalic head enjoyed a brief period of renewed popularity. However, in 1914, Dandy and Blackfan (Smith, 1965) first expressed the theory that it

was early surgery on the spinal defect that caused or served as the precipitating factor in the development of hydrocephalus. Dandy and Blackfan reasoned that the spinal sac acted as an absorbing surface for the cerebral spinal fluid and that removal of the sac resulted in disturbance of the dynamics of the absorption process. The acceptance of this theory, probably coupled with the continued discouraging results achieved by the surgical treatment methods, ushered in a period of conservative treatment that was to last until the 1960's. Studies of infants with spina bifida who received no treatment from birth (Laurence, 1967a; Laurence and Tew, 1971), indicate an 85-90 per cent mortality rate.

Smith (1965) summed up the attitudes toward treatment of myelomeningocele prior to 1960 by stating, "It is probably true that the classical neurosurgical approach has been to delay operation for as long as possible." Smith analyzed the major premises of this position to be: (1) the desire to allow "natural selection" to take place in order to do surgery only on those infants whose neurological status made further survival desirable; (2) the theory that early surgery precipitated increased hydrocephalus; (3) the belief that the surviving non-operated child would have less lower extremity disability by avoiding surgical trauma to nerves and spinal tissue in the sac; and, (4) the desire to eliminate needless surgery for those infants who would die in spite of all treatment.

In 1959 Dr. John Lorber and the staff of the University of Sheffield, Department of Child Health, began an intensive study of infants born with myelomeningocele. It was the belief of this staff

that sufficient advances had been made on shunting devices (Holter and Pudenz valves) for the treatment of hydrocephalus, in medical management of severe infections, and in the field of orthopaedic surgery to justify active and aggressive treatment of all infants with spina bifida. The Sheffield study, published in 1961, discredited the previously held theory that early repair of the spinal lesion aggravated or intensified the ensuing hydrocephalus. The report of the Sheffield study and the decrease in mortality rates obtained, resulted in wide-spread adoption of policies of early closure of the back lesion, early treatment of the hydrocephalus with sophisticated shunting procedures, and the administration of widespectrum antibiotics and sulfonamides to reduce and control infection. As a result of this change in philosophy toward treatment, recent studies have indicated that up to seventy-five per cent of the infants so treated will survive (Rickham, Mawdsley, 1966; Hide, Semple, 1970; Katzen, 1971; Lorber, 1971).

In less than a decade of treatment under the new "aggressive treatment regimen" myelomeningocele had become not only one of the most common major congenital malformations, but also a primary cause of multiple handicapped children (Freeman, 1974).

An interesting backlash to the early treatment program has recently developed. Some physicians are openly questioning the advisability of treating all spina bifida children (Matson, 1968; Zachary, 1968; Lightowler, 1971). Matson at the Children's Hospital Medical Center and Harvard Medical School has never adopted a policy of treating all infants. He has stated,

> Some surgeons will wish to ignore considerations of any moral or social issues and operate upon every patient as soon as possible; Others will wish to ignore all decisions by referring every patient on to someone who professes special interest in this area. I think most responsible neurosurgeons, however, will wish to evaluate all the factors involved and try within the limits of experience and judgement to arrive at the best decision for the particular patient at hand (Matson, 1968:226).

Eckstein (1972) believes that until such time as the community and State are willing to make the medical care, educational opportunities, vocational training facilities and sheltered employment places that are necessary available to the surviving individuals, it may be more unjust to the "unfortunate children" born with myelomeningocele to treat them than to allow them to die. Lightowler argues that it seems undesirable "to promote a nationwide policy of early closure of myelomeningocele...since to produce survivors who are then uncared for would be worse than to fail to produce survivors at all." (Lightowler, 1971:387). At the present time, it appears that the advice which will be given the parents concerning the advisability of treatment of the infant and the treatment regimen utilized with each infant born with myelomeningocele will be determined according to where the child is born and the prevailing philosophy of the physician responsible for the care of the infant.

Etiology of Spina Bifida with Myelomeningocele

There is no agreement concerning the specific etiology or exact pathology of the various forms of spina bifida. In 1769, Morgagni reported that the spinal lesion was a result of the increased pressure of the cerebral spinal fluid from the hydrocephalic

head which developed in embryo (Bunch, Cass, Bensman, Long, 1972). According to Morgagni, the increased pressure descended through the neural tube to the spine and forced the bones of the vertebrae apart while they were still forming. Von Recklinhous suggested in 1886, that the spinal defect was caused by a failure of the neural tube to close and was a form of anencephaly, totally independent of the hydrocephalus defect (Doran and Gulthkelch, 1961). It has recently been hypothesized that the hydrocephalus which is frequently associated with myelomeningocele originates because of the open nerve plate in the spinal cord which permits an imbalance of tissue pressure to exist within the central nervous system (Emery, 1972), thus reversing the original theory of the cause-effect relationship. Several anatomical deformities of the brain, including the Cleland-Arnold-Chiari deformity, the Dandy-Walker defect, the "forking" of the Aqueduct of Sylvius, and complete or partial aqueduct stenosis, have all been cited as the defect present in the myelomeningocele related hydrocephalus.

Several hypotheses concerning the exact cause of the myelomeningocele and the associated hydrocephalus were formulated in the twentieth century. Family studies and recurrence rates within families have resulted in a polygenic inheritance hypothesis (Carter, David, Laurence, 1968). Other researchers believe environmental factors are largely responsible for the defect (Lowe, 1972; Renwick, 1972). Dietary deficiencies and metabolism problems have also been cited as probable causes.

Renwick suggested in a recent study based on epidemiological evidence that spina bifida was caused by direct contact of the pregnant woman with certain types of potato tubers which are blighted with specific but as yet unknown substances (Renwick, 1972). This hypothesis set off a storm of controversy and provoked an abundance of epidemiological and laboratory studies both supporting and refuting the hypothesis (Emanuel, 1972; Pembrey, 1972; MacMahon, 1973). To date there has been no agreement on the worth of the hypothesis offered by Renwick.

The most widely accepted theory of causation is that myelomeningocele and related defects are due to a complex interaction of genetic constitution and the fetal environment (Swinyard, Sansaricq, 1969; Austin, Lindgren, 1972). There is agreement that the defect occurs quite early in fetal development, probably as early as the first four weeks, and that there is no known method of prevention (Badell-Ribera, Swinyard, Greenspan, Deaver, 1966; Austin, Lindgren, 1972; Bunch, Cass, Bensman, Long, 1972). Recently, antenatal diagnosis has been receiving attention and use. The amniotic fluid of a woman carrying a child with anencephaly or spina bifida demonstrates high levels of alpha-fetoprotein (Brock and Sutcliffe, 1972). Unusually high serum levels of alpha-fetoprotein in the early months of the pregnancy of a woman with a spina bifida fetus have also been reported (Brock, Bolton, Monaghan, 1973). Such tests are useful for pregnant women who have previously delivered an anencephalic fetus or an infant with spina bifida (Campbell, Holt, Johnstone, May, 1972). Antenatal diagnosis, however, is a solution to the problem only for those women for whom abortion is an acceptable solution.

One recent study indicated that over forty per cent of parents of one myelomeningocele child would reject abortion as a solution, even if antenatal diagnosis were positive (Swinyard, unpublished monograph, 1973).

The Dilemma Faced by Parents at the Time of Birth of the Infant With Myelomeningocele

The birth of an infant with myelomeningocele confronts parents with a unique problem situation. A decision is required concerning the infant which will not only determine the life and death of the newly born infant, but which will also manifest significant and permanent changes in the lives of other family members. Some of the characteristics of the situation faced by the parents which makes it unique are discussed below.

1. The child is born with a birth defect about which the parents have probably never heard. The attending physician and nursing staff, unless the infant is born in a large medical center, may also admit that they have seen very few infants with myelomeningocele. Usually a specialist whom the parents have never met will be consulted.

2. Depending on the treatment philosophy of the attending physician and the institutional policy, the parents may be asked to make a decision concerning whether to begin immediate aggressive treatment, including surgery on the infant, to try to save the infant's life, or to withhold treatment and hope that the infant will die. If "institutional policy" is for early closure and active treatment of all infants, the only way the parents can decide against

this procedure is to remove the infant from the hospital. In the last few years, court orders have been obtained forcing parents to allow surgery and treatment on infants born with myelomeningocele (Tragic Dilemma, 1972). If no hospital policy is involved, and the physician does not choose to give advice or to participate actively in the decision, the parents may be forced into a totally independent decision. This decision is usually necessary in the first forty-eight hours after birth.

3. The prognosis of the infant at the time the decision must be made to treat actively or to give conservative care is unclear. It is difficult, if not impossible, to forecast the future potential of the infant in the areas of mental ability, locomotion, bowel control, bladder control or psycho-social development. Although some "criteria" have recently been developed for projecting possible predictions of treatment outcomes and mortality risks (Matson, 1968; Katzen, 1971; Lorber, 1971), it is true that not all infants selected for active, aggressive treatment according to the criteria live; or if they do live, are able to escape mental retardation, severe paraplegia and chronic debilitating infections. In addition, not all infants who are left untreated die, and those who survive without treatment are grossly deformed with enormous heads, deformed limbs, and are often mentally retarded (Freeman, 1974).

4. The parents are asked to make the decision concerning the treatment of the infant at a time when they are least capable of making a rational decision. They have not had time to cope with their shock or grief, to resolve their shame arising from giving

birth to a malformed child, or to consider the long-term effects the infant may have on their family life and structure.

5. If the parents choose to have the infant treated, they cannot be assured of adequate and continuing resources to meet the medical, educational and emotional needs of the child.

Against this background, then, the parents of the infant born with myelomeningocele begin the parenting of their child. All parents will make a decision. Some parents will insist that the infant be given every possible treatment known; some will want minimal care given and will hope the infant dies; and, some will insist that the attending physicians do whatever they think is best in the case, thus making their decision by default. Whatever the decision is, however, and whether it results in the life or death of the infant, the parents will live with it for years to come.

CHAPTER II

CONCEPTUAL FRAMEWORK

Introduction to the Conceptual Components

The goal of service oriented professionals is to deliver care based on knowledge. When the profession involved is nursing, the knowledge must incorporate the needs of the clients, the ability of the professionals to meet those needs or to make provisions for others to meet them, and a method for determining the probability of achieving desired outcomes by employing various nursing measures or activities.

A conceptual framework directly related to nursing intervention in chronic illness would be of value to nursing. Nursing practitioners base decisions concerning care upon their individual conceptual frames of reference, regardless of whether or not the nursing practitioner is aware of the process (King, 1971). A far more advantageous position will be assumed by professional nurse practitioners when nursing theory is sufficiently advanced and tested to allow replacing the individual conceptual frames of reference now utilized. Until that time, it is beneficial to clearly describe observable phenomena in nursing interactions and to test specific nursing interventions for effectiveness in controlled situations and with measured results.

The framework for this study was developed from selected crisis intervention concepts to describe the unique situation which surrounds the parents of myelomeningocele infants and the resulting dysfunction which may result from that situation (Hill, 1958; Parad and Caplan, 1960; Rapoport, 1962a and 1962b). The variables studied were presented in a conceptual model which was developed by the author and grounded in systems theory. Findings of an exploratory study conducted by this author in the Fall, 1971, served as a pilot program. Documentation for the framework was obtained through observations and interactions with parents of children with myelomeningocele in clinics, homes, hospitals and parent organization meetings. Concepts explored in crisis intervention theory include: (1) an initiating stimulus, (2) the perception of the individuals involved in the situation that it is a crisis event, (3) the individual or family as an interacting and reacting unit, and, (4) the adaptation or adjustment of the individuals in the situation. Parad and Caplan (1960) have stated that the adaptation and resulting behaviors are composed of "a complicated field of forces including intrapersonal, interpersonal, and suprapersonal (or 'transactional') processes."

The concepts listed above were adapted to the study. The initiating stimulus to the crisis was the birth of the infant with myelomeningocele. Perception of the individuals involved was defined as the patterns of awareness which the parents of the infant have developed of themselves in various roles and of their environment. These patterns of perception determined to what extent the parents viewed the infant as a threat to their self-concepts, to the family

structure, and to the socio-economic well-being of the family. The interacting unit was defined as the parents seeking information and support from the immediate environment and engaging in identity work (Wallace, 1967). Adaptation or adjustment was defined as the behaviors adopted by the parents as a result of the birth of the infant.

Professionals interacting with the parents in the time period following the birth of the infant become important because they are the exclusive source of information concerning the medical condition and prognosis of the infant, and also because they serve as objects of the identity work which is done by the parents. Both verbal information given by professionals and their actions and attitudes toward the infant are important in the process of adaptation of the parents.

An open systems model for the framework is presented in Figure 2.1. The advantage of the systems model is that it allows for analysis of a single level of functioning or interactions, while recognizing the existence of many other subsystems and suprasystems that are operating simultaneously. The family is a complex maze of systems and subsystems and obviously functioning in other levels does not cease when an event like the birth of a malformed child occurs. The purpose of the model is to present the relationships and interactions which are occurring in relationship to the happening of the birth of the infant. Systems theory and an open systems model provided the investigator with a basic tool for data analysis. It was assumed that when nonfunction or malfunction in one subsystem occurs, disruption of other subsystems and suprasystems is likely and changes in behavior patterns can be observed.

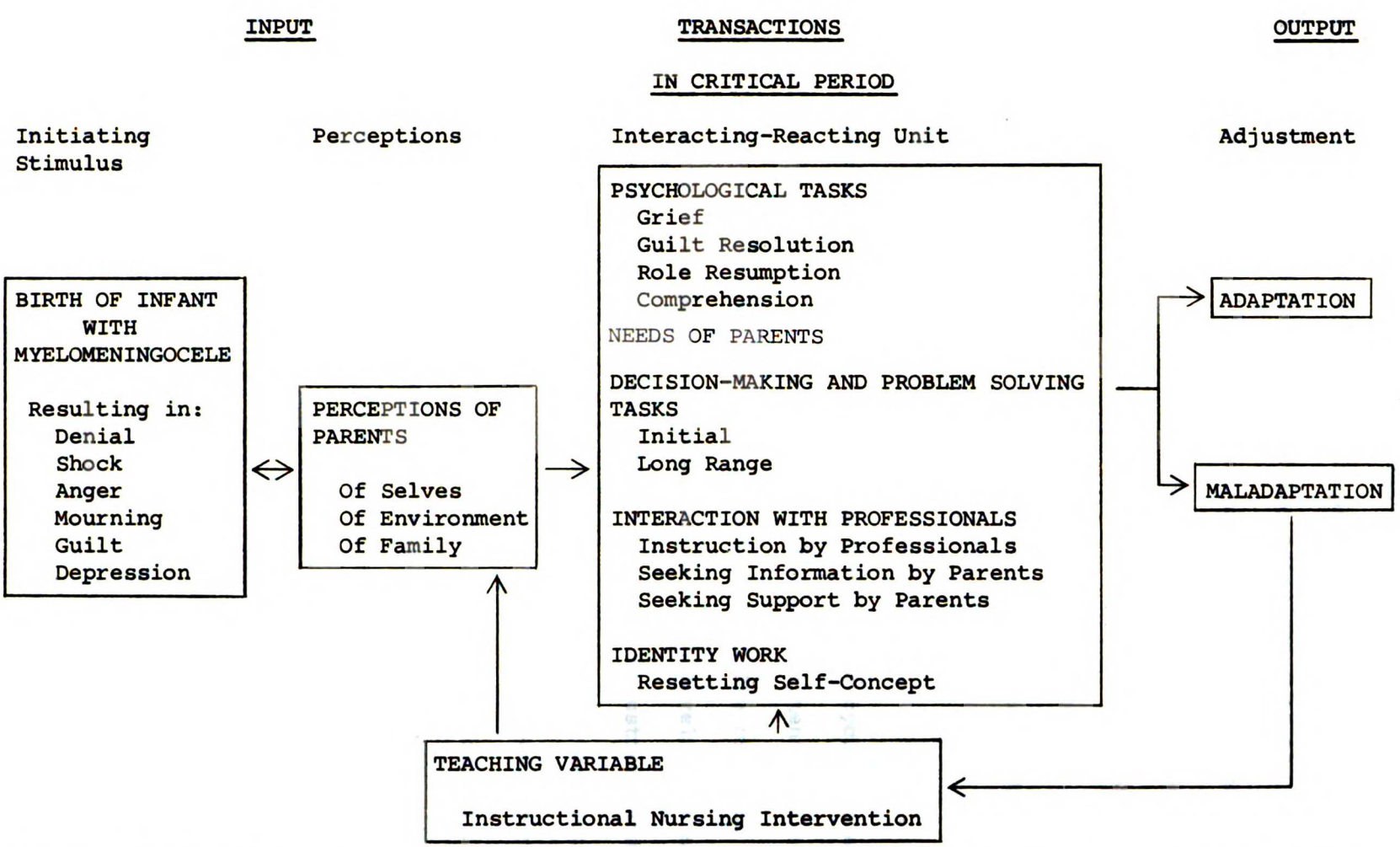


Figure 2.1 Conceptual Framework: Effects of Instructional Nursing Intervention on the Understanding, Self-concept, and Adaptation of Mothers of Children with Myelomeningocele.

The model includes in the input component the event of the birth of the malformed child and the perceptions that the parents bring into the event--predetermined and preexistent to the birth. These two components in the input section may be considered the "givens" of the situation. The transactional phase includes those concepts which are basic in determining whether a successful adaptation or an unsuccessful adaptation will occur. The output in the model is one of two alternatives: adaptation or maladaptation.

The Critical Period Concept

The concept of critical periods in the life cycle, generated and explored primarily in the field of child development (Erikson, 1963; Spitz, 1965) has relevence for this study. The critical period concept contends that particular periods in human development are crucial to any individual's healthy and positive adjustment and his readiness to progress to a different or higher level of development.

Lindemann (1944) and Caplan (1960) have developed the concept of critical periods into a useful concept in the study of crisis intervention. According to Lindemann and Caplan, the manner in which the family members respond to the initiating stimuli of the crisis situation and the success they achieve in ultimately coping with them may permanently influence future behavior and adaptations. They further postulate that in each episode of crisis there is a set of tasks which must be accomplished by the individuals involved if the situational problem is to be successfully resolved. Hurwits and Kaplan (1965) have stated that "grief work" following the loss of a

loved one is an example of such a psychological task. If mastery of the problem does not occur, according to the critical period concept, persons tend to rework previous tasks, develop past orientations, display diffuse anger and are unable to achieve current or future tasks. In short, they display the exact behaviors that were so evident in the families studied by this investigator during the pilot study of parents of spina bifida children.

Within the framework of this study, it was contended that the birth of the infant with myelomeningocele acts as an initiating stimulus for a crisis situation and requires that certain cognitive, emotional, and psychological tasks or functions be accomplished within the first few months of the infant's life. When the birth of the infant is so viewed, the ability of the parents to cope at this time with all the tasks with which they are presented influences their future behaviors and adaptations. If a successful or positive adjustment is made, the parents will be able to perform current tasks and attend to future problems. If the parents are unsuccessful in coping with the crisis, a period of maladaptation will occur. Parents will then tend to rework decisions, develop past orientations, will perform unsatisfactorily current tasks, and will be unable to plan for future needs or problems.

The Input Component of the Model

The Birth of the Infant with Myelomeningocele. The reaction of parents to the birth of an infant with a congenital malformation is well documented. The reactions of parents to such an event have been

studied on the basis of grief and mourning processes (Solnit, Stark, 1961; Olshansky, 1962; Tisza, 1962), as a crisis event in the lives of the parents (Owens, 1964; Gonzalez, 1971; Lis, Pruzansky, Koepp-Baker, Kobes, 1956), as an event creating threat to the self-esteem of the parents (Kaplan and Mason, 1960; Berg, Gilderdale, Way, 1969), and as a cause of reality perception distortion (Caplan, 1959; Farber, 1960; Cohen, 1966; Offord, Aponte, 1967). The cited studies support the assumption made in this study that the birth of a child with any degree of defect sets into motion a complex set of emotional, cognitive and behavioral reactions observable in the parents.

Numerous clinical studies which report the observations of and intervies with parents of infants with congenital defects (Tisza, 1962; Hare, Laurence, Paynes, Rawnsley, 1966; Love, 1970; Johns, 1971) verify the components of the initial reactions of the parents to include shock, denial, disbelief, anger, mourning, guilt and depression. Waterman (1948) reported that the feelings of guilt and failure were so great in parents of mentally retarded children that every parent interviewed engaged in defense mechanisms of some kind.

How the degree of disability of the infant with myelomeningocele effected the dependent variables in this study was not known. Previous studies had shown that in some cases the severity of the physical disability did not appear to correlate with the stress experienced by the family. Janis (1958) investigated the amount of stress experienced by individuals anticipating and experiencing surgical procedures and his findings indicated that the amount of

stress was not correlated with the severity of the medical condition. Davis' (1963) study of families in which a family member was afflicted with poliomyelitis, concluded that the severity of the resulting disability did not determine the degree of family disorganization and disruption. Offord and Aponte (1967) proposed that the impact of a child with a deformity was not dependent upon the actual severity of the deformity, but upon the mother's perception of the severity.

Davis (1963:132) tentatively concluded, however, that an "illness-generated adjustment process" proved much more difficult and prolonged for the parents in those cases where the child remained handicapped. Davis further suggested that in the case of permanent handicapping the disturbances in the family processes were "self-generating potential, forever giving rise to new...adjustments."

Generalizations from the cited studies to the families of myelomeningocele infants could not be made due to the vast differences in the degree of visibility of the defects, the severity and multiplicity of the defects, and the number of unique factors involved in parenting a child with myelomeningocele which have not yet been studied. This study assessed the degree of disability in the myelomeningocele children in the families studied and added additional information concerning the relationship between the degree of disability and family adjustment and adaptation.

Perception of Parents. Psychologists and sociologists have recently studied individual variations in the perceptions of what is and what is not stressful (Lowenthal, 1971). Lazarus (1967) has

emphasized the importance of cognitive appraisal which takes place in the individual observer as determining to a large extent what will be interpreted as stressful. Perception has recently been used to indicate cognition of factors and forces and the internalization of the implications of the meaning of observed events. Research indicates that perception is an individual characteristic and that the unique perception of an event by the observer will determine what response will occur to any given stimulus; that is, whether the individual will be anxious, challenged, or overwhelmed (Lowenthal, 1971).

Unrealistic perceptions of a stimulus or event may result from a number of factors. Lazarus (1967) emphasized unrealistic perceptions as a mechanism of defense to the self-concept. Thus a parent of a malformed child may suffer distorted perceptions of the disability as a component of the denial phase of adaptation. Comunication breakdowns, interpretations of previous experiences, and incompatibility of the stimulus to the self-concept and future goals of the individual have also been cited as causes for distortion in perception (Kuhlen, 1964).

Documentation for variations in reality perception of parents with myelomeningocele can be found in the studies that have been done. In a study of 97 spina bifida families, "...[parents'] replies appeared to indicate that fathers were more distressed than mothers by the news, of [the defect] but it became evident that mothers, at the time of the first interview, had not really taken in the situation." (Hare, Laurence, Paynes, Rawnsley, 1971, pg. 757). Another

study of one hundred and seven spina bifida families indicated that it was "difficult to generalize about the reactions of parents during the first days and weeks after the birth of the child" (Walker, Thomas, Russell, 1971, pg. 466). In the same study it was further reported that wide ranges in understandings, cognitions, and abilities to recall information were demonstrated by the parents studied.

In summary, concepts important to the input of the model are: (1) the birth of an infant with myelomeningocele; and, (2) the perceptions of the parents of the infant. Based on the findings of previous studies, it was assumed that the birth of an infant with spina bifida was a stressful situation for the parents. Stress would be manifested by denial, anger, mourning, guilt, depression or other adaptive processes. The parents bring into the situation predetermined patterns of perception of themselves and of their environments. These perceptions are based on individual factors inherent in the personality structures, past experiences and previously formed estimates of their self-concepts.

The Transactional Component of the Model

Psychological Tasks. Kaplan and Mason (1960) in analyzing the results of their study of maternal reactions to premature births, identified a "set of psychological tasks" essential for the mother of the infant to perform in order that successful mastery of the situation could take place. These tasks include: (1) anticipatory grief which is preparation for the possible loss of the child whose life is in jeopardy; (2) acknowledging failure to give birth to a normal

child;[1] (3) resumption of the process of relating to the infant in an altered manner and retrieving some of the mother's hopes for the child which were formulated during pregnancy and seriously threatened at the time of birth; and, (4) understanding of how her baby differs from normal in order to give the special care needed by the infant. Kaplan and Mason contend that the mother must be able to accomplish each of these tasks in an appropriate period of time to successfully deal with the stress of premature birth.

The assumption can be made that the needs of mothers who give birth to myelomeningocele infants are not unlike those described by Kaplan and Mason, but are intensified by the addition of decision-making tasks that are unique to the myelomeningocele situation. However, the obstacles which exist to successful accomplishment of these tasks by the mothers of myelomeningocele infants are formidable able. The anticipatory grief stage of mothers with premature babies may begin at the onset of premature labor and continue throughout the labor and delivery. Mothers of myelomeningocele infants are unable to experience an anticipatory grief stage since labor and delivery are usually quite normal. Acknowledging the failure to give birth to a normal child is equally difficult for parents of myelomeningocele infants because many parents are never allowed to touch or hold their infants prior to the initial surgery on the

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[1]Also see Eugenia H. Waechter, "The Birth of an Exceptional Child", Nursing Forum, IX, no. 2, (1970), 202-216, and Pat L. Jackson, "Chronic Grief", American Journal of Nursing, 74, no. 7, (1974), 1288-1291.

spinal lesion and until after the neurosurgical shunting procedure for control of hydrocephalus is completed. The inability to begin normal mothering functions prolongs the denial period and delays the guilt resolution process which would otherwise occur at this time.

The source of the impact of the infant with myelomeningocele on parents, therefore, is verbal or cognitive rather than sensory. The parents are told about the defect rather than seeing it. The possible deformities of the child are explained to the parents rather than the parents visually inspecting the infant's limbs. It is reasonable to question whether the impact of the severity of the infant's condition is realized by the parents until long after the surgery is completed and the plans for taking the child into the home are being formulated.

The last two psychological tasks defined by Kaplan and Mason, resumption of the process of relating to the infant in an altered manner and developing an understanding which will lead to comprehension of the special needs of the infant, are dependent both on how well the first two tasks have been accomplished and on the quality of information and support that is made available by the professionals caring for the infant and mother.

In summary, this study assumes that the psychological tasks identified by Kaplan and Mason and described above are also applicable to mothers of infants with myelomeningocele. Parents of myelomeningocele infants usually do not view the defect until after the surgical repair and are not allowed to hold or closely inspect the infant. The source of the information concerning the defect is

cognitive and the parent's denial stage is prolonged and the achievement of necessary psychological tasks delayed or inadequately accomplished.

The Decision-Making Tasks. The decisions concerning the treatment program for the infant with myelomeningocele may well be the most controversial subject in the consideration of the problem. There is evidence in the literature that in many instances it is not thought appropriate to consult with the parents concerning the initial decision to begin active treatment. Katzen (1967) has stated, " It is mandatory that considerable care be given to the decision to treat these unfortunate children on the first day of life...Though it is the doctor's duty to save life, he is entitled to use his discretion in not prolonging severe suffering under special circumstances." Zachary (1968) stated, "The first and most serious ethical problem arising in the case of a child with myelomeningocele is whether he should receive medical care or not." Zachary further asserts that a physician who accepts the responsibility for the early decision in the treatment of the infant also assumes a responsibility for the total long-term care of the child.

In a recent editorial appearing in Developmental Medicine and Child Neurology the position was taken that "Medicine can be regarded as a job in which the physician presents the probabilities to the patient who makes a decision. Parents faced with a new baby that is handicapped find it hard to comprehend the choices presented to them. This is one case when the doctor should give clear-cut advice." (MacKeith, 1971:277). An instance was recently reported

where The Social Services Committee had obtained a court order to allow surgery to be performed on an infant with myelomeningocele after the parents had refused to sign the operative permit.

In other instances a clear-cut decision is requested from the parents. In an article published by the parents of a myelomingocele infant, the interactions with four separate physicians were described by the father in his pursuit for information on which to make the decision demanded of him. Three physicians refused to give advice, while a fourth declared "I can't make this decision for you, but I think it's best you don't treat this baby." (Morse, 1972). In the population interviewed for this study, a clear majority of the parents were allowed to make a free decision.

Evidence suggests that all parents do not experience the same decision-making situation. There is no standard amount of information given concerning the condition of the child before the decision is required. Some parents are given a full explanation of the infant's defects and some are given only information concerning the spinal lesion before the initial surgery. Information concerning the accompanying disabilities is then given later, when the parents are better able to assimilate the information.

The initial decision to treat the infant does not complete the decision-making tasks of the parents, but is only one of a series of decisions which need to be made. After the first critical days of life, decisions concerning treatment of infections, decisions concerning treatment for developing hydrocephalus, decisions regarding institutionalization or home care, and decisions relating to all

facets of care and treatment will need to be made by the parents. Lorber (1971) points out, however, that once the initial decision to treat the child has been made by the parents, a decision to withdraw treatment at any point along the decision-making sequence is extremely difficult for the parents to make.

Needs of Parents and Interaction With Professionals. It is impossible to conceptually separate the needs of the parents at the time of birth of a defective child and the interaction with the professionals responsible for the care of the mother and infant. Theoretically, the principle responsibility of the professionals would be to assess and devise methods of meeting the needs of the parents.

One of the first needs manifested by parents after the birth of the infant is for information concerning the condition of the child. Without accurate information, a rational decision concerning the infant cannot be made by the parents. Without accurate information the parents cannot begin the cognitive and emotional tasks involved in adjusting to the new situation. Studies indicate that the handicap of the child has less influence on the child's ultimate level of functioning than the parental attitudes to which the child is exposed (Watson and Johnson, 1958; Haring, 1959; Miezio, 1973). Parental attitudes develop early in the life of the infant and may influence the entire adaptation process.

Studies suggest that the health professionals are not prepared to assist parents in making decisions relative to the treatment of a congenital malformation and further suggest that adequate

follow-up care is not provided to the families. Swinyard and Sansaricq (1969) reported the "...distressing tendency to call for neurosurgical consultation with reference to primary surgery on the meningeal sac and wait for the parents to learn by experience..." Freeston's (1971) study of eighty-five myelomeningocele families indicated that less than half of the parents believed that the information given to them had been adequate to meet their needs. Hare, Laurence, Paynes, Rawsley (1966) reported that more than half of a sample of ninety-seven mothers of myelomeningocele infants interviewed did not believe that the instruction and advice which they had received had been sufficient to meet their needs for information. Information obtained from parents in retrospective studies may include reports that are due to faulty memory and misinterpretation of what was told them. Professionals working with families under stress must recognize, however, that offering the information once, no matter how simply and well presented, can not be equated with teaching families what they need to know. An enormous amount of medical information must be comprehended by the parents. The problem of learning under stress is compounded by the problem of information overload. Freeston commented on the "unmet need for information from a health visitor calling on parents in their homes" (Freeston, 1971:459). Special qualifications for those visitors were cited by the mothers interviewed by Freeston. These qualifications included "a person capable of explaining the various complications which might arise...and ways of overcoming them...and able to interpret the treatments proposed by the medical staff" (pp. 459-460).

This need for special qualifications for the health visitors was supported by Kessler when he stated "The parent counselor, whatever his professional background, needs special knowledge of three kinds; technical information about the specific disability, a good background in child development, and a sympathetic understanding of parents' feelings." (Kessler, 1966:155).

The immediate need of parents is for information which is factual, relevant, and easily understood. The information should be given as often as necessary. The comprehension of parents may present a problem because of their anxiety level and grief. Attending professionals are responsible to see that the information is given with as little conflicting data and with a minimum of technical terminology. Joint planning among all workers associating with the parents can not be overemphasized. Conflicting information and advice may serve to increase the confusion and frustrations of the parents.

The second major need of parents at the time of birth of an infant with myelomeningocele is for support. This need is implied in all the studies which have been previously cited describing the emotional reactions of the parents involved in the birth of a defective child, including grief, mourning, guilt, and depression. Specifically, however, the parents will need reassurance that nothing either parent did caused the defect. They will also need support in their decisions concerning the treatment and care of the infant. After the initial decision is made, they will need support when they begin to rework the previously made decision. The importance of

supporting parents with factual information which is neither overly optimistic or overly pessimistic has frequently been stressed by many authors. (Zachary, 1968; Lavoie, Lierman, Fletcher, Corbett, 1973). Meizio (1973) emphasized the importance of supporting the parents by encouraging them to talk out the problem and all the possible solutions.

The non-verbal behavior of professionals and para-professionals in attendance is important to the perceptions of the parents. It is possible to communicate rejection of the infant and disapproval of the parents in behaviors which contradict the verbal support given. If persons in attendance are to give the needed support to parents they must have worked through their own feelings and reactions to the infant and be able to face the parents sympathetically, honestly, and without rejection or disapproval.

Identity Work. Identity work has been defined for purposes of this study as the activities performed within an individual's social environment for the purpose of "resetting" the self-concept along a feared-ideal continum. The work consists of individuals seeking input of new information, validating the input, interpreting the input and finally resetting the self-concept on the basis of the perceived input. Significant others in the environment are used as objects for the identity work.

When parents give birth to a malformed child, they must test their present self-concepts against new input which they receive from the environment. The environment in the initial period after delivery is most generally the Hospital environment. Mercer (1973)

has studied the processes of behavior displayed by mothers of infants born with congenital defects. In Mercer's study the incidence of self-appraisals was reported to be disparaging almost twice as often as they were expressing self-satisfaction. These findings support the assumption that a process of self-reevaluation follows the birth of an infant with a defect. Mercer also observed that in the first three months after the birth of the child with a defect that "...evaluation of other's reactions exceeded all other behaviors and increased proportionately over the three months." This finding supports the concept of the importance of significant others in the environment.

The processes described by Mercer in her study in light of Wallace's "resetting of the self-concept" theory assume added importance. In the first critical days following the birth of the malformed child the only individuals in constant contact with the mother are the professionals and paraprofessionals providing care. The processes of self-appraisal and evaluation of other's reactions described by Mercer and the work of resetting the self-image discussed by Wallace are closely related, and are accomplished by the use of significant others in the environment. In the case of the new mother of an infant with myelomeningocele the professionals and paraprofessionals constitute the significant others in the immediate environment. If the input received by the mother from the environment reinforces the guilt, depression, sense of failure and sense of inadequacy, the self-concept will be moved toward the feared end of the continum. If the input received by the mother from the

environment reinforces the parents as persons of worth who are free from guilt concerning the malformation of the child and provides support to the parents' capacities for coping with the present and future problems which the infant will precipitate, the possibility of retaining the previous self-concept held by the mother will be increased.

Rationale For Instructional Nursing Intervention By Professional Nurses

The independent variable of this research study is instructional nursing intervention by a registered professional nurse and is contained in the feedback loop of the proposed open systems model. Professional nurses have long recognized patient or client teaching as an inherent part of their responsibilities to furnish optimum care. Public health nurses and community health nurses especially have considered restorative and preventative health care through methods of individual and group teaching essential to quality.

Principles of teaching-learning and the professional nurse's responsibilities to be knowledgeable about them and skillful in applying them are common themes in nursing textbooks. Freeman (1963) stressed that family health counseling and teaching are "...inextricably interwoven with the other aspects of nursing care." Matheney recently emphasized the following responsibilities of professional nurses: (1) identify the learning needs of patients and families, (2) consider the learner in terms of the "factors that will impede or support learning", and to (3) apply the known concepts of the teaching-learning process, (Matheney, 1968). Presentation of health

information to families in such a manner and at such a time that it will enable the families to better understand their own needs and to actively participate in planning for providing their own care is no easy task. Effective health teaching by professionals presupposes a conceptual basis for interpersonal relations and counseling and suggests that competent nursing practice is grounded in artful application of communication skills and learning theories.

Meeting the needs for knowledge and understanding of families of severely malformed children may be one of the most difficult tasks facing professionals. The needs of the family must be assessed over a period of time, and the family allowed to request the information they need at the time they are prepared to receive it and, with help, can deal with the information. Professionals are needed to work with these families who can demonstrate overt acceptance of the child's disabilities and disfigurement and of the family's reactions to the disabilities. The teaching professionals need preparation in the special and complex scientific knowledge base surrounding the disease processes, probable complications and sequelae, and essential care components basic to the growth and development of the child. In addition, professionals who work with these families must have an understanding of the needs of the child for habilitation and continued care, and must be able to relate to the families with warmth and empathy (Peitchinis, 1972).

The professional nurse with theoretical and clinical expertise is the logical choice for the teaching role with families of myelomeningocele children. The professional nurse remains in

long-term contact with these families, combines the scientific knowledge of the pathology with the theoretical and practical communication skills, and is able to time the teaching so that optimal learning by the family members can occur.

SUMMARY OF THE CONCEPTUAL FRAMEWORK

A conceptual framework for studying parents of children with myelomeningocele has been developed on selected crisis intervention concepts and presented as an open systems model. The model has been used to describe the experiences which surround parents following the birth of an infant with myelomeningocele. The experience of the parents has been defined as a critical period in their lives. In a critical period, the ability to cope with the problems presented permanently influence future behaviors and adaptations. The input component of the model consisted of the initiating stimulus, which was the birth of the defective infant, and the infant's parents who have perceptions of themselves and their environment. The transactional phase of the model included the psychological tasks necessary for all parents of malformed children. The transactional phase of the model included: (1) psychological tasks necessary for all parents of malformed children, (2) decision-making tasks specific to parents of children with myelomeningocele, (3) interaction between parents and professionals in the process of meeting the needs of the parents, and, (4) identity work which involves resetting the self-concept of the parents in response to the input from the environment. The output component of the model was: (1) positive adaptation with the

ability to cope with present and future tasks, or (2) maladaptation which was characterized by the inability to cope with present and future problems. The independent variable of the study, instructional nursing intervention, was included in the feedback loop of the Model to Study the Effect of Instructional Nursing Intervention on the Understandings, Self-Concepts, and Adaptations of Parents of Children with Spina Bifida with Myelomeningocele.

CHAPTER III

THE PROBLEM OPERATIONALIZED; ASSUMPTIONS OF THE STUDY; OPERATIONAL DEFINITIONS AND HYPOTHESES

The Purpose of the Chapter

The purpose of this chapter is to relate the information concerning the nature of myelomeningocele and the status of the presenting infant offered in Chapter 1 to the conceptual framework developed to study the process of adaptation experienced by parents of children with myelomeningocele presented in Chapter 2. The first section of this chapter reviews the findings of several studies which investigated families of children with myelomeningocele, and lists assumptions of this study which are based on the findings of those reports. The second section presents the hypotheses and explicates the variables in the study from the many common usages each term has to the exact conceptual context in which it will be used in this study. These explications serve as the bases for the operational definitions which follow.

Related Studies

The literature on the subject of spina bifida is vast. Ingraham's classic treatise and bibliography (1943) included over one thousand entries. Interest in the condition has further expanded since 1960 with the institution of aggressive management regimens.

Despite the mounting interest in the clinical aspects of the condition, a search of the literature revealed only five studies which investigated the impact that the myelomeningocele child exerted on family life and family structure, and therefore had a direct relation to this study.

The nature of the stresses imposed on families by the birth of an infant with myelomeningocele was the focus of a study conducted by Hare, Laurence, Paynes and Rawnsley (1966). Interviews with ninety-seven mothers of spina bifida children at intervals of three days, one month, and six months after the birth of the affected child revealed the following information. (1) The majority of mothers believed the news about the infant had been given to them as kindly as possible. Those mothers who did not believe the news was given in an appropriate manner believed the anxiety of the physician or nurse prevented effective performance by the professionals in attendance. (2) Most mothers were unable to "take in" the news when it was first given. (3) The majority of mothers interviewed reported feeling "alone and isolated" once they were at home with their babies. (4) Health visitors and welfare workers knew very little about the special and complex problems of myelomeningocele infants. It was concluded by the investigators that the method and manner used by professionals to initially give the information concerning the infant to parents was of vital importance in the eventual adaptation of the parents to the situation. The authors, on the basis of the study, recommended: (1) special hospital centers for coordinated care be established, (2) one health worker with special training and

experience be assigned to work with the families of myelomeningocele children, and, (3) special efforts be made to involve parents in parents' groups.

The families of eighty-five myelomeningocele children living in the catchment area of Sheffield Children's Hospital were studied to assess the impact of the child on the family and the adequacy of existing social service to meet the needs of the families. Pertinent findings of the study included: (1) one-fourth of the fathers and "very few" of the mothers stated that they understood the explanation of the defect that was initially given to them; (2) neither parent was in a state to comprehend the information given to them when it was first offered; (3) anxiety rose in the mother when she was not allowed to hold, handle or care for the child; (4) numerous clinic visits which demanded five to six hours away from home was a common source of stress after the infant's discharge from the hospital; (5) nearly all parents accurately recalled genetic information by the time the affected child was one year old; (6) the incidence of marriage breakdown in the families studied was not significantly higher than in the general population; and, (7) less than one-half of the families were regularly visited in the home by a health visitor. Those who were visited regularly believed the health visitors were unable to provide the guidance and information needed by the family. Freeston concluded from his study that the greatest unmet need of families of spina bifida children was special home visitors who were knowledgeable about the complications of the medical problem and the treatment procedures proposed by the medical personnel. (Freeston, 1971).

Parental adaptation in families of myelomeningocele "survivors" seven through eleven years of age was studied by Kolin (1971). Parental adaptation was rated on the following criteria: (1) understanding of the parents of the child's defect; (2) the parents' role in the child's development; (3) marital status; and, (4) mental status. Adaptation was rated good if successful adjustments had been made in three of the four areas and only moderate impairment in one area. Adaptation was rated fair when there was moderate impairment in all four areas. Adaptation was rated poor with severe impairment in one or more areas and moderate impairment in the remaining areas. The total number of parents in the study was thirteen. Three couples were rated good, two fair, and eight poor in their adaptations. Kolin concluded from his study that: (1) degree of impairment of the child is not a critical factor in parental adaptation; (2) pessimism concerning spina bifida children led to parental and professional neglect of the children; (3) myelomeningocele children resulted in increased numbers of marital breakups; and, (4) denial, rejection and overprotection of the child were present in all of the parents studied, but was greatest in parents with poor adaptation levels. Finally, Kolin determined that the physician's initial and subsequent communications with the family was an essential component for family adaptation.

A study of 107 families of spina bifida children which investigated the parents' initial responses to the information concerning the infants' defect was reported by Walker, Thomas and Russell (1971). Important findings in this study conducted in the Newcastle on Tyne

catchment area included: (1) grief, shock, confusion and denial reactions were experienced by all parents; (2) increased anxiety was experienced by mothers who were immediately separated from the infant; (3) in many cases the infant was first handled by the mother on the day she took the infant home from the hospital; (4) few mothers spoke positively about the help received from the health visitor; (5) the majority of the mothers believed their general practitioner was less knowledgeable about the problem of spina bifida than the parents themselves; and, (6) less than 35 per cent of the parents had accurate information regarding the increased risk of spina bifida in future pregnancies.

The progress of three years of "coordinated care and social management" at the Royal Alexander Hospital for Children, Sidney, Australia, was the subject of the final study reviewed (Field, 1972). Although not a formal research study, Field reported personal observations of more than 265 children with myelomeningocele and their parents. Children's groups and mothers' groups have been formed with group or individual therapy available. Although measurement criteria were not given, the author reported decreased anxiety and more positive adjustment among family members as two of the outcomes of the group sessions. Field's study did not support the findings of increased divorce rate, but cited the extended family group as an important factor in the maturing of the parents under crisis.

ASSUMPTIONS OF THE STUDY

The findings of previously reviewed studies supported the basic assumptions of the research study reported by this investigator. The assumptions included:

1. The birth of an infant with myelomeningocele produced high levels of stress in the parents of the child. For most parents, the birth of the infant precipitated a crisis situation which effected each parent individually and the family as a unit.

2. Knowledge concerning the condition of the infant or child and understanding of the diligence necessary for proper care of the child with meylomeningocele are important factors in the adaptation process of parents of children with myelomeningocele.

3. Information regarding the infant's condition frequently was not assimilated or understood when it was first presented.

4. Adequate sources for continued information at the time the parents demonstrate a readiness for it do not presently exist in the current health care system.

5. The quality of the relationship formed between the parents and the professionals who served the family influenced the adjustment processes of the family.

It was further assumed, for purposes of the study, that due to the interaction of the above factors, the problems encountered by parents of children with meylomeningocele tended to be self-perpetuating and that families with children who were forty-eight months

old would display similar problems to families with children six months old. It was further assumed that a teaching sequence could be developed relevant to the problems and needs of parents of myelomeningocele children and that the effectiveness of that teaching sequence could be measured.

HYPOTHESES

Chapter 2 described and illustrated a conceptual framework in which the variables investigated were presented in a systems framework. Instructional nursing intervention performed in the homes of parents of children with myelomeningocele was conceptualized as the independent variable. One of the purposes of the study was to systematically investigate the relationship between instructional nursing intervention and the understanding, self-concept and adaptation of mothers of children with myelomeningocele. The expectation of the researcher was that the scores on the understanding and self-concept measures would show significant differences between the experimental group and the control group, and that the differences would favor the experimental group. It was also expected that the scores on family adjustment would change significantly more in the experimental group than in the control group. The direction of the change was not predicted.

Primary Hypotheses

H_{1a}: Instructional nursing intervention would significantly increase the understanding of mothers of myelomeningocele children.

H_{1b}: Instructional nursing intervention would significantly increase the self-concept of mothers of myelomeningocele children.

H_{1c}: Instructional nursing intervention would significantly change the adaptation of mothers of myelomeningocele children.

Subhypotheses

(A) Mothers in the experimental group would demonstrate significantly greater increase from pretest to posttest on understanding scores than mothers in the control group.

(B) Mothers in the experimental group would demonstrate significantly greater increase from pretest to posttest on total self-concept scores than mothers in the control group.

(C) Mothers in the experimental group would demonstrate significantly greater increase from pretest to posttest on personal self scores than mothers in the control group.

(D) Mothers in the experimental group would demonstrate significantly greater increase from pretest to posttest on family self than mothers in the control group.

(E) Mothers in the experimental group would demonstrate significantly greater increase from pretest to posttest on Self Criticism than mothers in the control group.

(F) Mothers in the experimental group would demonstrate significantly greater change from pretest to posttest on total family adjustment than mothers in the control group.

(G) Mothers in the experimental group would demonstrate significantly greater change from pretest to posttest on inter-parental friction-harmony than mothers in the control group.

(H) Mothers in the experimental group would demonstrate significantly greater change from pretest to posttest on rejection of the child than mothers in the control group, in the direction of less rejection of the child.

EXPLICATION OF TERMS

The dependent variables in this study were: (1) understanding, (2) self-concept, and, (3) adaptation. Each of these terms are in common usage and have a variety of meanings and interpretations. This section presents the exact context from which each term was derived for the purposes of the study and offers the explication of each of the terms.

Nursing Intervention. From the basic general definition of intervention as coming between as an influencing force, it has become popular to view the entire nursing process as intellectual or physical acts which are to somehow separate or come between the patient and illness or the client and the barriers which exist in his immediate psycho-social, emotional, and physical

environment separating him from wellness. The patient's environment is considered to be composed of biomedical, psychological, and sociological environments that are interacting with the patient. Nursing process has been described as a series of acts "which connote action, reaction, interaction..." on the part of both client and nurse (King, 1971). The schematic design of the process described by King clearly indicates perception, judgment and action being undertaken by both the client and the nurse, followed by a series of reactions, interactions, transactions, and feedback. Even when the nurse decides in this model to take no action when she has completed her assessment of patient's needs, intervention into the client's life process has already occurred due to the changed interpersonal relationships experienced by both nurse and client.

A conceptual frame of reference for nursing based on mutual interaction by patients and nurses was proposed by Peplau (1952). The basic component of the interaction was an interpersonal process which Peplau offered as a "rational basis for nursing care." In Peplau's framework, the foundation of the nursing process was an intervention in the lives of both nurse and patient which lead to changes in both participants. During the process, each participant learns from the relationship, and hopefully moves toward some desired, predetermined goal. More recently the patient has been conceptualized as a conjunction of several systems and nursing intervention defined as actions to modify the interaction between the systems (Bailey, McDonald, Claus, 1971). This useful model builds on the interactional component of the nurse-patient relationship, but allows for

delineation of specific problems and actions individualized for the specific patient and nurse.

The construct "nursing intervention" as used in this study described explicit nursing actions based on previously determined needs of a specific population and used patient-nurse interaction as the basic tool. This use did not alter or expand the general definitions in any way.

Understanding is frequently used to indicate the quality of "knowing," "comprehending," or "awareness." The practice of defining the two terms, knowledge and understanding by the use of the other term is quite common and is indicative of the problem encountered in theoretical separation of knowledge and understanding. Bloom (1956), referred to the common practice of writing objectives utilizing the term understanding and testing those objectives only by factual recall of information or data which is indicative of knowledge acquisition.

Contemporary authors suggest that the lower levels of Bloom's taxonomy which deals with knowledge of specifics such as terminology, specific facts, classifications, etc. may be prerequisites for that which is commonly referred to as "understanding." Brubacher has offered five steps to knowing: report from the senses, memory, activity of the intellect, essence of image presented to the cognitive intellect, and conceptualization of the essence or image. He then emphasized, "...Of course, the learner should not stop with this morphology of knowledge. From a knowledge of things he should go on to an understanding of the relation of one known thing to another." (Brubacher, 1962;81-82).

This prerequisite relationship between knowledge of specifics and the attainment of understanding was further implied when Bloom stated, "Evaluation of objectives at higher levels in the taxonomy is often impaired because of...inability to perform the initial step in problem solution: the translation of the problem into known terms." (Bloom, 1956:98).

Recent remarks on language learning patterned after Piaget's formulations of successive stages in cognitive development (Sinclair, 1973), emphasized that although basic learning may be divided into two separate and distinct "kinds of concepts", both depend on the subject's interaction with his environment and are constructed according to the individual's level of development. Sinclair cites unpublished studies of Bovet which illustrate that what may be an obstacle to learning at one stage may well be an incitement to learning at another stage.

Viewed epistemologically a logical separation of knowledge from understanding may well be that knowledge is indicated by the ability to recognize and utilize isolated concepts or to perform individualized activities without forming linkages from the concept fragments and activities to the associated constructs or related operations. Understanding does not occur until the relationship between the knowledge obtained and related concepts can be internalized and the implications of the information is realized and regulatory mechanisms are activated. Knowledge can be equated to precognitive operations where information can be repeated and acted upon and understanding equated to use of information in a "solid

framework of logical thinking" (Hinde and Stevenson-Hinde, 1973) which orders and links concepts.

An interrelationship between the two concepts, knowledge and understanding, was assumed. The difficulties in reliably measuring the concept understanding were acknowledged and the beliefs of Bloom and other authors concerning knowledge being prerequisite to understanding were accepted for purposes of this study. The term understanding will be used to refer to knowledge of specific facts, terminology relating to the medical condition of the involved child, knowledge concerning treatment options, treatment methods and possible outcomes, the ability to identify and recall information concerning myelomeningocele, and the ability to choose priority actions under certain given conditions or in specific situations. This definition does not seek to give new meaning to the term understanding, but only to give it more precise meaning for the purposes of the study.

Self-Concept is one of the most widely investigated concepts in behavioral science. As a basis for the use of the term self-concept in this paper the following major schools of thought and frequently cited definitions are presented.

The modern concept of self was introduced by Freud and the Freudian School which used the term "self" synonymously with "ego". The term "self" was later conceived as a "structural aspect of personality" (White, 1963),. The social interactionists, exemplified by the writings of Mead (1934), believed that the self was not a structure permanently formed prior to or shortly after birth, but that the self grows and developes in the individual as a result of

social interaction. Wallace (1967), an anthropologist, carried this definition one step further by asserting that not only does the potential for change exist in the self, but that each individual is constantly engaged in efforts to move the cognitive setting of his real identity (as he defines the self-concept) along a linear continuum which places the feared or undesirable identity at one end and the ideal or most desirable identity at the other end of the continuum. Wallace claimed that each individual will do given amounts of "identity work" which he defined as "measurable physical and mental effort which is designed to bring into perception evidence which will justify the cognitive resetting of real identity at a more desirable state." The identity work is performed within the social environment of the individual and consists of seeking input of new information, validating input, interpreting input, and resetting the self-image along the feared-ideal continuum.

These definitions of self and self-concept as a composite of many images that the individual holds of himself as a person at any one point in time furnishes the basis for the definition as used in this study. Self-concept was defined as that full set of opinions, perceptions, and images an individual holds of himself as a person and involves the satisfaction and the dissatisfaction he feels concerning his abilities to manage those things expected of him by the significant others in his environment. The fact that self-concept is defined as a composite of many aspects recognized that certain of the aspects of an individual's self-concept may move in one direction along the feared-ideal continuum while other aspects remain stable

or even move in the opposite direction. It also recognized the importance of the input of others in the individual's interacting social environment.

Adaptation in its broadest sense can be defined as any change or adjustment made by an organism that occurs in response to an internal or external stimulus. In a sociological sense, adaptation involves a change in behavior; that is, the individual is said to "adapt" when behavior changes in response to a perceived stimulus. Adaptation is frequently used to imply a positive adjustment, one which will allow the individual to maintain or achieve an improved state.

Adaptation in adult life has been defined as the individual's "efforts to achieve, restore, or maintain some yet to be determined degree of congruence or equilibrium between his conscious goals and his behavioral pattern" (Lowenthal, 1971). In response to a stimulus which causes "dysfunction", "disequilibrium", loss of "homeostasis" or a period of disorganization, an organism will respond with certain cognitive, emotional, and behavioral manifestations. These adjustments can be said to be positive or successful when they lead to greater homeostasis or resistence to stress, and can be termed unsuccessful when they result in increased, chronic tension and anxiety. Lowenthal (1971) suggested that the difference between "successful adaptation and "unsuccessful adaptation" might depend on how well the imposed and necessary behavior changes "fit" or allow for congruency between behavior and the basic goals of the individual. For example, the addition of the care of a severely handicapped child

to a family in which the mother's global goal is to be the best possible mother will present a different adaptation process than when the care of a severely handicapped child is added to a family in which the mother retains global goals of a successful professional career or a life style offering great amounts of flexibility and freedom of movement.

For the purposes of this study adaptation was used to indicate the adjustment made by the parents studied in relation to their feelings and attitudes toward intrafamily relationships.

Operational Definitions

Instructional Nursing Intervention. For purposes of this study instructional nursing intervention was defined as an organized, interactional teaching sequence between a professional nurse investigator and the parents of a child diagnosed as having spina bifida with myelomeningocele. The interactional teaching sequence consisted of three home visits and included information concerning the etiology, physiology, pathology, diagnosis, treatment methods and care considerations of a child with myelomeningocele.

Understanding. For purposes of the study understanding was defined as knowledge of specific facts and terminology relating to the medical condition of myelomeningocele, knowledge concerning treatment options, methods and possible outcomes, and the ability to recall information concerning myelomeningocele and to choose priority actions under certain given situations involving the care of the child. A multiple choice test composed of twenty-five questions

based on the previously listed items was constructed, tested and validated by the investigator. A maximum of ten points could be scored on each of the twenty-five items, making the highest possible score 250 points. The understanding score was the total number of points achieved by the mother of the child on this test.

Self-Concept. For the purposes of the study, self-concept was defined as the full set of opinions, perceptions, and images an individual holds of himself at any one point in time, and involved the satisfaction and dissatisfaction he feels concerning his abilities to manage those things expected of him by the significant others in his environment. The Tennessee Self-Concept Scale was selected as an appropriate indicator of self-concept. The total self-concept score, indicated by the P score and the subscale scores of self-criticism, self-satisfaction, and family self were chosen as the most appropriate measures of self-concept for the purposes of this study.

Adaptation. For the purposes of this study, adaptation was defined as an indication of the adjustment made by parents to the infant born with myelomeningocele and specifically the parents feelings and attitudes toward intrafamily relationships. The Elias Family Adjustment Test in the disguised form, The Elias Family Opinion Survey, was selected as an appropriate indicator of adaptation. Total test scores measuring warmth and love felt toward family members and subscores of Interparental Friction-Harmony, and Rejection of the Child were used as additional indices of adaptation. Adaptation was measured by the scores received by the mother of the affected child on the Elias Family Adjustment Test.

Mother. For purposes of the study, mother was defined as the biological mother of the myelomeningocele child and the principle caretaker of the child. Families were excluded from the study sample if the child was institutionalized, in a foster home placement, or had been adopted.

Children with Spina Bifida with Myelomeningocele. Children six months of age to forty-eight months of age who were receiving treatment or health supervision at one of four major medical treatment centers and lived within a 150 mile radius of the investigator's school residence served as the basis for family participation in the study. All children had been clinically diagnosed as having spina bifida with myelomeningocele, and they had no major unassociated congenital defects apparent at birth.

SUMMARY OF THE CHAPTER

The purpose of the chapter was to relate the conceptual framework underlying the study to the problem studied. Relevant research studying parents of myelomeningocele children was reviewed. The previous research supported the major assumptions of the conceptual framework of this study and included the following: (1) the birth of a malformed infant is a crisis event in the lives of parents; (2) all the information concerning the malformation can not be understood by the parents when it is initially offered; (3) the knowledge and understanding of the mother concerning the child's condition will at least partially influence the adaptation

process of the parents; and, (4) when parents are ready for more information, it is difficult for them to find access to it.

In the next section of the chapter the research hypotheses were presented, based on the framework and the assumptions. Terms that were used in the study that have broad general usages were explicated and exact meanings for the purposes of the study offered. Operational definitions based on the explicated terms completed the chapter. The design of the study, the sample characteristics and the methods of data collection and analysis are presented in Chapter 4.

CHAPTER IV

QUASI-EXPERIMENTAL DESIGN AND METHODOLOGY

Purpose

One of the major purposes of this study was to evaluate the effects of instructional nursing intervention on mothers of children with spina bifida with myelomeningocele. To determine the effect of the instruction, three questions were formulated: (1) Was the understanding of the mother concerning the child's condition increased? (2) Did the self-concept of the mothers move in a positive direction? and, (3) Did the adjustment made by the mothers move away from maladaptation toward adaptation?

Design

The design used to assess the effect of the independent variable was a Nonequivalent Control Group Design.[1] The form of the design is diagrammed as follows:

$$\begin{array}{ccc} O & X & O \\ \hline O & & O \end{array}$$

The O's represent pretests and posttests administered to the experimental group (above the line) and to the control group (below the

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[1]Donald T. Campbell and Julian C. Stanley, "Experimental and Quasi-Experimental Designs for Research on Teaching," Handbook of Research on Teaching, (ed.) N. L. Gage (Chicago: Rand McNally and Co., 1963,)pp. 217-220.

line). The X represents the experimental treatment which in this study was instructional nursing intervention.

The basic design as outlined by Campbell and Stanley (1963) was used. However, the assumption that the groups constituted "naturally assembled collectives such as classrooms" (pg. 218) was not appropriate in this study, since the families did not belong to aggregates of any kind except the medical centers where the spina bifida children were receiving their medical care. This was not used as a criterion for assignment to experimental and control groups. See Table 4.1 for details of the study design. A summary of procedures used with the experimental and control groups appear in Table 4.2.

The Dependent Variables

There were three dependent variables in this study: (1) Understanding, measured by a multiple choice test constructed by the investigator; (2) Self-Concept measured by the Tennessee Self-Concept Scale developed and standardized by W. H. Fitts; and (3) Adaptation which was measured by the Elias Family Adjustment Test (symbol FAT) in the disguised form, Elias Family Opinion Survey, developed and standardized by Gabriel Elias.

The Independent Variable

The independent variable was instructional nursing intervention conducted in the homes of the subjects. Three instructional sessions were conducted with each of the mothers in the experimental group. The sessions involved an audio-slide presentation, open-ended question and answer sessions, structured interview sessions and

TABLE 4.1 DESIGN OF THE STUDY

	PRETEST (DEPENDENT VARIABLES)	TREATMENT (INDEPENDENT VARIABLE)	POSTTEST (DEPENDENT VARIABLES)
CONTROL[1]	Tests: Elias Family Adjustment Tennessee Self-Concept Understanding		Tests: Elias Family Adjustment Tennessee Self-Concept Understanding
EXPERIMENTAL[1]	Tests: Elias Family Adjustment Tennessee Self-Concept Understanding	Instructional Visit #1 Open-ended questions with probes re: initial reactions to information concerning infant's condition; Problems identified and explored. Instructional Visit #2 Audio-slide presentation; Discussion: mother's feelings during presentation; Identify new information, analyze similarities and differences in family on audio-slide presentation. Instructional Visit #3 Review and Application Session; Open-question and answer period Review of factual information Exploration of special or unusual problems of family Exploration of future problems	Tests: Elias Family Adjustment Tennessee Self-Concept Understanding
	(Week 1)	(Weeks 2 - 4)	(Week 5)

[1]Family Information Tool was administered and families assigned to Experimental or Control Group by the investigator during the initial home visit to all families.

TABLE 4.2 SUMMARY OF PROCEDURES USED WITH

EXPERIMENTAL AND CONTROL GROUPS

Pretesting	Experimental	Control	Time Range in Minutes
Elias Family Adjustment Test	X	X	
Tennessee Self Concept	X	X	60-110
Myelomeningocele Understanding Test	X	X	
Treatment			
Teach 1:	X		60-120
Information Obtaining and Problem Identification;			
Reaction to Initial News of Defect;			
Problems Encountered Initially			
Initial Decision-Making			
Teach 2:	X		90-150
Audio-Visual Presentation			
Question and Answer Period			
Terminology;			
Professionals-Family Interactions;			
Early Adjustment Problems;			
Care of Child			
Teach 3:	X		60-120
Application;			
Review and Projection of Future Concerns.			
Interaction Session on Individual Problems and Concerns			
Posttesting			
Elias Family Adjustment Test	X	X	
Tennessee Self Concept	X	X	60-100
Myelomeningocele Understanding Test	X	X	

review sessions. All experimental subjects received the same teaching sequence based on the same protocol (Appendix B). The subjects themselves determined how much of the teaching sessions were devoted to any one given teaching segment.

Sample

Twenty mothers of spina bifida children comprised the sample. The mean age of the mothers was 27 years, and the age range was 19 years to 37.5 years. Half of the mothers were between 21 and 25 years of age. One of the twenty mothers had done graduate work, three were college graduates, ten mothers were high school graduates and six had not completed high school. Additional descriptive data of the spina bifida children and the mothers is presented in Table 4.3.

Names of the spina bifida children and their families were obtained from the clinic and hospital records at the four cooperating medical centers. A list was made of all families who met the following criteria for inclusion in the study: (1) the affected child was at least six months and not more than forty-eight months old; (2) no major birth defects unrelated to the myelomeningocele were apparent at birth; and (3) the family lived within a 150 mile radius of the investigator's school residence. Each family was then sent a letter of introduction to the investigator and the study (see Appendix C). The letter briefly explained the interest of the investigator in the subject, the purpose of the study and asked the parents to consider participating. The letter closed by telling the parents they would

TABLE 4.3

DESCRIPTIVE DATA FOR EXPERIMENTAL AND CONTROL SUBJECTS N=20 Mothers

Group	N	Mean Age of Mothers	Age Range of Mothers	Mean Age of Affected Children (months)	Sex of Affected Children		Mean Years Education of Mothers
					Boys	Girls	
Experimental	10	25.0	20.3-29.9	25.7	4	6	11.7
Control	10	29.8	19.3-37.5	26.8	3	7	12.9
All: Affected Children	20			26.25	7	13	
Mothers	20	27.0	19.3-37.5				12.2

be contacted in the near future by telephone. The study was again explained briefly and the time commitments required for participation in the study were explained. An appointment was made for the initial home visit at a time convenient to the family.[1] During the initial home visit the investigator furnished the parents with identification materials including her Registered Nurse License and graduate student identification. A copy of the letter from the cooperating medical center's Committee on Human Subjects granting the investigator permission to contact the families was also presented. After the parents agreed to participate in the study, the consent form (Appendix C) was read, explained and signed by one or both parents. The family information form was then completed by the investigator from information furnished by the parent(s) (Appendix A).

The families were not assigned to experimental and control groups until the initial visit was made in the home and the consent form to participate in the study had been signed. The rationale behind this procedure was the importance attributed by the investigator in preventing families from self-selecting experimental and control groups. The investigator believed that if families had been informed to which group they would be assigned, it would influence the decision concerning participation. Because random assignment of the subjects to control and experimental groups was not possible, the families were assigned to the control and experimental groups

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[1]Thirty families were actually contacted by telephone. Four of these thirty declined to participate in the study; all four declined at the time of the first telephone contact.

on the basis of the age, sex, and degree of disability of the affected child.[1] Since the degree of disability of the child could not be accurately assessed from clinical records, direct observation of the child and information from the parents was needed to complete the assessment.

The twenty families completing the study represent a non-probability sample (Kerlinger, 1973,pg. 129) drawn from an estimated population of forty-five families who could have qualified for the study. Table 4.4 presents a summation of the families from which the sample was drawn.

Data Collection Procedures

A number of data gathering techniques was used. The following tests were administered: (1) A multiple choice test, constructed by the investigator based on information concerning myelomeningocele, was used to test the mother's understanding of the child's condition; (2) The Tennessee Self-Concept test was used as a measure of the mother's self-concept, with attention to the subscales on self-criticism, personal self and family self. These factors were identified from the conceptual framework as having special importance to the study; (3) The Elias Family Adjustment test was used to measure the mother's positive feelings of warmth, love, harmony and other unifying qualities and to measure negative feelings of coldness,

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[1] See section titled Difficulties Encountered.

TABLE 4.4 ESTIMATED POPULATION FROM WHICH SAMPLE WAS DRAWN WITH SUMMARY OF REASONS FOR NONINCLUSION IN THE STUDY

Estimated Population of Families		Number of Families
Families Estimated Eligible by Four Clinic Directors		45
Families entered into the Study		24
Did not complete the Study		4
Withdrew	2	
Removed from Study by Investigator[1]	2	
Completed Study		20
Additional Families Identified		16
Reasons for Non-Inclusion in the Study:		
Lived outside the 150 mile radius[2]	6	
Refused Participation	4	
Could Not Be Located	2	
Other Severe Birth Defects at Birth[2]	2	
Foster Home Placement or Institutionalized[2]	2	

[1]In two instances the nursing care needed by the children exceeded the limits of the protocol and the nurse-investigator elected to provide the necessary care and remove the families from the study.

[2]Did not meet study criteria.

hatred, lovelessness and family friction. Attention was given to the subscales of Rejection of the Child, and Interparental Friction-Harmony because of their relevance to the conceptual framework.

Two additional instruments were used. A family information survey form was used to collect the following demographic data concerning the families: (1) economic status; (2) obstetrical history of the mother; (3) initial reactions to the information concerning the child's deformity; (4) views of the parents concerning professionals and agencies offering aid during the period following the birth of the infant; and, (5) unusual or unique problems encountered by the parents. (See Chapter 6 for further discussion.) The affected child was also rated according to degree of disability using an adaptation of the Scherzer and Gardner Rating Scale (1971). The rating was made by a combination of data from hospital and clinic records, information from the parents, and personal observations by the investigator. See Chapter 5 for the procedures used to modify the degree of disability rating scale.

Data Analysis

Nonparametric statistical methods were selected to analyze the data. These methods eliminated the need for the assumption of a normally distributed population, and allowed for the best use of the ordinal data. Computation was done at the Computer Center at San Francisco State University when possible and by a hand calculator when computer programs were unavailable. The programs used were selected from the International Timesharing Corporation Library, Mathematics

and Statistics Handbook (1971),[1] and an on-line typewriter terminal was used to enter data.

The families were entered into the study in groups of seven and interaction between the families was a possibility. To learn whether biases might have been introduced by discussions between families who had already served as subjects with those who participated later, the one-sample runs test was used to test the randomness of the sequence of pretest scores. (Siegel, 1956, pg. 53).

In order to determine whether the two independent samples N_1 and N_2 were drawn from populations with the same distributions, Mann-Whitney U tests were performed on all pretest measures; age of affected child, degree of disability of the affected child, understanding scores, total self-concept scores and total family adaptation scores. Interrelationships between the attribute variables of age of affected child and degree of disability of the affected child and the dependent variable measures of understanding, self-concept and adaptation of the mother were investigated. To test the intercorrelation of variables, Spearman rank coefficients were computed. Variables indicating mild to strong relationship were further investigated on crossbreak tables with chi-square tests calculated when appropriate.

The prediction that the scores of the experimental group would be higher than those of the control group was tested by the

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[1] I T S STAT User's Manual, UM-06-0673-01 International Timesharing Corporation, Chaska, Minesota, 1973.

Kolmogorov-Smirnov Two Sample Test (Siegel, 1956, pg. 127) and verified by computation of the Wilcoxon Sign Test for Differences Between Related Samples (Bruning, Kintz, 1968:205).[1]

Validity of the Design

When samples are small and random assignment is not possible, a compromise design to a "true experiment" results. (Campbell and Stanley, 1963, pg. 204; Kerlinger, 1973, pg. 341). The validity of the design depends on how well the experimenter establishes the equivalency of the two groups. When random assignment cannot be made and matching is impossible, efforts should be made to make the two groups as similar as possible (Kerlinger, 1973). In this study the groups were made similar on age and sex and degree of disability of the affected child. In addition, precautions were taken by the investigator to prevent self-selection by the study participants. According to Campbell and Stanley (1963), internal validity problems are minimized when similar recruitment methods are used for the experimental and control groups and similarity is confirmed on pretesting. Both criteria were met in this study. The threats to the external validity of this design are discussed in the section Limitations of the Study.

The study was deemed internally valid on the basis of the following: (1) identical recruitment methods were used for the experimental and control groups; (2) selection problems were minimized

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[1]I am grateful for the assistance given me by staff members of the Information Systems Department, Research Division, University of California at San Francisco, in selecting these tests.

by preventing self-selection by study participants; and, (3) history and maturation were assumed controlled by the non-equivalent control group, because factors effecting the experimental group should also effect the control group.

Difficulties Encountered

Entré and the Resulting Changes in Study Design. Myelomeningocele children are treated in major treatment facilities throughout the area and also by physicians in private practice. There was no one source of entré that would provide an adequate sample size for this investigation.

In February, 1973, initial contacts were made with medical personnel of five major medical centers to determine the approximate number of families meeting the study criteria. The probability of obtaining permission from the medical staffs to contact the families was explored at that time. The estimate of the total population obtained during these initial contacts was approximately sixty families. After the initial contact with the clinic directors, the investigator, with the permission of clinic director, began attending the clinics where the children were being seen. The purpose for these clinic visits was to allow the physicians serving the clinics to become better acquainted with the investigator and to ask questions about the proposed research study. Three of the five clinic directors[1] agreed to take the proposal to the appropriate hospital

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[1]The clinic affiliated with the Medical Center where the investigator was enrolled as a graduate student accepted the approval of the Committee on Human Experimentation of the Graduate Division of the University without further action.

committee for evaluation of the proposal in relation to patient safety and human rights.[1] The fifth clinic director preferred that the families served by the institution he represented not be included in the study, which reduced the potential study population to fifty families. This estimate was later reduced to forty when the investigator discovered that several of the families were known to two or more of the clinics and were included in the original estimate more than once. Two families had been seen at three of the four clinics and six families had been seen at two of the four clinics. This resulted in the original estimate being artifically inflated by ten families.

Data collection was scheduled to begin on December 3, 1973. Permission had been received from three of the cooperating institutions to contact the families served by their medical staffs and was pending in a fourth. The best estimate that could be made was that this would provide total maximum sample size of thirty families. Since the protocol called for thirty families randomly assigned to control and experimental groups of fifteen each, this left no allowance for refusals, withdrawals, or ineligible families. At this point the investigator considered deleting the control group and changing the protocol to a descriptive study of the effects of nursing intervention on one sample.

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[1]The names of the committees varied between institutions. For convenience, they are all referred to as Committee on Human Experimentation.

Home visits were begun with the first seven families on the list. It was learned by the investigator that making the telephone contacts long before home visits could start was rarely effective. Families preferred not to commit themselves to the program more than two or three weeks before visits were to start. Therefore, an alphabetical list was maintained of families to whom initial contact letters had been sent. Families were added or subtracted from this list as information became available, such as--"has moved", "lives too far for study", or the child became old enough for the family to participate in the investigation. For example, a child born in October 1973, was not eligible for the study in December, 1973, when the study began, but became eligible in April, 1974, when the baby was six months old.

Eight families were admitted to the study between December 3, 1973, and March 1, 1974, and all received all or part of the Teaching protocol.[1] Early in March, 1974, permission was received from the clinic director of the fourth cooperating medical facility, increasing the total estimate of the study population to forty-five. At that point it was feasible to have a control group. Due to the fact that six families had already received the teaching sequence, it was impossible to randomly assign participating families to the

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[1]Two of these families did not complete the study, and therefore did not receive the entire protocol. One family refused to sign the consent form, although verbally agreeing to the study, promising to sign "next time after I study it thoroughly." Family was visited twice and then dropped from study. The second family required nursing intervention far in excess of that allowed by the protocol and was removed from the study by the investigator.

experimental and control groups as required in the original research proposal. A non-equivalent control group design (Campbell and Stanley, 1973) was substituted for the pretest-posttest control group design with random assignment of participants. The rationale for this decision was that an unmatched and non-equivalent control group added strength to the research design in providing controls over problems of internal validity.

The procedure for assigning families to the experimental and control groups from that point was based on the following criteria: (1) include families from each treatment center in each group; (2) maintain an even distribution of the sex of the affected child in the control and experimental groups; and, (3) maintain equal ages of the affected child in both groups. These criteria are not offered as a substitute for recognized matching procedures, nor are they presented as such. The criteria were instituted in an attempt to make the groups as equivalent as possible.

Unexpected Delays in Data Collection. The data collection period was planned to extend over a five-week period for each family. The home visits were planned to be scheduled at one week intervals with the exception of the posttest which was two weeks following the last instructional visit. Only four families were finished according to this time schedule. Delays were caused by vacations, illness in the family, unexpected doctor or clinic appointments, family emergencies or inadvertently missed appointments. The earliest completion was five weeks. The longest study period was ten weeks.

Control of the Teaching Environment. Home visits were planned as an important factor of the study. The rationale was that families would be more relaxed, more responsive and freer to ask questions in the familiarity of their own surroundings. The extent to which the investigator would lose control of the teaching environment was not anticipated. The teaching sessions varied in respect to the following: (1) the number of children present varied from one to three; (2) the presence or absence of the father during the sessions; (3) other interested persons such as grandparents and neighbors were sometimes asked by the mothers to join the sessions; and, (4) the number of interruptions during the teaching sessions caused by telephone calls, visitors, needs of the children in the family, and arrival and departure of other family members. Lack of control of the teaching environment by the investigator resulted in some teaching sessions extending to two and one-half hours in order to cover the entire protocol.

CHAPTER SUMMARY

This chapter has described the quasi-experimental design utilizing an experimental group and a non-equivalent control group with pretesting and posttesting administered to both groups. The primary purpose of the design was to determine the effect of instructional nursing intervention on mothers of children with spina bifida with myelomeningocele. Measures of the dependent variables were: (1) a multiple choice test concerning aspects of myelomeningocele; (2) the Tennessee Self-Concept Scale (W. M. Fitts); and, (3) the

Elias Family Adjustment Test. The independent variable consisted of three teaching sessions conducted by the investigator in the homes of families with children with the diagnosis of spina bifida with myelomeningocele. The study sample was described in relation to characteristics of the affected child and the mothers participating in the study. Data analysis by non-parametric statistical methods was presented, and the validity of the design was discussed. The difficulties of entré and control of the independent variable were discussed in relation to the effects of the study design and study procedures. The next chapter will describe the development, testing and selection of the research instruments.

CHAPTER V

DEVELOPMENT, TESTING, AND SELECTION OF THE RESEARCH TOOLS

Rationale Behind the Independent Variable

The independent variable for the study was identified as instructional nursing intervention. Findings of a preliminary investigation, cited in Chapter 2, supported the premise that not all parents of myelomeningocele children interviewed had made a positive adaptation to the birth of the child. The denial by the parents of information that had been previously presented to them at least once and in some cases several times was an example of the observed behavior. The responsibility of the researcher was to develop a conceptual rationale to explain why further instruction in the form of a planned nursing intervention in the homes of the parents would make a difference if information had been given to the parents previously and either lost, rejected, or denied.

A useful distinction between the term instruction and teaching has recently been made (Conley, 1973). Instruction, as defined by Conley, refers to a broad range of activities that take place in an educational setting and includes those conditions which are external to the learner. Teaching, in contrast, refers to human interaction between the teacher and student, and "Cognitive accomplishments depend upon affective involvement for behavior modification." (Conley, 1973). This reference was not available, of course, when

this investigator began the conceptual development of what was to become the independent variable of the research study. Conley's writings, however, do summarize the beliefs of the investigator concerning why the information offered to the parents had not been processed or, if processed, later lost. The educational setting for these families had been primarily the hospital where initial information had been given to the parents, the clinics where follow-up information had been offered, and offices of the physicians responsible for the care of the child. The settings were unfamiliar to the parents, the timing of the instruction frequently followed long periods of waiting. Appointment times were often inconvenient for parents. The interviews were conducted in noisy physical surroundings which were confusing to parents. For example, in the coordinated clinics there were frequently five physicians representing as many medical specialties, several medical students, a nurse, a social worker, a secretary and other interested observers which included physical therapists, student nurses, siblings, and relatives. Sixty per cent of the parents interviewed reported difficulty in identifying the physician with the particular medical specialty he represented. One mother stated,

> I know after the first visit or two you are supposed to know which doctor is which and what his special interest is--the bladder or the head or the feet and legs but it took me months to straighten them all out and by that time they had all changed. Of course I knew Dr._____, he was a love; and Dr._____, after they started the shunts, but you never talked to him, in fact, I think he ran when he saw a parent coming.

Instruction--as defined by Conley--was being offered, but effective human interaction was not taking place, except in rare instances.

Several principles compiled by Rogers served as the foundation for the content and presentation of the independent variable. The following principles were selected as having particular relevance to this study:

1. "Significant learning takes place when the subject matter is perceived by the student as having relevance for his own purposes" (Rogers, 1969:158). At the time of the birth of the infant and shortly thereafter, the overriding concern of most parents is the life or death of the infant. Information that is not directly related to life or death may not be perceived as relevant at that time. Later, as the relevancy of the information increases for the parents, access to the information from a reliable source decreased. The instructional nursing intervention in this study was developed with certain definite and limited parameters, but the parents were free to dwell on any segment of the child's condition within those parameters. Therefore, it was possible for parents to choose the area of concentration of the teaching sessions, as long as they were within the predetermined content limits. In this way relevancy for the learner was enhanced.

2. "Learning which involves a change in self-organization--in the perception of oneself--is threatening and tends to be resisted" (Rogers, 1969:159). This principle offers at least a partial explanation concerning why much information was lost when offered immediately following the birth of the infant. Instructional nursing intervention after the initial period in which denial and self-reevaluation activities are so dominant was thought to be less threatening to the parents and therefore more effective.

3. "Those learnings which are threatening to the self are more easily perceived and assimilated when external threats are at a minimum" (Rogers, 1969:159). The teaching sessions in this study were conducted in the homes of the parents and at a time selected by them. The reduction of the external threats the hospital and clinic situations imposed upon the families was believed to enhance learning. By allowing the parents the option of fixing the time and to some extent the limits of the interview, the parents were more relaxed and had more feeling of power and control. They retained the right to terminate the teaching sessions at any time without threat to the quality of care received by their child.

4. "Self-initiated learning which involved the whole person of the learner--feelings as well as intellect--is the most lasting and pervasive" (Rogers, 1969:161). The study families were engaged in self-initiated learning in as much as the parents were voluntarily participating in the study. Efforts were made to build into the protocol exploration of the emotional and intellectual attitudes of the mothers concerning the condition which affected the child.

In summary, the teaching sequence in this study offered material perceived as relevant to the family in a low external threat situation of the parents' own homes where the parents controlled the learning environment. The teaching sequence was offered at a time when the initial denial and self-reevaluation activities had decreased. It was believed that significantly more learning would result, with increased understanding and positive adjustment to the self-concept than traditional methods of information-giving employed with families had produced.

Planning and Construction of the Independent Variable. The first step in planning and constructing the teaching sequence was to determine the exact content necessary to include in the presentation. Since no literature directly related to this question existed, another source was sought to answer the question "What is essential information for parents of myelomeningoclel children?"

One of the questions that was asked of parents participating in the pilot study of 1971 was "What information do you believe is important for parents to be given about myelomeningocele in the first few months of the baby's life?" The tape recorded answers to that question formed the basis for the initial content of the teaching sessions.

The teaching sessions were formulated in an open-ended interview-type protocol. The protocol was tested on three families of spina bifida children which were ineligible for the research study. The pretesting of the protocol indicated that a set or stimulus was needed to focus the learners' attention on certain predetermined areas of concern, and that exact parameters of the teaching sessions needed to be identified in order to insure that all families were being exposed to the same treatment.

The second step was to design an audio-visual tool which would provide the set to which the parents could respond and which would define the parameters of the teaching sequence. The content of the teaching sessions was then broken down into three major components, each to be contained in one of the three teaching sessions. Included in the components was content such as: (1) etiology, pathology and terminology associated with the birth defect;

(2) terminology involving medical specialists and treatment procedures; (3) decision making points and factors influencing decisions; (4) parental feelings toward the condition and the child initially and later; (5) effect of the child on siblings; (6) identification of possible sources of help; (7) examination of a variety of view points on treatment programs for the malformed child; and, (8) specific care considerations for the child. Specific behavioral objectives were then written for each session and a multiple-choice test related to those objectives written and tested. The method of constructing and testing this tool is presented later in this chapter. The task of introducing all the defined parameters of the teaching sessions on the audio-visual tool was then addressed. A script was written for the audio portion of the tool, relying heavily on the input from the parents who had been interviewed on the pilot study. Interactional sequences were designed to present conversation between: (1) professionals and parents, and, (2) between parents. The sequences were separated by informational and transitional items. The script was first read to the spina bifida families who had participated in the pretesting of the protocol. Many unnecessary technical terms were eliminated and the script re-written to be more realistic with the situation. The script was then edited and sent to an Associate Professor in the Department of Neurosurgery at the Medical Center for careful attention to the medical accuracy of all information given.[1] A second revision was then made and the scrip again sent to the

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[1]I am indebted to Dr. Julian Hoff for his guidance and assistance in this phase of the construction of the audio-visual tool.

consulting physician. All medical information was documented by a minimum of two sources from the current literature. Players were recruited to play various roles during the interaction.[1] Slides were made to portray the action taking place in the audio portion. Necessary medical illustrations were created by CORT Division of the University of California Medical Center. Other scenes were made into slides by use of a copy camera, or, when the material was too large or needed professional work, a professional photographer. The finished product was a 22 minute audio with 55 slides synchronized with the tape. The audio-visual tool was constructed to present on a Coxco Sound-slide projector (SP-120)[2] which was light, easy to transport and had a self-contained screen, eliminating the need for a screen. This projector is especially useful for small group presentations. Planning, designing and constructing the teaching tool required nine months from inception to completion.

Construction of the Criterion Measure for Understanding.

Because no testing instrument was in existence which had been designed to test knowledge and understanding concerning the etiology, physiological defect, incidence, terminology, treatment procedures

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[1]I am indebted to Marlene and Dick Mayers, Rev. James Bessey, Albert C. Rugos and to my husband Vernon Q. Scearse for their contributions to the production of the audio-visual tool.

[2]I am indebted to Dr. June T. Bailey, Director, Creative Leadership Project, University of California, San Francisco, for allowing me the use of the Coxco Sound-slide projector.

and care considerations of the child with myelomeningocele, it was necessary for the investigator to construct and test one. The content of the test questions was based on the statements of behavioral objectives prepared for the teaching sessions. Valuable sources of reference were pamphlets designed for distribution to parents of handicapped children and articles and excerpts from medical and nursing textbooks which discussed the care and management of the spina bifida child (Smith, 1965; Matson, 1969; Swinyard, 1971; Bunch, Cass, Bensman, Long, 1972).

The appropriate length for the test was set at 25-30 questions. The content could be covered with this number of questions and the test would not be sufficently long to tire, bore or annoy the subjects when taken in combination with the other criterion measure tests. A multiple-choice test was chosen for ease and efficiency in grading. Forty items were written and distributed to five graduate students. These students were asked to comment upon the following: (1) the clarity of the wording, (2) the design of the stem and answers, and (3) opinions concerning the appropriateness of the test for the target population. Questions were then edited on the basis of this feedback. When three of the five students objected to a question, that particular question was discarded. Replacement questions were then written if the discarded questions represented important aspects of the test. Revised questions were then sent to parents of normal children. These parents had no medical background, but were educated on the graduate level in elementary education. Again comments concerning the clarity of the questions and answers,

and the appropriateness of the question for the target population were received. The questions were again re-written on the basis of feedback and all medical terms except those requisite to the meaning of questions were deleted. Correct answers were documented by at least two medical references. Controversial material was either represented as such in the test or was deleted.

The next step was to ascertain that all behavioral objectives were covered, and that new items had been constructed when a deficiency was discovered. The test items now numbered thirty.

The questions were sent to a group of nursing faculty, clinical nurse specialists employed primarily in the neurosurgical clinical area, physicians and parents of older spina bifida children. (See Letter of Instruction, Appendix C). These individuals were asked to: (1) take the test, indicating their choice and correct answers; (2) comment on the instructions for the test; and, (3) comment on the clarity, structure, organization and composition of the questions and answers. Answers were received from three physicians, six nursing faculty, two clinical specialists and two mothers of myelomeningocele children. Appropriate revisions were made and items deleted that were repetitious or which the responding physicians failed to agree on the correct answer.

Validity of the Understanding Instrument

Content Validity of the Instrument. No comparable test or instrument was available. The claim for content validity was made on the basis of the representativeness of the sources used for content

construction, the extensive review of the nursing and medical literature upon which the questions were based, and opinions of experts on the validity of the questions. Questions regarding the concerns of each medical specialty involved in caring for the child were included, combined with the questions centered around care and nursing management of the child which is vital to parents.

Face Validity. Evidence that the instrument had face validity included the following: (1) content was contributed by parents of spina bifida children; (2) medical content was supported by current medical references; and, (3) the content areas of the test represented areas of special interest and skills of the professionals serving the families, including neurosurgery, urology, orthopaedic surgery, general pediatrics, nursing care, and social services.

Reliability of the Understanding Instrument

Split-Halves. The stability of the tool was evaluated by administering the test to a group of 36 sophomore nursing students. Sophomore students were considered appropriate since the test was intended for parents who had had some exposure to medical terminology, but lacked in-depth knowledge of the subject. To determine to split half reliability, the single test was divided into two tests consisting of the odd numbered items and the even numbered items. A reliability coefficient of .60 was established as the minimum acceptable level. The correlation coefficient of the two tests was then computed using the formula:

$$r = \frac{\Sigma(x - \bar{x})\quad(y - \bar{y})}{\sqrt{\Sigma(x - \bar{x})^2\quad\Sigma(y - \bar{y})^2}}$$ (Walker and Lev, 1969)

The reliability of the entire test was then computed according to the Spearman-Brown Prophecy formula:

$$R = \frac{2r}{1 + r}$$ (Walker and Lev, 1969)

This yielded an estimated reliability of R = 0.804. This was a satisfactory reliability coefficient for an instructor-made test. (Ebel, 1965:330).

Test-retest Reliability. The same test was administered to the same group of students one week after the first administration for an additional measurement of reliability by the test-retest procedure. A minimum reliability coefficient was established at .60. Each student had identified themselves by a four digit number known only to themselves on the pretest. The same number was used on the posttest so that the scores could be matched. In this manner the anonymity of students choosing to participate and those who chose not to participate was assured.[1] Five of the 36 students who took the pretest either were not present for the posttest or did not choose to participate. Scores on the pretest which did not have a matching identification number on a posttest were discarded. The pretest-posttest calculations were based on a N of 31. The reliability was computed by the same formula used previously and yielded a reliability coefficient of 0.824.

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[1]The above procedures met the requirements stipulated in the request to the Committee on Human Experimentation to use students for experimental purposes.

Degree of Disability Rating Scale

Physical disability of the Spina Bifida child has been rated by the Scherzer-Gardner Scale by assigning numbers of 1 to 3 where 1 indicates no or minimal disability and 3 indicates maximal or severe disability to the five areas of physical functioning most frequently involved in Spina Bifida pathology. This results in a total disability rating of 5 to 15 where 5 indicates minimal disability and 15 indicates severe disability. Please refer to Degree of Disability Rating Scale, Appendix A. The five areas rated were: (1) hydrocephalus, (2) neurological status, (3) urologic status, (4) orthopaedic procedures, and, (5) ambulation.

Face Validity. Evidence that these five rated areas are the major important dimensions of the total disability of the child with Spina Bifida include: (1) medical texts (Swinyard, 1971; Bunch, Cass, Bensman, Long, 1972; American Academy of Orthopaedic Surgeons, 1972), (2) the repeated emphasis in recent studies on the need for coordinated services including specialists for treatment in each of the named areas (Zachary, 1968; Walker, 1971; Lightowler, 1971), and, (3) the actual structure and composition of the medical staffs that have been recently organized to meet the needs of Spina Bifida patients and their families in coordinated clinics. The face validity of the measure on the basis of the three factors cited was adequate.

Content Validity and Rating Results. Difficulties were encountered in using the Scherzer-Gardner Rating Scale in the areas of hydrocephalus, urological status, and orthopaedic status. The children who received ratings of 3 were sometimes not displaying greater degrees of disability (functioning) than children receiving ratings of 2 in those areas. The scale was not ordinal in as much as individuals receiving total disability scores of 13 could have less disability than those with scores of 11 or 12. With the cooperation of three urologists, two orthopaedic surgeons and two neurosurgeons who were serving in the myelomeningocele clinics, the degree of disability scale was revised slightly by rewording the ratings in the areas of hydrocephalus, urological status and orthopaedic status. (See revisions in the Scherzer-Gardner Rating scale, Appendix A). Three physicians then ranked five myelomeningocele children on the revised tool. The total disability scores agreed with the physicians' ranking of the children according to disability in all cases. The degree of disability scores as rated by the physicians demonstrated 86 per cent agreement. (Three physicians each rated five children = fifteen ratings. Thirteen out of fifteen agreed). The disagreement occurred in the area of neurological status, a section which had not been revised. The 86 per cent agreement was considered satisfactory.

Reliability of the Degree of Disability Rating Scale.

How consistently the rating scale would yield the same degree of disability rating for an individual child was explored.

Summaries of four case histories of spina bifida children seen at the UCMD clinic were made. An instruction sheet for raters was constructed and three nurses with education and experience in maternal-child nursing independently rated the summaries. No further information or instructions were given. The raters were instructed not to consult with each other, or to use texts or references. The results indicated 100 per cent agreement on the Total Disability Rating on two of the four cases. On the remaining two cases, there was 67 per cent agreement on the Total Disability Rating, even though the total scores were not arrived at by assigning the same numbers to the same factors. To be certain there was not major disagreement on a particular factor which was being hidden by the totals, agreement on each individual Disability Area was inspected. (Note: three raters rating four cases rated each Disability Area 12 times.)

TABLE 5.1

RATER AGREEMENT ON DEGREE OF DISABILITY ITEMS

Items	Agreements	% Agreement
Hydrocephalus	11 of 12	92%
Neurologic Status	11 of 12	92%
Urologic Status	11 of 12	92%
Orthopaedic Procedures	11 of 12	92%
Ambulation	11 of 12	92%

Satisfactory inter-rater reliability for the use of the tool was concluded.

It was hypothesized that there would be no significant difference in the ratings assigned by the investigator and the mean scores of the three raters on Total Degree of Disability Scores and on each disability item score. A one way analysis of variance with a .95 confidence level allowed the hypothesis of no difference to be accepted and the investigator used the scale to rate the degree of disability without independent raters. (See Appendix A for Revised Degree of Disability Rating Tool.).

TENNESSEE SELF-CONCEPT SCALE

The Tennessee Self-Concept Scale (TSCS) was selected as an effective measuring tool for this study for the following reasons: (1) The TSCS was well standardized; (2) The TSCS is useful for individuals with a wide range of educational backgrounds (at least sixth grade); and, (3) The TSCS offered subscales appropriate to the definition of self-concept explicated for this paper.

Scores on the TSCS.

The total P. The total P score is the "most important single score on the counselling form." (pg. 2, TSCS Manual). It reflects an overall level of self-esteem. High scores tend to indicate persons who like themselves, feel of value and worth, and have self-confidence. Low scorers are doubtful about their own worth, feel anxious, are depressed and unhappy.

Subscales on the TSCS. Self-Critism (SC) is a subscale of ten items taken from the L-scale of the Minnesota Multiphasic Personality Inventory (1951), and used by special arrangement. High scores tend to indicate a normal healthy capacity for self-criticism. Low scores indicate defensiveness and may indicate that the P score is artificially high. (TSCS Manual, 1965, pg. 2). Personal Self (PS) reflects the respondant's sense of personal worth and sense of adequacy as a person. Family Self (FS) indicates the person's sense of adequacy and worth as a family member.

Reliability of the TSCS. The reliability data reported for the tool is based on test-retest of sixty college students over a two-week period. Reliability was .75 on self-criticism scale (SC), .92 on the Total Positive (P), .85 on Personal Self (PS) and .89 on Family Self (FS). Other evidence has indicated a similarity of profile patterns on the same individuals over long periods of time (TSCS Manual, 1965, pg. 14,15).

Validity of the TSCS. Extensive content validity procedures have been used to test content validity, discrimination between groups, correlation with other personality measures and personality changes under particular conditions. All evidence tends to indicate a high degree of validity of the tool.

CHAPTER VI

CHARACTERISTICS OF THE FAMILIES OF MYELOMENINGOCELE CHILDREN

Introduction

A major objective of the study was to obtain information concerning the parents of children with myelomeningocele and the problems they encountered which related to unmet needs and unresolved problems arising from the birth of the affected child. The literature reports that recent advances in the medical and surgical management of infants with myelomeningocele has produced increased numbers of surviving children who are afflicted with severe, chronic physical handicaps, and a cluster of unprecedented problems for the families involved in the care of these children. Specific information concerning these problems is limited, however. This chapter reports descriptive information obtained from the twenty families who participated in the study, and who represent both the experimental and control group.

Method

Interviews were conducted by the investigator during the initial visit to the home to obtain demographic information from the families. A pretested interview schedule was used. Both parents were present in nine of the interviews; there was no father in residence in two homes; and in three instances the fathers were interviewed separately at a later date. In six homes there was no contact

with the father of the child. Since one-half of the study group was visited by the investigator repeatedly for instructional sessions, there was opportunity for checking the initial information given in ten of the interviews. The data from the control group was validated by the clinical records at the clinics or hospitals where the child received care. No substantial deviations from the initial information was detected.

Results

Socio-economic Data. All the families resided in urban areas, and they represented a wide range in socio-economic indicators. The number of families who reported incomes below $5,000 per year equalled the number who reported incomes between $10,000 and $20,000. The income of one family was in excess of $20,000 per year. Range of incomes is presented in Figure 6.1. Housing is presented in Figure 6.2. Half of the families owned their own homes or were in the process of buying a home. Five families lived in rented homes and three families lived in apartments. Although nine children in one of the families studied were housed in a seven room dwelling and an extended family group of six lived in a four room apartment, none of the families occupied dwellings which were substandard.

The educational levels of the parents comprising the sample were as widely diversified as the income levels. Eighteen of the nineteen fathers[1], and fourteen of the twenty mothers had at least

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[1]No information other than ethnic background was available concerning the father of one child.

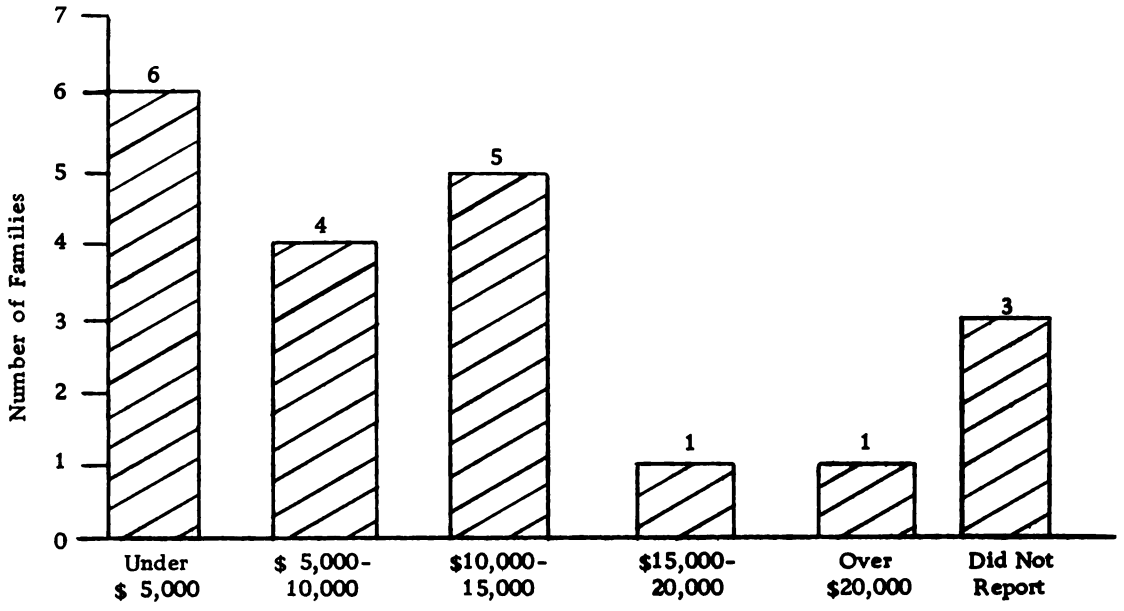

Figure 6.1 Income Ranges of Study Participants. N = 20

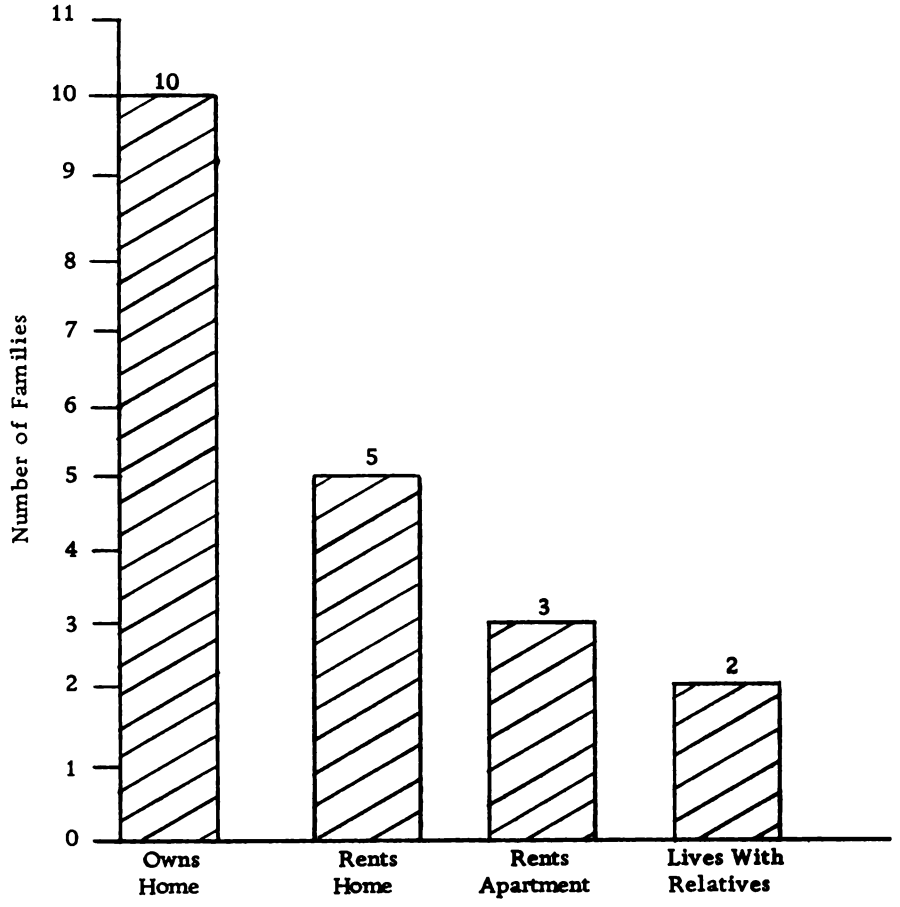

Figure 6.2 Housing of Study Participants. N = 20

a high school education. Seven of the fathers and three of the mothers were college graduates. Four fathers had done graduate studies, including one with an earned doctorate and one mother had done graduate work. It is not known whether or not this distribution significantly differs from the general population of the area where the sample resides. The educational achievement level of the study group strongly suggested that there would be no problem in the intellectual ability of the parents to grasp the medical information offered to them concerning myelomeningocele or to cope with the terminology involved in the explanation of the pathology, treatment, and prognosis of the medical condition, all other factors being equal. It was reasonable that low scores on the understanding test on pretest could not be explained on that basis alone.

The range in educational background of the study group did raise the question of how much this variable influenced the scores obtained by the mothers on the measures of the dependent variable, and this factor had to be considered during data analysis. The levels of educational attainment for the sample are summarized in Figures 6.3 and 6.4.

Racial Distribution. The ethnic composition of the sample was diverse. Eighteen of the twenty mothers were Caucasian and two of the mothers were Black. Of the twenty fathers, twelve were Caucasian, three Mexican, two were Chicano, and two were Black. Twenty-five per cent of the families studied represented mixed marriages. Review of the literature failed to reveal any conclusive evidence related high incidence of myelomeningocele births in

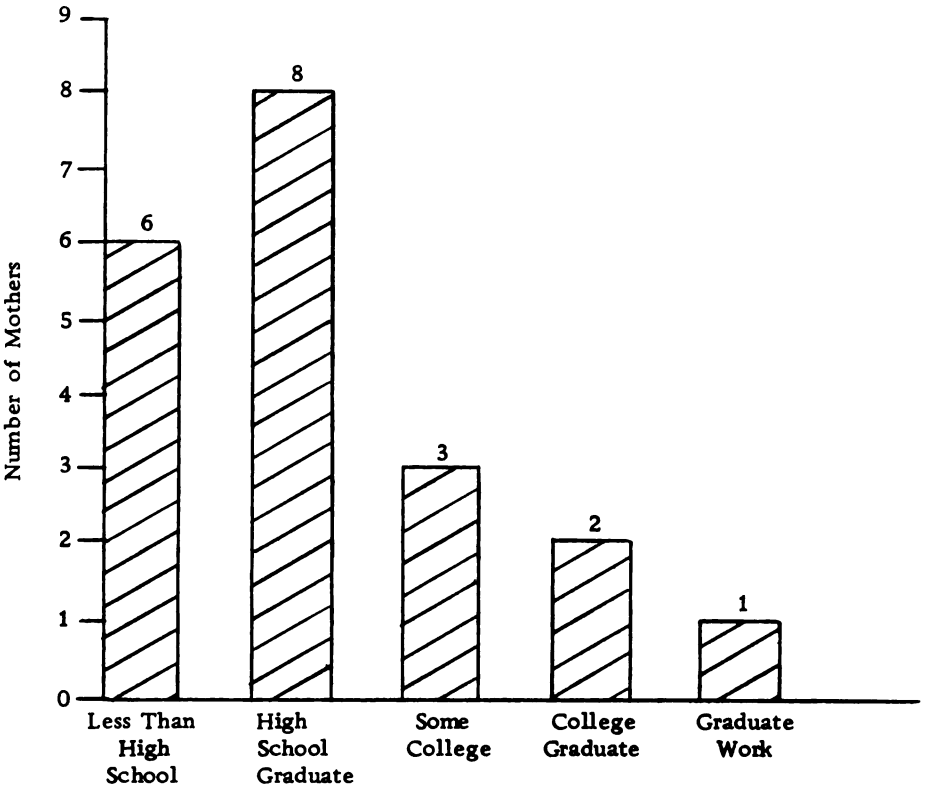

Figure 6.3 Educational Achievement of Mothers. N = 20

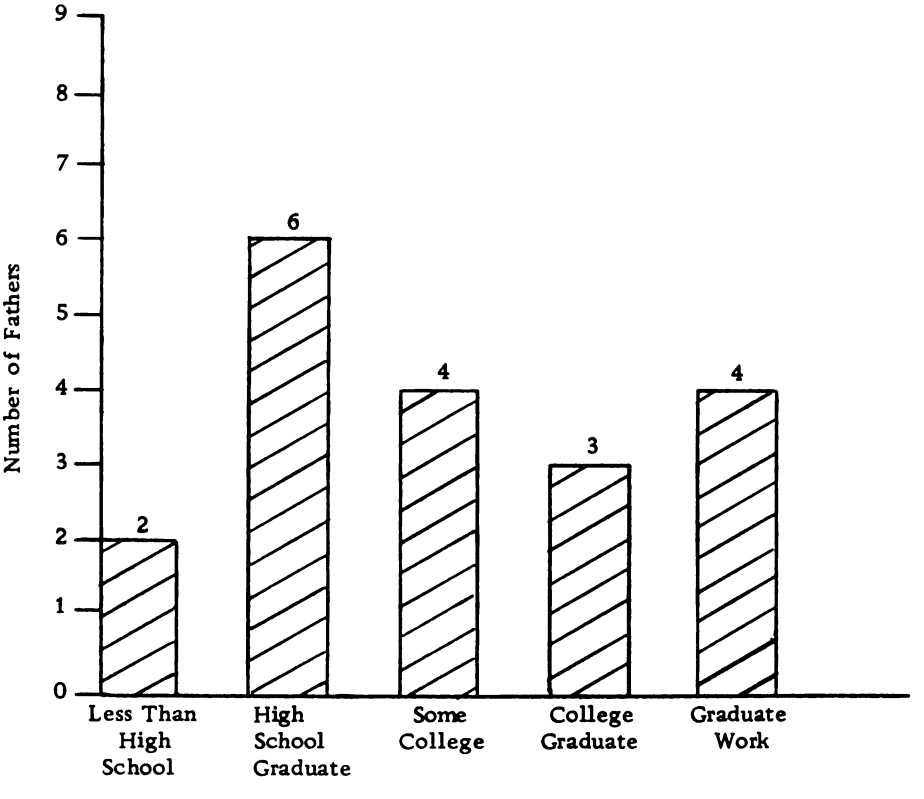

Figure 6.4 Educational Achievement of Fathers. N = 19

racially mixed marriages, although racial incidence has been a factor frequently explored by investigators of Spina Bifida incidence. Predispositons to high incidence have been reported to occur in the Irish, Pakistanians, Puerto Ricans (living in New York) and immigrant groups in Hawaii (Renwick, 1972). Exceptionally low incidence has been reported in American Indians, American Negroes (Cassady, 1969), the Bantu tribes in South Africa (Stevenson et al, 1966), and the Maori peoples of New Zealand (Howie and Phillips, 1970). Previous theories have held that the predisposition to high incidence in specific populations are a result of dietary patterns.

Maternal Age. Walker, Thomas and Russell (1971), reported in a study of 107 families a "relative deficit of mothers in the 20-24 age range and an excess of mothers over 35" years of age, with a mean maternal age of 27.1 years. As indicated in Figure 6.5, the mode age range for the mothers in this study at the time of birth of the child was 20-25 years. Although the mean maternal age in the study group was 24.1 years, a finding different than reported by Walker and others (1971), it should be noted that the present study represents an N of 20.

The age of the father at the time of birth of a defective child is not frequently reported. However, since the etiological factors contributing to spina bifida are not yet determined, the data was collected. The mode age range for the fathers in the study was 26-30 years. The mean paternal age was 25.3 years. (See Figure 6.6).

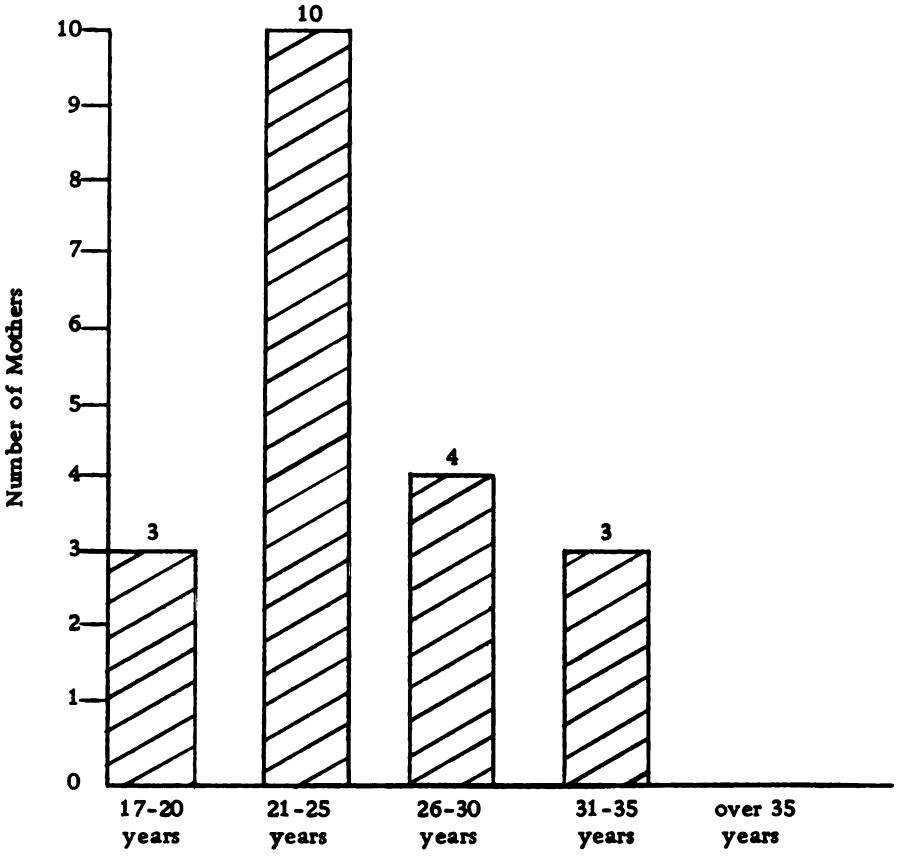

Figure 6.5 Age of Mothers at Time of Birth of Myelomeningocele Child. N = 20

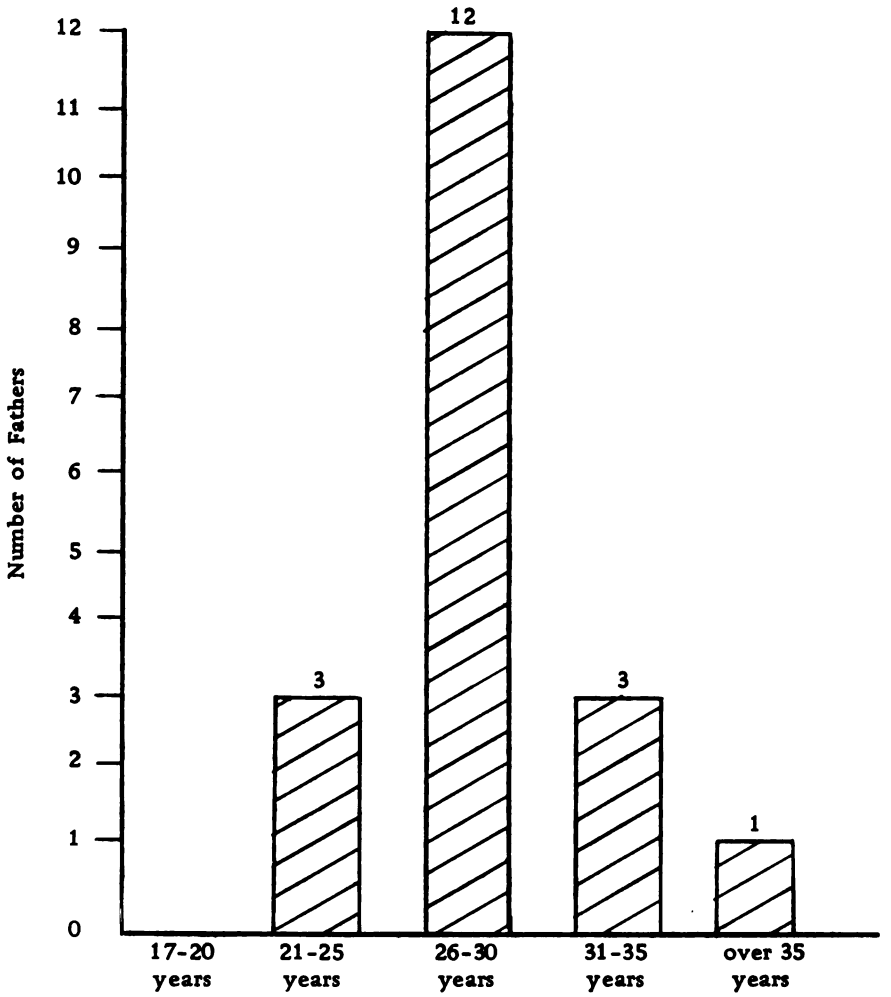

Figure 6.6 Age of Fathers at Time of Birth of Affected Child. N = 19

Birth Order of Affected Child. The data in this study failed to support previous findings of increased incidence of spina bifida in first-born children and only children. Excluding the two unmarried mothers who were 17 and 18 years of age at the time of the birth of the child and the two families who had been married less than a year at the time of birth, only one of the remaining sixteen families had a first born affected child and there were no only children in the study group. Seven families had one additional child, three families had two, one had three including a twin to the affected child, two had four, and one had eight additional children. This data is summarized in Figure 6.7.

Obstetrical History. In all of the families studied, the pre-natal care for the mother had begun prior to the sixth month of pregnancy. Sixteen of the twenty mothers were seen by an obstetrician prior to the fourth month. Both mothers in the over 30 years of age group (N = 2) had previously given birth to normal infants and would not be placed in a high risk group for this reason alone. As indicated in Figure 6.5, 65 per cent of the mothers were under 25 years of age at the time of birth of the child. One mother had spontaneously aborted a previous pregnancy and one had delivered a stillborn infant with no apparent congenital malformations. No other clinical evidence of abnormal obstetrical history was elicited from the parents or obtained from the charts. A previous study, in contrast, reported a total of 39 miscarriages, 7 stillbirths, and 2 infant deaths from unrelated causes in a study population of 107 mothers (Walker, Thomas and Russel, 1971).

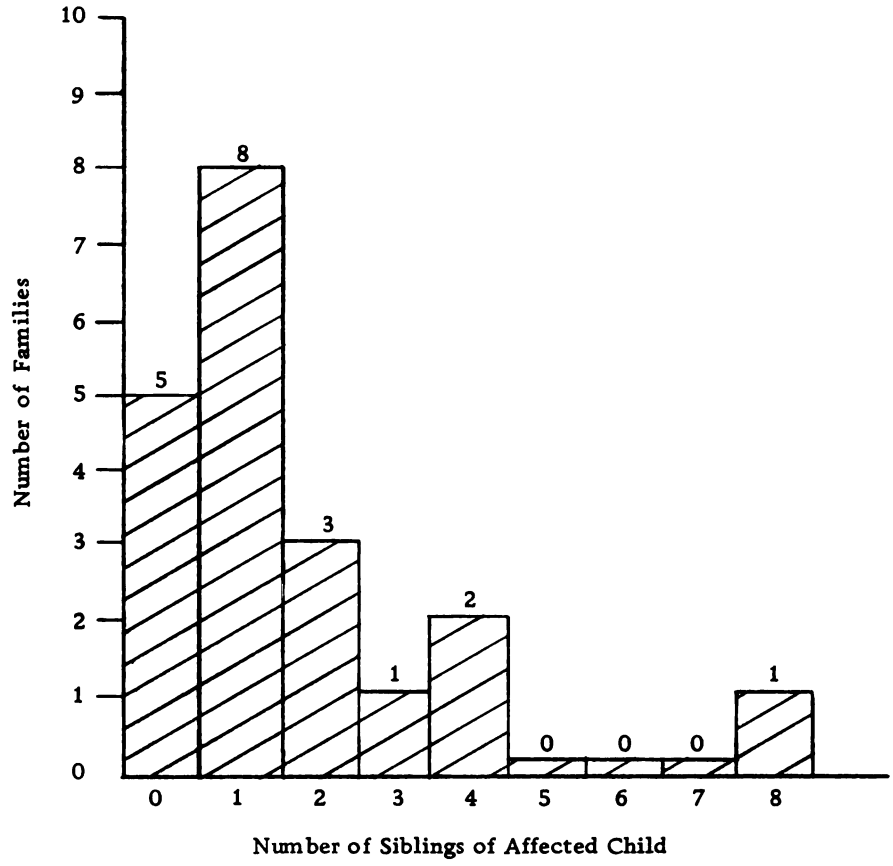

Figure 6.7 Number of Siblings in Study Families. N = 20

Seventeen of the families had never heard of myelomeningocele or spina bifida prior to the birth of the child. A positive family history of spina bifida was elicited in three of the study families (15 per cent). The 15 per cent of the families with documented cases of spina bifida among close relatives tends to support the familial tendency cited in the literature. (Doran and Guthkelch, 1961; Renwick, 1972). There was no incidence of congenital malformations among the 33 living siblings of the affected children. However, one family reported a deceased child who had had a congenital heart condition.

In twelve of the twenty families the pregnancy had been planned by the parents, in the remaining eight it had been unplanned. None of the parents had sought therapeutic termination of the pregnancy.

Genetic Counseling. All of the mothers interviewed had received some form of genetic counseling following the birth of the affected child. Five mothers had received the information from speakers at parents' group meetings. The other fifteen had been given information concerning the increased risk of future pregnancies from one of the physicians caring for the child. One mother denied the increased risk factor, stating that she had asked her doctor and had been told, "It was simply a medical catastrophe that could never happen again." All other parents seemed aware of the increased risk, but reported risk estimates varying from 1 in 10 to 1 in 50. This reflects the difference of opinion in the literature which also cites the risk factor ranging from 1 in 15 (Carter and Laurence, 1966) to

1 in 35 (Austin, Lindgren, 1972). The risk to future pregnancies was a popular area of discussion among the experimental group of parents. Most mothers admitted "knowing the figures, but not knowing what they really mean."

Marital Status and Relationship of the Parents. Seventeen of the mothers were married at the time of the birth of the child. Two of the seventeen married couples were separated. After the birth of the child, one couple reconciled and one finalized the divorce after a brief period of "trying again to make it work." The other three mothers were single when the child was born and remain so. Two of these single mothers live with relatives and one lives with the father of the child.

Seven respondants reported the birth of the child had made the marriage stronger. Sample responses falling into this catagory included, "We knew we had to make it work...before we had talked occasionally of divorce, but now we know we have to stick it out for Julie's sake." "We were forced to talk to each other a lot more. We knew this problem wasn't going to just go away." Marital status prior to the birth of the child and at the time of the study is summarized in Table 6.1 Six couples stated the effect was to force them to learn more about the baby and about themselves. Two admitted increased levels of stress and anxiety. Three mothers stated the child had made no more impact on the marriage than any other child would have made.

TABLE 6.1

MARITAL STATUS OF MOTHERS

N = 20

At Time of Birth of Child	f	At Time of Study	f
Married (to father of child)	15		15
Separated	2		0
Divorced	0		1
Widowed	0		1
Single	3		3

Causes of Stress During Initial Period Following the Birth. There were three areas cited more frequently than any others when the families were asked about stress-producing stimuli. Lack of understanding of the child's condition and erroneous and conflicting information that was given to them was cited most often. One mother stated,"One thing I learned, ask four different doctors the same question and you get four different answers." Fifteen of the mothers volunteered examples of conflicting information or information that they were later to learn was incorrect. Some of this incorrect information was probably due to faulty communication. For example, three mothers told the interviewer of being given the information that the "baby will have difficulty in urinating and making his bowels move." All three of the mothers interpreted this to mean the infant would be unable to urinate or have bowel movements. When the parents checked with nursery personnel and found out that the babies were urinating and having bowel movements, they believed that the

problem was over. "I never dreamed he meant she wouldn't be able to control her bladder and bowels", one of the mothers reported. Such misinformation was actually misinterpretation of information and was a frequent topic of discussion during the teaching sessions. The feeling of "aloneness" was often reported in combination with misinformation. Not having anyone to talk to who had information was a source of stress. More aggressive parents sought out information from other families with myelomeningocele children. One family learned of an eighteen year old myelomeningocele girl living three blocks from them. "I never knew the girl was alive before I had John, but her mother was a life-saver to me." Three of the parents learned there were other myelomeningocele infants in the hospital at the same time their child was hospitalized and made contact with these families. "We became quite a grapevine of misinformation," one mother reported, "because we would pool all the information everyone gave us, and of course, most of it didn't apply to our own babies."

The second major source of stress was mental depression, which occurred during the initial hospitalization of the infant. In 60 per cent of the families, the initial hospitalization period for the infant was six weeks or longer with nine weeks being the average initial hospitalization period. Most of the parents were unable to identify the source of the depression, but defined it as "being in a daze" or "being in limbo." "You are a mother," said one respondant, "but you don't have a baby. You plan your life around the hospital visits and you know that's not fair to the rest of the family." Many families spoke of being "unable to plan", because "you

didn't know whether you were going to have a baby to bring home, or never have a baby to bring home."

The third major source of stress was behavior changes in siblings. Other studies have reported high incidences of myelomeningocele in only children and the concern with siblings is rarely reported. Reasons underlying the expressed concerns of the parents in the study included: (1) behavior changes in older siblings in school and home, (2) difficulties in school work of children where previously there had been no problems, (3) resentment by the siblings of the time and attention given to the affected child, and, (4) worry and anxiety in the parents about being "unfair" to the other children.

Unmet Needs and Unsolved Problems. Eighty per cent of the parents mentioned the need for additional information about the condition and problems of the child. Most families acknowledged that they were unable to "take in" all that was told them initially. Three mothers indicated they did not want to know all the problems at first but thought it was better to get the information a little at a time. When the families were ready for the information, or had questions they wanted answered, however, "No one was around to give a straight answer." Three mothers recalled going to the clinic with specific questions to be answered but forgetting to ask them by the time the appropriate physician was examining the child.

The difficulty of proper identification of the medical specialties was a recurrent problem. A question concerning the shunt, for example, would be asked of the urologist or pediatrician, only to be referred to the neurosurgeon. By the time the family was seen by

the neurosurgeon, the question had been forgotten or the family members were "embarrassed to ask again." In analyzing the reports, most of the problems were in the timing of the teaching. When professionals were available and attempting to answer all the questions of the parents, the families were pre-occupied with other considerations such as financial problems or transportation arrangements. When parents urgently needed the information and answers to questions, the health professionals were unavailable.

The second unmet need mentioned was contact with other parents who also had a child with myelomeningocele. One mother said, "I know the doctors tried, but nothing helps quite like talking to others who have been there." The parents' group was not always seen as a viable option by parents. "We went one time," recalled one mother, "they were so depressing! We swore we would never go back." This same mother was one of the most vocal concerning her need to talk with knowledgeable people. Although 75 per cent of the families interviewed listed this as a serious problem, only 30 per cent were members of a parents' group, and 15 per cent considered themselves active members. The dynamics involved in the ability of parents of a seriously malformed child to utilize parents' groups is undoubtedly complex and worthy of further investigation.

There was no concensus in the remaining answers concerning unmet needs. In two families, financial concerns remained a problem. "I've asked for a wheelchair, but it doesn't seem to be something they (Crippled Children's Service) can supply. They suggested we rent one, but I feel that it is taking things away from the other

children, and that's not right." Future needs of the child was a concern to three families. Needs in this area centered around schools, potential employment, and in one case, the possibility of marriage and a family for the affected child. Information concerning treatment centers for myelomeningocele children in other localities was a pressing need for two families who were considering moves to other locations. Two other families needed information about the location of treatment centers so that they could plan family trips. They were afraid the baby would need attention and they would be unable to find anyone who knew about spina bifida. Directly or indirectly, the loss of mobility of the family because of inability to secure sitters who would stay with the child, fear of a medical emergency, and lack of information concerning treatment centers was a concern to 50 per cent of the families in the study.

Summary of the Chapter. Information obtained from interviews with the twenty families participating in the study has been presented. The families represented a wide range of racial, educational and economic backgrounds. No one socio-economic groups predominated the study sample. The maternal age at the time of birth of the myelomeningocele child was under thirty years in 85 per cent of the families. Fifteen per cent of the families had had a relative born with spina bifida.

Causes of stress were reviewed and included the following:

1. Lack of understanding of the child's condition.

2. Lack of a ready source of reliable information, coupled with a feeling of aloneness.

3. Mental depression which lasted until after the child was released from the hospital, usually nine weeks or more.

4. Concern over changes in the behavior of siblings.

The unmet needs listed by parents related to the above concerns. The next chapter will present the findings of the pretesting and the effect of the teaching sessions.

CHAPTER VII

FINDINGS

The major purpose of the study was to determine the effect of instructional nursing intervention on mothers of myelomeningocele children in the areas of: (1) understanding of the child's condition; (2) the mother's self-concept; and, (3) the mother's total family adaptation following the birth of a child with myelomeningocele. This chapter presents the results of the nursing intervention.

Some of the assumptions underlying the use of parametric statistical methods (a normally distributed population and variables measured on an interval scale) could not be met in this study. For this reason, nonparametric statistical procedures were used to analyze the scores and to test the hypotheses.

PRETEST SCORES

Randomness of the Sequence of Scores. To determine whether interaction between families who had already served as subjects with families who had participated in the study at a later time introduced biases into the data, the randomness of the sequence of scores was tested. The following null hypotheses were tested by the one-sample runs test.

(1) H_1: Scores below and above the group median on the measure of understanding on pretest occurred in random order.

(2) H_2: Scores below and above the group median on the measure of total self-concept on pretest occurred in random order.

(3) H_3: Scores below and above the group median on the measure of adaptation on pretest occurred in random order.

The level of significance was established at p = .05 and a two-tailed test was chosen. The N for all three tests was twenty. The rejection region was equal to or less than 6 and equal to or greater than 16. Computed r for understanding was 12, for self-concept was 10, and for adaptation was 11. The null hypotheses that the sample scores occurred in random order were accepted, and it was concluded that bias introduced through interaction of the subjects was not significant (See Table D.1 in Appendix D)

Mann-Whitney U Tests on Pretest Scores. To test whether experimental group A and control group B were drawn from the same population the Mann-Whitney U test was applied. The Mann-Whitney U test is "a powerful nonparametric test and is used as an alternative to the t test when the assumptions underlying the t test are not valid." (Siegel, 1956, pp. 116-127). The following hypotheses were examined:

(1) Ho_1: There would be no significant difference in the median scores on the understanding measure on pretest for population A (experimental) and population B (control). (Bruning and Kintz, 1968, pp. 201-204).

(2) Ho_2: There would be no significant difference in the median scores on total self-concept on pretest for population A (experimental) and population B (control).

(3) Ho_3: There would be no significant difference in the median scores on total adaptation on pretest for population A (experimental) and population B (control).

(4) Ho_4: There would be no significant difference in the ages of the affected children for population A (experimental) and population B (control).

(5) Ho_5: There would be no significant difference on degree of disability of the affected children for population A (experimental) and population B (control).

A two tailed test was used with a significance level of $p = .05$. The sample sizes were: $N_1 = 10$ and $N_2 = 10$. The critical value of U was less than or equal to 23 (Bruning, Kintz, 1968:232). The computed U values are presented in Table 7.1.

TABLE 7.1

COMPUTED U VALUES FOR AGE AND DEGREE OF DISABILITY OF AFFECTED CHILD, AND UNDERSTANDING, TOTAL SELF-CONCEPT AND TOTAL ADAPTATION OF THE MOTHER. N = 20

Variable	U Statistic
Age of Myelomeningocele Child	47.5
Degree of Disability of Affected Child	35.0
Understanding of Mother	33.5
Total Self-Concept of Mother	44.0
Total Adaptation of Mother	33.5

The following hypotheses were accepted. There was no significant difference at the time of pretest in the experimental and control groups on: (1) age of myelomeningocele child; (2) disability of the myelomeningocele child; and, (3) scores of the mothers on the tests of understanding, total self-concept, and total adaptation. The assumption of equivalence of the experimental and control groups at the beginning of the study was made since there was no evidence of nonequivalence.

Intercorrelations of Variables on Pretest Scores. The conceptual framework of the study and review of the literature indicated that the following relationships would exist.

1. The degree of disability of the affected child would not be associated with the total adaptation of the mother of the child.

2. Total self-concept of the mother would vary with the total adaptation of the mother. (The direction of the relationship was not predicted.)

3. Understanding of myelomeningocele by the mother would vary with the total self-concept of the mother. (The higher the self-concept, the greater the amount of learning that would take place.)

4. Understanding of myelomeningocele by the mother would vary with the total adaptation of the mother. (It was believed that understanding of the child's condition was necessary for positive adaptation.)

5. The age of the affected child would vary with the understanding of the mother. (The mother learns primarily from experience; therefore, the older the child, the higher the understanding.)

To test the above interrelationships, Spearman Rho Rank Order correlation coefficients were computed. The computed data is presented in Table 7.2. The assumption of normality of distribution is not necessary when statistical inferences beyond the sample are not being made (Kerlinger, 1973). The significance of the rho values was tested using the formula for small samples (Bruning, Kintz, 1968:158, 159). A two-tailed test with 18 degrees of freedom was used. As indicated in Table 7.2, the following associations were found significant: (1) the degree of disability of the child and the understanding of the mother, (2) the degree of disability of the child and the self-concept of the mother, and, (3) the self-concept of the mother and the understanding of the mother.

Interpretation of the Correlations. On the basis of the information summarized in Table 7.2, the following statements could be made.

(1) The results agreed with previous studies which had shown no significant relationship between the degree of disability of a handicapped child and the adjustment or adaptation of the mother. The degree of disability of the child did show a significant correlation, however, with the understanding of the mother of the child's condition ($p = .05$). This would indicate that the greater the degree of disability of the child, the more knowledge and understanding the mother demonstrated concerning the child's condition.

TABLE 7.2

INTERCORRELATION MATRIX FOR VARIABLES ON PRETEST

N = 20 MOTHERS

Variable	Age of Affected Child	Degree of Disability of Affected Child	Understanding	Self-Concept	Adaptation
Age of Affected Child	1.0				
Degree of Disability of Affected Child	.039	1.0			
Understanding of Mother	.125	.461*	1.0		
Self-Concept of Mother	- .101	.465*	.635**	1.0	
Adaptation of Mother	.326	.049	.062	- .305	1.0

* significant at .05 level
** significant at .01 level

The degree of disability of the child also correlated at a significant level ($p = .01$) with the self-concept of the mother. This indicated that mothers of children demonstrating high levels of disability possessed higher levels of self-concept than mothers of children with low disability. It should be noted that this study excluded families who children had been institutionalized or placed in foster homes. It is possible that mothers with low self-concepts with children with high disabilities more frequently decided not to maintain the child in the home and would therefore, not be included in the study sample. Another possible explanation for the strong positive correlation between degree of disability of the child and the self-concept of the mother is that mothers derive satisfaction from being able to cope with all the problems associated with caring for a severely deformed and handicapped child.

(2) The expected correlation between the self-concept of the mother and the understanding of the mother of the child's condition proved statistically significant. This finding supported the premise derived from the conceptual framework that mothers with high self-concepts would more readily "take-in" the information concerning the child's condition. It also supported a previous finding of the exploratory study that more aggressive parents sought out additional information. This finding also has implications for professionals who are attempting to teach parents concerning the child's condition. This will be discussed in the next chapter.

(3) The expected correlation between self-concept of the mother and total adaptation of the mother was not supported by the data. It is interesting to note that it was one of two negative correlations (- .305). It is possible that, had the sample size been larger than N = 20, this correlation would have reached a significant level. A negative relationship would indicate that mothers with low self-concept show higher levels of adaptation than mothers with high self-concepts.

(4) The expected relationship between understanding of the mother about the child's condition and the total adaptation was not supported. The data showed no relationship to the amount of understanding demonstrated by the mother and the mother's total adaptation.

(5) The expected relationship between the age of the child and the understanding of the mother was not supported. According to the data from this sample, mothers in the study did not increase their understanding of the child's condition as the child increased in age. This possibly supports a previous assumption of the study based on information from spina bifida families that as the parents need for information and ability to interpret information increased, ready access to the information decreased.

Effects of Educational Background. The effects of the wide variation in educational background of the mothers participating in the study on the pretest scores was investigated by means of a simple Chi-square and Phi coefficient. The mothers were divided into two groups: (1) less than a high school education, and (2) high school graduates or beyond high school. The scores on the understanding

pretest were divided into scores above the median and below the median. A contingency table was formulated and is presented in Table 7.3.

TABLE 7.3

EDUCATIONAL LEVEL OF MOTHERS AND UNDERSTANDING PRETEST SCORES. N = 20

	Below Median on Understanding Pretest	Above Median on Understanding Pretest	
Less Than High School Education	4	2	6
High School Graduate or Had Attended College	6	8	14
	10	10	

The computed chi^2 statistic was .95 with one degree of freedom. This was not significant at the .05 level. To further check this effect, the less than high school and the high school graduates were compared with the mothers who had attended or completed college. The computed chi^2 statistic obtained was 3.80, not significant at the .05 level. It was concluded that the educational background of the mothers did not significantly effect the understanding pretest scores.

POSTTEST SCORES

Treatment Effects

The analysis of the pretest ratings and scores failed to demonstrate any significant difference in the experimental and control groups at the beginning of the study. It was assumed that changes that occurred in the experimental group from pretest to posttest could reasonably be attributed to the operation of the independent variable.

Posttest scores were tested by use of the Kolmogorov-Smirnov two sample test on the change scores between pretesting and posttesting. The minimum level of significance established was $p = .05$. The critical value of K_D was equal to or greater than 6 for a one-tailed test. The scores were also tested by use of the Wilcoxon Sign Test for Differences Between Related Samples on the scores of the experimental group. A significance level of $p = .05$ was established. The critical value was equal to or less than 8 for the smaller of the scores of the positive and the negative ranks.

The Understanding of the Mother. A major hypothesis of the study was that instructional nursing intervention by a professional nurse in the homes of mothers with spina bifida children would increase the understanding of the mothers of information concerning the child's defect. The change in the experimental group was found significantly greater than the change in the control group on both the Kilmorov-Smirnov test and the Wilcoxon Sign Test. (See Tables 7.4 and 7.5). All of the scores of the mothers in the experimental

TABLE 7.4

UNDERSTANDING SCORES: KOLMOGOROV-SMIRNOV TEST N = 20

	Cumulative frequency distributions of Change Scores						
	-21-0	1-22	23-44	45-66	67-88	89-110	111-132
Experimental Group N = 10	0/10	3/10	8/10	9/10	9/10	9/10	10/10
Control Group N = 10	6/10	9/10	10/10	10/10	10/10	10/10	10/10
$S_{N1}(X) - S_{N2}(X)$	6/10	6/10	2/10	1/10	1/10	1/10	0

$K_D = 6$; significant at the .05 level (Siegel, 1956:130;278).

TABLE 7.5

UNDERSTANDING POSTTEST SCORES: WILCOXON SIGN TEST N = 10

Family	Posttest	Pretest	Difference	Rank
E_1	178	144	+ 34	6
E_2	161	128	+ 33	5
E_3	150	114	+ 36	7
E_4	223	207	+ 16	2
E_5	186	169	+ 17	3
E_6	192	80	+112	10
E_7	167	132	+ 35	8
E_8	204	180	+ 24	4
E_9	142	87	+ 55	9
E_{10}	204	195	+ 9	1

Sum of Negative Ranks 0

Sum of Postive Ranks 55

Level of Significance for one-tailed test = .001 (Bruning and Kintz, 1968:242)

group increased on understanding; the scores of four mothers in the control group increased and six decreased. The median score on the understanding measure increased 44 points in the experimental group and decreased 8 points in the control group. (See Table D.2, Appendix D). It was concluded that instructional nursing intervention increased the understanding of the mothers concerning the defect of the child.

Self-Concept of the Mother. A second major hypothesis of the study was that instructional nursing intervention would significantly increase the total self-concept of mothers of children with myelomeningocele. Subhypotheses (B), (C), (D) and (E) predicted changes in the self-concept subscale scores. Scores of the total self-concept measured by the Total P of the Tennessee Self-Concept test and the subscale scores on personal self and family self were not significant. (See Tables 7.6-7.13.) The only score indicating a statistically significant change was the Self-Criticism subscale. (See Table 7.5-7.12.) The hypotheses that nursing instruction would increase the total self-concept of the mothers and the subhypotheses that personal self and family self would increase were rejected. It was concluded that instructional nursing intervention would not significantly effect the total self-concept of mothers of myelomeningocele children or the level of scores on personal self or family self.

The significant change in the experimental group on the self criticism subscale (I) indicated that the independent variable operated to increase "healthy openness and capacity for self

TABLE 7.6

TOTAL SELF-CONCEPT (P SCORE): KOLMOGOROV-SMIRNOV TEST N = 20

	Cumulative frequency distributions on Change Scores							
	-33;-26	-25;-18	-17;-10	-9;-1	0;+8	9;17	18;26	27;34
Experimental Group N = 10	0/10	1/10	1/10	4/10	6/10	9/10	9/10	10/10
Control Group N = 10	2/10	2/10	3/10	7/10	8/10	9/10	10/10	10/10
$S_{N1}(X) - S_{N2}(X)$	2/10	1/10	2/10	3/10	2/10	0	1/10	0

$K_D = 3$

TABLE 7.7

TOTAL SELF-CONCEPT POSTTEST SCORES: WILCOXON SIGN TEST N = 10

Family	Posttest	Pretest	Difference	Rank
E_1	355	357	- 2	4
E_2	346	335	+11	7.5
E_3	350	357	- 7	3
E_4	390	387	+ 7	5.5
E_5	400	393	+ 7	5.5
E_6	311	300	+11	7.5
E_7	326	313	+13	9
E_8	421	388	+33	10
E_9	268	286	-18	1
E_{10}	329	338	- 9	2

Sum of Negative Ranks 10

Sum of Positive Ranks 45

TABLE 7.8

PERSONAL SELF (SUBSCALE C): KOLMOGOROV-SMIRNOV TEST N = 20

	Cumulative Frequency Distributions on Change Scores					
	-9;-7	-6;-4	-3;-1	0;+2	3; 5	6; 8
Experimental Group N = 10	1/10	2/10	3/10	5/10	8/10	10/10
Control Group N = 10	2/10	3/10	6/10	8/10	10/10	10/10
$S_{N1}(X) - S_{N2}(X)$	1/10	1/10	3/10	3/10	2/10	0

$K_D = 3$

TABLE 7.9

PERSONAL SELF (SUBSCALE C): WILCOXON SIGN TEST N = 10

Family	Posttest	Pretest	Difference	Rank
E_1	65	57	+ 8	10
E_2	68	64	+ 4	7
E_3	67	76	- 9	1
E_4	75	76	- 1	3
E_5	75	74	+ 1	5
E_6	58	55	+ 3	6
E_7	60	54	+ 6	9
E_8	87	82	+ 5	8
E_9	48	54	- 6	2
E_{10}	68	68	0	4

Sum of Negative Ranks 10

Sum of Positive Ranks 45

TABLE 7.10

FAMILY SELF (SUBSCALE D): KOLMOGOROV-SMIRNOV TEST N = 20

	Cumulative Frequency Distribution on Change Scores					
	-9;-7	-6;-4	-3;-1	0;+2	3;+5	6;+9
Experimental Group N = 10	2/10	3/10	4/10	8/10	9/10	10/10
Control Group N = 10	2/10	3/10	6/10	8/10	9/10	10/10
$S_{N1}(X) - S_{N2}(X)$	0	0	2/10	0	0	0

$K_D = 2.$

TABLE 7.11

FAMILY SELF (SUBSCALE D): WILCOXON SIGN TEST N = 10

Family	Posttest	Pretest	Difference	Rank
E_1	71	75	- 4	3
E_2	74	72	+ 2	7.5
E_3	73	64	+ 9	10
E_4	82	85	- 3	4
E_5	82	81	+ 1	6
E_6	67	65	+ 2	7.5
E_7	70	70	0	5
E_8	85	82	+ 3	9
E_9	56	65	- 9	1.5
E_{10}	66	75	- 9	1.5

Sum of Negative Ranks 15

Sum of Positive Ranks 40

TABLE 7.12

SELF-CRITICISM (SC) SCORES: KOLMOGOROV-SMIRNOV TEST N = 20

	Cumulative Frequency Distribution on Change Scores				
	-5;-2	-1;+2	+3;+6	+7;+10	+11;+14
Experimental Group N = 10	2/10	7/10	10/10	10/10	10/10
Control Group N = 10	1/10	7/10	9/10	9/10	10/10
$S_{N1}(X) - S_{N2}(X)$	1/10	0	1/10	1/10	0

$K_D = 2$. Not significant at the .05 level.

TABLE 7.13

SELF-CRITICISM (SC) POSTTEST SCORES: WILCOXON SIGN TEST N = 10

Family	Posttest	Pretest	Difference	Rank
E_1	36	37	- 1	3
E_2	28	27	+ 1	5
E_3	29	28	+ 1	5
E_4	24	29	- 5	1
E_5	39	38	+ 1	5
E_6	42	39	+ 3	8
E_7	36	34	+ 2	7
E_8	35	30	+ 5	9.5
E_9	44	39	+ 5	9.5
E_{10}	33	36	- 3	2

Sum of Negative Ranks 6[1] Significant at the .025 level for one tailed test

Sum of Positive Ranks 49

criticism" (TSCS Manual, pg. 2). The subscale is composed of ten mildly derogatory items that "most persons admit as being true. Individuals who deny most of these statements most often are being defensive..." (TSCS Manual, pg.2). The change on this subscale was interpreted as a positive effect of the teaching sessions.

Adaptation of the Mother. The third major hypotheses of the study stated that the total Adaptation of the mother, as measured by the Elias Family Adjustment Test would significantly change as the result of instructional nursing intervention. Subhypotheses (G) and (H) predicted significantly greater change in the experimental group on Interparental Friction-Harmony and significantly lower scores on Rejection of the Child. None of the scores were statistically significant. (See Tables D.11-D.12, Appendix D). The hypotheses that nursing instruction would change the adaptation of the mother, the score on Interparental Friction-Harmony and reduce the Rejection of the Child were rejected. To determine whether a significant correlation between the degree of disability of the child and the rejection of the child by the mother existed, A Spearman Rho rank order correlation table was constructed (See Appendix D, Table D.13). The computed Rho value was +.195 and the t statistic .843. This was not significant at the .05 level. It was concluded that the degree of disability of the child was not correlated in the study sample with the level of rejection of the child.

SUMMARY OF THE CHAPTER

Hypotheses Accepted. The following hypotheses were accepted on the basis of the data obtained from the study sample of twenty mothers of myelomeningocele children:

H_{1a}: Instructional nursing intervention would significantly increase the understanding of mothers of myelomeningocele children.

Subhypothesis (A): Mothers in the experimental group would demonstrate significantly greater increase from pretest to posttest on understanding scores than mothers in the control group.

Subhypothesis (E): Mothers in the experimental group would demonstrate significantly greater increase from pretest to posttest on self criticism scores than mothers in the control group.

Hypotheses Rejected. The following hypotheses were rejected on the basis of the data obtained from the study sample of twenty mothers of myelomeningocele children:

H_{1b}: Instructional nursing intervention would significantly increase the self-concept of mothers of myelomeningocele children.

H_{1c}: Instructional nursing intervention would significantly change the adaptation of mothers of myelomeningocele children.

Subhypothesis (B): Mothers in the experimental group would demonstrate significantly greater increase from pretest to posttest on total self-concept scores than mothers in the control group.

Subhypothesis (C): Mothers in the experimental group would demonstrate significantly greater increase from pretest to posttest on personal self scores than mothers in the control group.

Subhypothesis (D): Mothers in the experimental group would demonstrate significantly greater increase from pretest to posttest on family self than mothers in the control group.

Subhypothesis (F): Mothers in the experimental group would demonstrate significantly greater change from pretest to posttest on total family adjustment than mothers in the control group.

Subhypothesis (G): Mothers in the experimental group would demonstrate significantly greater change from pretest to posttest on interparental friction-harmony than mothers in the control group.

Subhypothesis (H): Mothers in the experimental group would demonstrate significantly greater change from pretest to posttest on rejection of the child than mothers in the control group, in the direction of less rejection of the child.

CHAPTER VIII

DISCUSSION AND IMPLICATIONS FOR NURSING PRACTICE AND FURTHER RESEARCH

> What...ought we really to be teaching patients? At what stage of their illness do they need what kinds of information?... Carrying out clinical research is a process fraught with problems.
>
> Ada Jacox[1]

In the past decade the number of surviving myelomeningocele children needing specialized medical treatment and nursing care has dramatically increased. Until the early 1960's over ninety per cent of the infants born with meylomeningocele died in the first year of life from meningitis, encephalitis, complications of paraplegia or progressive hydrocephalus. Recent advances in medical and surgical management of infants with myelomeningocele have reduced the mortality rate to less than thirty per cent. The decrease in the mortality rate for the children has been accompanied by an unprecedented increase in social, psychological, and financial problems for the families involved.

Initial Reactions of Parents

Similarities and Differences of Parents to Other Parents of Congenitally Malformed Children. Initial reactions of parents of myelomeningocele children to the birth of the child are similar

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[1]Jacox, Ada. Nursing Research and the Clinician. *Nursing Outlook*. June, 1974, *22*, 383.

to the reactions of parents of children with other forms of congenital malformations. These reactions include: (1) denial of the situation or defect; (2) grief and mourning for the lost child they had anticipated; (3) guilt concerning the child's defect; and, (4) shock and depression. In at least one aspect, however, the experiences of the parents of myelomeningocele children are unique. The parents are asked to make a decision or participate in making a decision concerning the treatment regimen of the infant which may determine whether the infant lives or dies. When the infant lives, the initial decision to institute immediate treatment or to delay treatment in favor of a "wait and see" approach invariably effects the quality of life and the maximum potential of the surviving child.

Role of Health Professionals. Health professionals in contact with the parents during the first few weeks after the birth of the infant influence the adaptation made by the parents to the birth of the child and also contribute to the formation of early attitudes toward the care of the child which are formed by the parents. The adaptation and attitudes of the parents , in turn, determines the quality and consistency of the care given to the child. The influence exerted by the health professionals occurs as the result of verbal and nonverbal responses made to the child and to the parents during the initial periods of shock, denial, mourning, identity work and information gathering processes described in Chapter 2. These processes, interacting with the self-concepts and perceptions of the parents, combine to determine

the eventual adaptation or maladaptation of the parents to the child, and to the changes in life style caused by the birth of the child.

Objectives and Findings of the Study

Objectives. Two objectives provided the basis for the study: (1) to obtain information concerning the parents of myelomeningocele children relating to the unmet needs and unresolved problems of the parents, and, (2) to systematically investigate the effect of instructional nursing intervention on the understanding, self-concept and adaptation of mothers of myelomeningocele children.

Descriptive Findings. The findings, presented in Chapters 6 and 7 included the following: (1) families in the study (N = 20) reside in urban areas and represented all levels of socio-economic indicators; (2) the educational backgrounds of the parents ranged from eighth grade to doctoral degree; (3) a variety of racial backgrounds were represented in the sample including Caucasian, Black, Mexican, and Chicano; (4) fifteen per cent of the families reported other family members with some form of spina bifida (none of the affected family members were siblings of the myelomeningocele child; (5) obstetrical histories of the myelomeningocele mothers were essentially normal with few reported abortions or miscarriages; (6) sixty-five per cent of the mothers were under 25 years of age at the time of the birth of the child; (7) several parents reported that the event of the birth of the child had

strengthened the marriage by increasing communication between the parents; and, (8) no divorces or marital separations occurred after the birth of the myelomeningocele child that had not been in progress prior to the birth of the child.

Sources of Stress. Major sources of stress reported by the parents included: (1) lack of understanding of the child's condition; (2) erroneous or misleading information obtained concerning the child's defect; (3) the sense of aloneness experienced by the mother; (4) mental depression of the mother especially during the hospitalizations of the child; (5) behavior changes in siblings; and, (6) fear of being unfair to other children in the family. Unmet needs and unresolved problems included: (1) additional information concerning the child's condition; (2) contact with parents of other myelomeningocele children; (3) financial problems; and, (4) concerns about the future of the affected child.

Results of Hypotheses Testing. Hypotheses concerning the efficacy of instructional nursing intervention were tested and results indicated that a planned teaching sequence conducted in the homes of parents over several weeks time resulted in a significant increase in the understanding of the mothers concerning the child's condition. Openness and capacity for self-criticism of the mothers increased and defensiveness of the mothers decreased.

Discussion of Descriptive Data Findings

The purpose of this chapter is to further examine the findings obtained in relation to clinical nursing practice and relevance for further research.

Socio-economic Status. Effects of the wide range in socio-economic levels in the sample was an unexpected finding. Previous studies had indicated that myelomeningocele families represented a skewed population, composed predominantly of persons from the lower socio-economic groups. It is important to note, however, that the studies which are available concerning myelomeningocele families have been conducted in countries other than the United States: (1) Wales, (2) England, (3) South Africa, and, (4) Australia. These countries represent different cultures, social systems, medical health care systems and hundreds of other factors including diet and environmental conditions which differ from the United States. Information based on samples from the United States is fragmentary at best. Given the information in the literature and the discrepancies between that information and the findings in this study, information is desparately needed concerning the following:

1. Who are the families with children with myelomeningocele born and residing in the United States? It is important to know whether the information in this study was chance findings or whether the United States population of myelomeningocele families does differ from that in other countries. Speculations could be made that variables such as the high standard of living in this country as compared with many other countries of the world, change not only the characteristics of the population but also the incidence rates, the severity of the defects and survival rates. The absence of such basic information makes it virtually impossible

to plan programs designed to meet the present problems and future needs of the myelomeningocele children and the families involved.

2. Does the economic status of the family determine the amount and quality of care received by the child? Preliminary findings in this study indicate that the socio-economic status of the family influenced the quality of care received by the child. Families with very low incomes did not report financial problems to be of major importance. This probably is because these families were eligible for substantial amounts of financial aid from state and federal sources. Families who reported incomes of over $10,000, however, tended to indicate more concern over the costs of treatment and therapy for the children. As indicated in Chapter 7, interview data indicated that some families of moderate incomes did not believe that they were providing therapy often enough for the childrens' needs. The families reported they were unable to secure all the equipment the affected child needed without depriving the siblings of necessary supplies. If these findings are supported by data in other samples, then it would indicate that an inverse relationship exists between the economic position of the family and the quality and amount of supplies and therapy received by the child. These findings could be interpreted to mean that in the areas of major medical expenses the health care system is more responsive to the medical needs of lower income families than it is to moderate or high income families.

Discussion of the Study Findings in Relation to Clinical Practice

Elements of the Framework. A conceptual framework related directly to the effect of chronic illness on family structure and family life and the influence of nursing intervention on the process of adaptation to chronic illness is of value to nursing practitioners. The framework presented in Chapter 2 organized some of the elements believed to operate in the process of adaptation and maladaptation of parents following the birth of a child with myelomeningocele. The defects of a myelomeningocele child are highly visible and permanent. Although some defects can be alleviated by surgical procedures and therapy, the child remains handicapped in certain aspects of functioning throughout his life. The framework, by considering the period following the birth of the myelomeningocele infant a critical period in the lives of the parents, emphasized that the birth of the child can also result in permanent handicaps for the parents. These handicaps include: (1) inability to cope with present problems or plan for the future; (2) constant reworking of previously made decisions; (3) failure to utilize resources appropriately; and, (4) the expenditure of large amounts of energy in diffuse anger and in combating depression. The framework also emphasized that the interaction of professionals with parents in the period following the birth of the child was important not only to the information gathering tasks of the parents as they attempt to make decisions concerning the child, but also to the identity work of the parents as they reset

their self-concepts in response to the stimulus of the birth of the child and the reactions of significant others to the birth.

Relationship of Variables in the Framework. Significant correlations were found among three of the five variables described in the framework:

1. High degree of disability of the myelomeningocele child and high level of understanding of the mother of the child's condition;

2. High degree of disability of the myelomeningocele child and high level of self-concept of the mother; and,

3. High level of self-concept of the mother and high level of understanding of the mother of the child's condition.

These correlations tend to support the assumption of the investigator that each are important factors in the adaptation or adjustment made by parents to the birth of the myelomeningocele child. To what extent each of the factors influence the adaptation process can only be speculated upon until more studies are initiated and more information is available concerning the total adaptation process.

Degree of Disability of the Child and Level of Understanding of the Mother. The relationship between the high degree of disability of the child and high levels of understanding of the mother had not been predicted by the investigator. It is possible that mothers with children with high degrees of disability are less able to deny the condition of the child than mothers of children with low degrees of disability. Therefore, they would pass more

quickly through the denial phase of adaptation, and would become ready for information earlier, perhaps during the time when hospital personnel and physicians are undertaking the presentation of the information concerning the defect. Another possible explanation is that the care problems are so very great in a myelomeningocele child with a high degree of disability that mothers tend to learn more because the child experiences more complications and undergoes more procedures. This relationship between the degree of disability of the child and the understanding of the mother implies that health practitioners should be alert to the fact that parents with children with high level of disability may be ready for additional information concerning the defect and interested in signs and symptoms of danger signals much earlier than mothers of children with low disabilities.

Degree of Disability of Child and Self-Concept of the Mother. High degree of disability of the child also correlated at a significant level with high self-concept of the mother. One selection criterion for families in this study was that the affected child was maintained in the home of the biological mother. It is possible that mothers with children with high disabilities who possess low self-concepts have decided not to treat the child, or have decided to place the child in an institution or a foster home. These mothers would not have been included in the sample studied. Another explanation of the relationship between high degree of disability of the child and high self-concept of the mother is that the ability to cope with the tremendous problems

of the care of a myelomeningocele child tends to enhance the self-concept of the mother who succeeds in the task.

If these speculations concerning the meaning of the relationship between the degree of disability of the child and the self-concept of the mother were verified by further research, professionals in contact with parents during the initial decision-making periods should be alert to the needs of the parents for identity work which would elevate the self-concept and increase the mother's feelings of adequacy in caring for the affected child.

The third significant relationship was between the self-concept of the mother and the understanding of the mother. This is discussed in the next section titled, Increased Understanding of the Mothers.

The Increased Understanding of the Mothers

Education of the Mothers. The concern of the investigator that the wide range in educational backgrounds of the mothers participating in the study would introduce an uncontrolled variable into the study was not substantiated. Mothers with college educations did not possess any more or less information concerning the child's condition than did mothers who had not finished high school. This raised questions concerning what factors do operate in the process of the mother learning the necessary information concerning the child and the child's care. For health professionals engaged in teaching these families, the implications are that other factors should be assessed prior to attempting to teach essential information to parents.

Self-Concept of Mother and Understanding of the Mother. Due to the significant correlations found in this study to exist between the low self-concept of the mother and the low level of understanding of the child's condition by the mother, it would be appropriate for health professionals engaged in teaching and counseling of patients to be aware that the strengthening of the client's self-esteem and feelings of worth about himself may at times need to preceed the offering of new and threatening information.

Timing of the Teaching of Parents. Another critical factor in increasing the parents' understanding of the child's defect may be the timing of the presentation of information. In this study, all families who were offered the teaching sequence increased their scores from pretest to posttest on the instrument used to measure understanding of the child's condition. This finding may have resulted because of the timing factor. Because all families had children at least six months old, the initial denial and mourning period was assumed to have passed. The parents had been caring for the child in the home for several weeks or months. The information which had previously been offered to the parents at a time when it was not perceived relevant may have been perceived very relevant after the parents had experienced the total care responsibilities imposed by the myelomeningocele child. If the findings are substantiated that parents do not retain information concerning problems and situations which are not of immediate concern, the responsibility of the health teacher would be to

arrange for health teaching at a time when it is most relevant for the parents to know and utilize. This would also indicate that the presentation of large quantities of information at any one time may be inappropriate and that learning is enhanced when the health teacher is able to separate the more immediate concerns from those of less urgency. In this way information overload can be avoided and relevant materials can be supplied as the patient is ready for them.

Need for Follow-up. Adequate and appropriate follow-up of teaching for families with any kind of chronic condition is essential. The easy trap of assuming that, because information has been presented to a patient, the patient has learned the information must be avoided. Consideration should be given to low threat testing methods which would be appropriate for patients to demonstrate the information they have learned and have been able to utilize that are more sophisticated than the basic demonstration-procedure, return-demonstration technique. Instruments are needed which can measure not only a patient's manual skills relevant to a procedure but also his basic understanding of the conditions under which the procedure is appropriate and inappropriate.

External Stresses. Another factor that may have been important to the success of the teaching sequence in the study is that reduction of external stresses was planned as a part of the independent variable. Teaching situations in the clinics, hospitals, and physicians's offices have previously been described.

The noise, confusion and many times the necessary haste that were part of the teaching situation may have limited the intake of information or the retention of information by the parents. On the other hand, many of the families had been visited by community health nurses or public health nurses. Of these families, 10 per cent perceived the health workers as valid sources of needed information. In most cases the families had no clear idea concerning the purposes of the visits by the nurse. How can practicing health professionals be helped to more effectively meet the needs of families with myelomeningocele children? In fairness to the practitioners it must be mentioned that learning about the care of a child with myelomeningocele is not an easy task. The references are scattered throughout urological, neurosurgical, orthopaedic and physical therapy references. The practicing clinician has little time or energy for such in-depth literature review for constructing care plans for possibly one or two cases in her case load of hundreds. In the present day of widespread use of audio and video tapes, casettes, computer retrieving systems, and reasonably inexpensive teaching aids, methods can and must be found to assist practitioners in identifying the needs of families and quickly and efficiently locating the information and resources needed to meet those needs.

Unmet Needs and Unsolved Problems

Information About the Defect. Many of the unmet needs cited by parents and the sources of stress reported were very

similar. The most frequently named unmet need was for additional information about the condition of the child. Two major sources of stress reported were lack of understanding of the child's condition and erroneous information concerning the child's condition. Health professionals must address themselves to the need for consistent, accurate information that can be offered as many times as is necessary for the parents to comprehend the meaning of the information. Coordinated clinics for children with myelomeningocele have been a great asset to families in the following respects: (1) families are able to see physicians representing all medical specialties on the same day and at the same place, which saves time, energy and money for the families,and (2) medical specialists have been able to consult together concerning the best plan of treatment for the child so that problems such as placing an ileostomy opening in the same location where an orthopaedic pelvic band must be worn are avoided.When health teaching is also done at the clinics, the experience may be too overwhelming to the parents to take in all the information and retain it. To respond to the parents expressed needs, more detailed plans for teaching and follow-up must be made.

CHAPTER SUMMARY

Clinical research is attended by many problems. One of the most vexing of the problems is that every piece of clinical research tends to ask more questions than it answers. Control of the experimental setting is difficult and sometimes impossible to

attain. Extraneous variables haunt the interpretation of the findings. Especially in naturalistic settings does the investigator tend to lose control over those variables which would ideally be rigidly fixed. The studies are worthwhile, however, and must be scrutinized for possible implications for nursing practice.

In this study a framework was developed to describe the process experienced by parents of myelomeningocele children as they adjust to parenting of a chronically disabled child. The framework will be modified and refined as further research concerning adaptation to chronic illness is completed. A population which is emerging, growing, and assuming greater importance for health care facilities and delivery systems was described. The problems and needs of the population was defined and one form of nursing intervention was tested for efficacy in meeting some of the identified needs. Some of the nursing implications of the findings have been discussed.

If clinical nursing practice is ever to really move forward toward meeting its commitments to high standards of health care for all clients, implications of studies such as this one will need to be examined critically, and if found promising, enlarged and refined until the understanding of the processes of family adaptation to chronic illness is achieved.

APPENDIX A

DATA GATHERING INSTRUMENTS

APPENDIX A

FAMILY INFORMATION FORM

I. D. Number_____

A. Birth Date of the Affected Child_____.

B. Birth Date of Siblings a._____1. Male___2. Fe.___
b._____1. Male___2. Fe.___
c._____1. Male___2. Fe.___
d._____1. Male___2. Fe.___

C. Have You Ever Been Married? _____1. yes _____2. no
If yes, complete following:
Date of Marriage_____
Date of Termination of Marriage_____
(Please Circle Reason)
1. Divorce 2. Death of Spouse

Date of Marriage (2nd)_____
Date of Termination of marriage (2nd)_____
(Please Circle Reason)
1. Divorce 2. Death of Spouse

D. Is the father of the affected child living with the family at this time? _____1. yes _____2. no

E. Are there other persons living in the household other than Father, Mother, children? _____1. yes _____2. no

If yes, what relation, if any, are they to the family?_____

F. Birth Date of Mother_____

G. Birth Date of Biological Father_____

H. Computed age of mother at the time of birth of child_____

I. Computed age of father at the time of birth of child_____

J. Race of mother
_____1. American Indian
_____2. Black
_____3. Chicano
_____4. Oriental
_____5. White
_____6. Other (specify)_____

K. Race of father
_____1. American Indian
_____2. Black
_____3. Chicano
_____4. Oriental
_____5. White
_____6. Other (specify)_____

L. Religion
_____1. Catholic
_____2. Jewish
_____3. Protestant
_____4. None
_____5. Other (specify)_____

M. Do you consider yourself active in your church?
_____1. yes _____2. no

N. Housing
_____1. Owns Home
_____2. Rents Home
_____3. Rents, apartment
_____4. Lives with relatives
_____5. Other (specify)_____

O. On an average, what is your family's average yearly income?
_____.

P. Do you have expenses which you consider to be different from the average family? _____1. yes _____2. no

If yes, please explain_____

Q. Educational Level of the Mother
_____1. Less than high school
_____2. High School Graduate
_____3. Some college
_____4. College graduate
_____5. Post College studies
_____6. Other (specify)_____

R. Educational level of the father
_____1. Less than high school
_____2. High School Graduate
_____3. Some college
_____4. College graduate
_____5. Post College studies
_____6. Other (specify)_____

S. Type of employment, Mother
_____1. None
_____2. Unskilled labor_____
_____3. Skilled Labor_____
_____4. Technician_____
_____5. Professional_____
_____6. Other_____

T. Type of employment, Father
_____1. None
_____2. Unskilled labor_____
_____3. Skilled Labor_____
_____4. Technician_____
_____5. Professional_____
_____6. Other_____

U. Medical Insurance or financial aid
_____1. Prepaid health plan
_____2. Coverage under group medical insurance, ie. B. C., B. S.
_____3. Private medical coverage, individual policy
_____4. Crippled Childrens' Service
_____5. Military facility or health care coverage by military benefits
_____6. None
_____7. Other (specify)_____

V. Abortions or Miscarriages?
_____1. yes _____2. no

If yes, number prior to birth of affected child?_____
If yes, number after the birth of affected child?_____

W. Was pregnancy which resulted in affected child planned?
_____1. yes _____2. no

X. Was pregnancy abnormal in any way?
_____1. yes _____2. no

If yes, explain_____

_____

Y. Prenatal care begun in what month of pregnancy?
___1, ___2, ___3, ___4, ___5, ___6, ___7, ___8, ___9.

Z. How old was the child when he was brought home from the hospital the first time?
_____1. Under one week
_____2. 1-2 weeks
_____3. 2-3 weeks
_____4. 3-4 weeks
_____5. Over 4 weeks

AA. How many times was the child hospitalized in the first year of life?
___0, ___1, ___2, ___3, ___4, ___5, ___6, ___7, ___8, ___more +8

BB. Did Public Health Nurse(s) visit in the home?
_____1. yes _____2. no

If yes, how many times?_____

CC. Who told you about your baby's condition?
_____1. Physician, Obstetrician
_____2. Physician, Pediatrician
_____3. Physician, Specialist, eg. neurosurgeon
_____4. Nurse
_____5. Other health worker (specify)_____
_____6. Other non-health worker (specify)_____

DD. Where did you learn the most information concerning the condition of your child?
_____1. Physician, Obstetrician
_____2. Physician, Pediatrician
_____3. Physician, Specialist, eg. neurosurgeon
_____4. Nurse
_____5. Other health worker (specify)_____
_____6. Other non-health worker(specify)_____
_____7. Books, magazines, or other written material
_____8. Parent's Group
_____9. Other (specify)_____

EE. Do you attend a Spina Bifida Parent's Group
_____1. yes _____2. no

FF. If yes, what was the age of your child when you started attending?

_____

GG. If yes, do you consider yourself a regular attender of the meetings?

_____

HH. What was the greatest problem you had in the first few months after the birth of the affected child?

_____
_____1. Financial
_____2. Transportation
_____3. Lack of understanding of the child's condition
_____4. Mental Depression
_____5. Physical care of the child
_____6. Other (specify)_____

II. Who was the greatest help to you during the first few months of the baby's life?_____

JJ. What was the greatest help to you during the first few months of the baby's life?_____

KK. What is your present marital status?

_____1. Married to father of child
_____2. Separated
_____3. Divorced
_____4. Widowed
_____5. Single, living with father of child
_____6. Single, living with relatives other than father of child
_____7. Remarried, not to father of child
_____8. Other_____

LL. How do you feel the child has affected your family? (Marital relationship)

_____1. Stronger
_____2. Weaker
_____3. Greater anxiety and/or stress
_____4. Learned alot
_____5. No more or less than any other child would.

MM. How would you rate your own health today (Mother)

_____1. Very good
_____2. OK
_____3. Worried and Depressed
_____4. Poor
_____5. Very Bad
_____6. No answer

NN. How would you rate your husband's health today?

_____1. Very good
_____2. OK
_____3. Worried and Depressed
_____4. Poor
_____5. Very Bad
_____6. No answer

APPENDIX A

QUESTIONS ON SPINA BIFIDA

Directions: Read carefully each question on the test. Each question will have at least one correct answer. Some of the questions will have two or more correct answers. Place an X on the line in frcnt of the answer or answers which you believe correctly responds to the question asked. Those questions which have more than one correct answer should have an X placed in front of each of the correct answers.

Example: 1. In a leap year, the total number of days in the year is:

____A. 365
_X_B. 366
____C. 356
____D. I Don't Know

Example: 2. Which of the following numbers are divisible by the number 3?

_X_A. 963
____B. 239
_X_C. 69
____D. I Don't Know

After you have carefully read the directions and examples, go on to the test questions. YOU ARE NOT EXPECTED TO KNOW ALL THE ANSWERS. When you are not reasonably sure of the correct answer, please do not guess, but place an X beside the "I Don't Know" response. YOU SHOULD NOT SPEND TOO MUCH TIME ON ANY ONE QUESTION.

3. The birth defect which is commonly called Spina Bifida is also called by other names. Which of the following terms are generally used to refer to the same condition as Spina Bifida?

_____A. Hydrocephalus
_____B. Meningomyelocele
_____C. Myelomeningocele
_____D. Ventriculocele
_____E. I Don't Know

4. When a baby is born with Spina Bifida, which of the following major organs or body parts are most likely to be affected?

_____A. Heart
_____B. Lungs
_____C. Bladder
_____D. Muscles and Nerves
_____E. I Don't Know

5. Many different doctors will be needed to provide complete care for the baby born with Spina Bifida. You would expect a doctor whose title is Orthopedic Surgeon to be consulted mainly for problems that relate to:

_____A. Removal of the "sac" from the back of the baby.
_____B. The muscles and joints which allow movement such as crawling and walking.
_____C. General physical care of the child including preventing and treating routine infections, immunizations and general information about the child's problems.
_____D. The bladder and kidneys
_____E. I Don't Know.

6. A doctor known as a Neurologist or Neurosurgeon will be especially interested in:

_____A. The spinal "sac" or the shunt of cerebral spinal fluid.
_____B. The muscles and joints which allow movement
_____C. The general physical care of the child
_____D. The bladder and kidneys
_____E. I Don't Know

7. When Spina Bifida occurs, the damage to the embryo (the baby growing in the mother's womb) occurs:

_____A. In the first few weeks of pregnancy
_____B. In the fourth or fifth month of pregnancy
_____C. Shortly before labor begins
_____D. I Don't Know

8. Which of the following is accurate concerning the "cause" of Spina Bifida?

_____A. Activities of the mother during the final stages of pregnancy are often the cause of the condition.
_____B. Drugs taken by the father or mother before pregnancy can be responsible for the defect.
_____C. Parents whose families have had other types of back problems usually have a child with Spina Bifida.
_____D. The true cause of Spina Bifida is not yet known.
_____E. I Don't Know

9. Since 1960 many more children with Spina Bifida defects have been entering public schools. This is because:

_____A. Parents are becoming aware that these children need educational opportunities as do all other children.
_____B. Improved medical and surgical treatment methods have increased the survival rate of children with Spina Bifida
_____C. More special classrooms are being made available in many areas for handicapped children.
_____D. The children need less frequent hospitalizations now than they formerly did.
_____E. I Don't Know.

10. Parents generally find it difficult to believe that their child has been born with a birth defect. Which of the following strong feelings do parents often have during the first year of the child's life?

_____A. Shock
_____B. Anger
_____C. Guilt
_____D. Hurt
_____E. I Don't Know

11. Some surgeons remove the "sac" on the infant's back within hours after birth. Other times, several days, weeks, or even years may go by without surgical removal of the "sac". Factor(s) affecting this decision include:

_____A. If any amount of Hydrocephalus is present, the surgery must be delayed.
_____B. Some infants are too weak and critical to operate on immediately.
_____C. Some defects are so large they are difficult to repair while the infant is still very small.
_____D. The presence or absence of other defects or physical problems must be considered in the decision.
_____E. I Don't Know

12. Certain health workers can be especially helpful to families of Spina Bifida children. The worker most likely to be able to tell the families about sources of help, to counsel the parents about family problems caused by the birth of the child, and who can explain the hospital or clinic routines of appointments, x-rays, tests, and admission procedures is the:

_____A. Physician in charge of the care of the child.
_____B. Office nurse of the family's physician.
_____C. Physical Therapist
_____D. Social Worker
_____E. I Don't Know

13. Which of the following factors will in part determine the extent of the physical disability of the child with Spina Bifida?

_____A. Whether or not a shunt must be inserted to prevent head enlargement.
_____B. The number of surgical procedures that must be performed before the child is one year old.
_____C. The amount of spinal cord tissue which is contained in the "sac" on the infant's back.
_____D. The level on the vertebral column where the defect occurs.
_____E. I Don't Know

14. Many doctors recommend to the parents of an infant born with Spina Bifida that they seek genetic counselling before planning to have another child. This is because:

_____A. The only way to prevent Spina Bifida is treatment of the genes of the parents.
_____B. The decision to have another child lies with the couple, but the parents should be aware of their individual risk factors.
_____C. Parents who have had one Spina Bifida child have an increased risk of having another.
_____D. I Don't Know

15. Some infants born with Spina Bifida will need to have daily routines of range-of-motion exercises or other special exercised prescribed for their specific problems. The doctor will either tell the parents how to do these exercises, or he will send the parents to a:

_____A. Urologist
_____B. Public Health Nurse
_____C. Physical Therapist
_____D. Neurologist
_____E. I Don't Know

THE FOLLOWING GROUP OF QUESTIONS DEAL WITH THE SPECIAL CARE THAT IS NEEDED BY INFANTS BORN WITH SPINA BIFIDA, AND WILL ASSUME FOR PURPOSES OF THE QUESTIONS, THAT THE CHILD SUFFERS FROM NO OTHER DEFECT OR ABNORMAL CONDITIONS.

16. When the child is first brought home from the hospital, a special surgeon may have removed the "sac" from the baby's back, leaving a surgical scar. When this is true, it is important while caring for the child that:

_____A. The child is not placed lying on his back at any time.
_____B. A rigid feeding schedule is maintained to prevent too much weight gain.
_____C. The child is treated like any other newborn, paying special attention to keeping the skin as clean and dry as possible.
_____D. The child is handled as little as possible to assure proper rest and recuperation.
_____E. I Don't Know

17. Parents are frequently cautioned by their doctors to watch the child closely for blisters, pressure marks from clothes that are too tight, and/or shoes that are too tight. Special attention must also be paid to the temperature of the bath water used for the child. These are important points for children with Spina Bifida because:

_____A. They tend to be less active than other children. This results in poor circulation to the feet and legs.
_____B. The lower extremities (feet, legs) are often insensitive to heat, cold, or pressure and they feel little or no discomfort in those areas of the body.
_____C. They frequently suffer malnutrition from not absorbing their food properly.
_____D. I Don't Know

18. Certain diseases and problems may be more dangerous to children with Spina Bifida than they would usually be to other children. Which of the following conditions would you report to the doctor very quickly if you were caring for a child with Spina Bifida?

_____A. A sudden increase in appetite or activity level
_____B. A fever not accompanied by a runny nose or signs of a head cold.
_____C. A small ulcer or open sore on the leg which the child is least able to move.
_____D. Drainage or discharge near or around the area where the "sac" was removed or around the "sac" if it has not been removed.
_____E. I Don't Know

19. As the child approaches the second half of the first year of life, most supervising physicians will want complete tests done on the child's bladder and kidneys. A physician specializing in problems of the kidneys and bladder is called a:

_____A. Urologist
_____B. Pathologist
_____C. Neurologist
_____D. Neurosurgeon
_____E. I Don't Know

20. As the Spina Bifida child gets older, bowel and bladder problems increase in importance. Sources of help with these prcblems include:

_____A. Nursing Consultants from the California Department of Public Health.
_____B. Nursing Specialists employed at some coordinated care clinics
_____C. The Pediatrician responsible for the care of the child
_____D. The Neurologist caring for the child
_____E. I Don't Know

HYDROCEPHALUS, (SOMETIMES CALLED "WATER HEAD" OR "WATER ON THE BRAIN") IS A SERIOUS CONDITION WHICH DEMANDS IMMEDIATE MEDICAL ATTENTION. THE NEXT SECTION OF QUESTIONS CONCERNS THIS SUBJECT.

21. The relationship between Hydrocephalus and Spina Bifida is described in which of the following statements?

_____A. Hydrocephalus is caused by Spina Bifida
_____B. Spina Bifida is caùsed by Hydrocephalus
_____C. Hydrocephalus and Spina Bifida always occur together.
_____D. Hydrocephalus occurs in about 70 to 80 per cent of all infants born with Spina Bifida
_____E. Hydrocephalus has no relationship to Spina Bifida
_____F. I Don't Know

22. Hydrocephalus results in rapid and excessive growth of the head of an infant and is due to:

_____A. Too much spinal fluid being produced in the brain.
_____B. A blockage of the passageway which the spinal fluid usually follows, causing it to collect in the brain.
_____C. Acute infection localized in the brain and spinal cord.
_____D. Deformity in the large, flat bones of the skull.
_____E. I Don't Know

23. When the head of an infant does start to enlarge more rapidly than normal, a surgical procedure called a "shunt" will probably be done on the baby. This shunt:

_____A. Allows the spinal fluid to drain down from the head to the heart or other parts of the body where it is absorbed.
_____B. Reduces the amount of cerebral spinal fluid produced by the brain.
_____C. Corrects the physical deformity which is causing the head to get bigger.
_____D. Provides for draining of the cerebral spinal fluid from the brain to the exterior (outside) of the body.
_____E. I Don't Know

24. In most infants who have "shunting" operations done, the shunt will need to be revised surgically one or more times. This is because:

_____A. As the head enlarges, a larger catheter is needed to drain the increased amount of fluid produced by the brain.
_____B. Infection
_____C. Obstruction of the tubing or catheter.
_____D. Normal growth of the child
_____E. I Don't Know

25. Danger signs indicating that the shunt is not working properly in a young infant include:

_____A. Loss of appetite
_____B. The soft spot on the baby's head may swell or seem "tight".
_____C. Vomiting
_____D. Irritability and increased activity level
_____E. I Don't Know

THIS ENDS THE SECTION ON HYDROCEPHALUS. PLEASE ANSWER THE LAST QUESTION NOW.

26. Various agencies are available to aid the family of a child with Spina Bifida. The agency most likely to be able to provide financial assistance for the medical expenses of the child is:

_____A. The Spina Bifida Parents' National Organization
_____B. The Crippled Childrens' Service of California
_____C. The nearest medical center
_____D. The Society for Crippled Children and Adults
_____E. I Don't Know

DEGREE OF DISABILITY RATING SCALE

INSTRUCTIONS TO RATERS: YOU WILL BE GIVEN SUMMARIES OF SEVERAL CLINICAL CASES OF CHILDREN WHO HAVE BEEN DIAGNOSED WITH SPINA BIFIDA. YOUR TASK WILL BE TO ASSIGN TO EACH CASE A TOTAL SCORE WHICH WILL INDICATE THE DEGREE OF DISABILITY ON A 5 TO 15 POINT SCALE WHERE 5 INDICATES LOW OR MINIMAL DISABILITY AND 15 INDICATES HIGH OR SEVERE DISABILITY. READ AND FOLLOW THE FOLLOWING DIRECTIONS CAREFULLY. THANK YOU FOR YOUR COOPERATION.

1. READ THROUGH THE ENTIRE SUMMARY FOR ONE CHILD. PAY CLOSE ATTENTION TO THE FOLLOWING FACTORS: A. HYDROCEPHALUS, B. NEUROLOGICAL INVOLVEMENT, C. UROLOGICAL STATUS, D. SURGICAL ORTHOPAEDIC PROCEDURES, AND, E. ABILITY TO AMBULATE, PRESENT OR POTENTIAL.

2. AFTER READING THE ENTIRE SUMMARY, GO BACK AND ASSIGN A NUMBER IN EACH OF THE FOLLOWING AREAS OF INVOLVEMENT AS INDICATED BELOW: PLACE THE NUMBER IN THE INDICATED SPACES ON THE ATTACHED SCORE SHEET.

A. HYDROCEPHALUS. ASSIGN:
   1 point, if none.
   2 points, if arrested spontaneously or by successful shunt(s).
   3 points, if untreated hydrocephalus, unsuccessful shunt, or severe infection of the shunt has occurred.

B. NEUROLOGICAL STATUS. ASSIGN:
   1 point, if apparently normal, or minimal flaccidity is demonstrated.
   2 points, if mild flaccidity or other deficit is present and/or no anal sensation is present.
   3 points, if moderate to severe flaccidity or other deficit and no anal sensation.

C. UROLOGICAL STATUS. ASSIGN:
1 point, if apparently normal.
2 points, if incontinent without acute or chronic infections, reflux, or severe skin breakdown with resulting complications.
3 points, if history of acute or chronic urinary infections, primary deformities or urinary tract and/or severe skin breakdown.

D. ORTHOPAEDIC PROCEDURES. ASSIGN:
1 point, if none required or performed.
2 points, if one or more has been performed or is needed.
3 points, if surgical intervention have failed to yield desired effects, or child is poor candidate for orthopaedic procedures.

E. AMBULATION. ASSIGN:
1 point, if independent ambulation is potential or achieved.
2 points, if independence with appliance is potential or achieved.
3 points, if complete dependence on others is potential or achieved.

SCORING SHEET: DEGREE OF DISABILITY RATING SCALE

INSTRUCTIONS TO RATERS: Use this sheet to record your rating assessments of the disability of each child according to the instructions on page 1.

CASE AA SCORES.

_____A. HYDROCEPHALUS
_____B. NEUROLOGICAL STATUS
_____C. UROLOGICAL STATUS _____TOTAL
_____D. ORTHOPAEDIC PROCEDURES SCORE
_____E. AMBULATION

CASE JSS SCORES.

_____A. HYDROCEPHALUS
_____B. NEUROLOGICAL STATUS
_____C. UROLOGICAL STATUS _____TOTAL
_____D. ORTHOPAEDIC PROCEDURES SCORE
_____E. AMBULATION

CASE DB SCORES.

_____A. HYDROCEPHALUS
_____B. NEUROLOGICAL STATUS
_____C. UROLOGICAL STATUS _____TOTAL
_____D. ORTHOPAEDIC PROCEDURES SCORE
_____E. AMBULATION

CASE TL SCORES

_____A. HYDROCEPHALUS
_____B. NEUROLOGICAL STATUS
_____C. UROLOGICAL STATUS _____TOTAL
_____D. ORTHOPAEDIC PROCEDURES SCORE
_____E. AMBULATION

CASE KT SCORES

_____A. HYDROCEPHALUS
_____B. NEUROLOGICAL STATUS
_____C. UROLOGICAL STATUS _____TOTAL
_____D. ORTHOPAEDIC PROCEDURES SCORE
_____E. AMBULATION

CASE RS SCORES

_____A. HYDROCEPHALUS
_____B. NEUROLOGICAL STATUS
_____C. UROLOGICAL STATUS _____TOTAL
_____D. ORTHOPAEDIC PROCEDURES SCORE
_____E. AMBULATION

APPENDIX B

INSTRUCTIONAL NURSING INTERVENTION

PROTOCOL AND SCRIPT FOR

AUDIO-VISUAL TOOL

INSTRUCTIONAL NURSING INTERVENTION PROTOCOL

The independent variable was defined as instructional nursing intervention. The planned program of teaching consisted of three periods of open-ended questions, reflective responses and information giving. Basic principles concerning etiology, pathology, treatment procedures and treatment devices were offered. Medical terminology was used only when it was essential to the understanding of the learners. Emphasis was placed on eliciting from the parents primary areas of concern and possible factors resulting in anxiety or guilt.

Teaching Session One: Problem Identification and Information Obtaining.

Objectives:

The parents will be able to:

(1) Recall the initial experiences surrounding the birth of the child.

(2) Recall the decision making process following the birth of the child.

(3) Share verbally with the investigator feelings concerning the handicapped child.

(4) Share verbally with the investigator feelings of their-self-image as parents of the handicapped child.

(5) Demonstrate awareness of the impact the malformed child has had on family life style.

(6) Demonstrate a willingness to investigate previous decisions and their implications.

(7) Demonstrate a willingness to explore their feelings and attitudes toward the malformed child.

The following statement will be used to introduce the discussion in the first session: "You remember we talked briefly

last time about the goals and purposes of these visits. One area that I wanted to discuss with you was that initial period when you learned that your baby had spina bifida."

STEM

1. WILL YOU RECALL FOR ME HOW YOU FELT AND ACTED WHEN YOU LEARNED SOMETHING WAS WRONG WITH YOUR BABY?
   Probes:
   a. Who first told you about your baby's condition?
   b. What information were you given at that time?
   c. Were you alone or with your (husband, mother, sister) when you were told about the problems?
   d. Who told you additional information about myelomeningocele?
   e. Try to remember for me your initial reactions.
   f. When did you first see the baby?
   g. Did you ever hold or touch the baby prior to surgery?
2. TELL ME ABOUT THE DECISION MADE CONCERNING WHETHER OR NOT TO HAVE _____TREATED.
   a. How was the decision made?
   b. Were you given any choice of treatment methods?
   c. What time limits were set as far as the surgery was concerned?
   d. How did you feel about the decision to do the surgery?
   e. How do you feel now? Would you want the same decision made?
   f. When did you first realize that the condition would have permanent effects--that it could not be "corrected"?
3. DOES ONE PARTICULAR HEALTH WORKER STAND OUT IN YOUR MEMORY AS BEING ESPECIALLY GOOD OR ESPECIALLY MISLEADING?
4. IN YOUR OPINION, IS THERE AN IDEAL TIME TO TELL PARENTS ABOUT THE INFANT?
5. IS THERE AN IDEAL WAY TO TELL PARENTS?

6. HOW INVOLVED IN THE DECISION CONCERNING THE TREATMENT OF THE CHILD DO YOU BELIEVE THE PARENTS SHOULD BE?

7. WHAT INFORMATION IS ABSOLUTELY ESSENTIAL FOR PARENTS TO HAVE PRIOR TO SIGNING A CONSENT FORM?

8. DO YOU THINK YOU WOULD MAKE THE SAME DECISION AGAIN IF YOU WERE TO HAVE ANOTHER CHILD WITH SPINA BIFIDA?

9. TELL ME SOME OF THE MAJOR WAYS _____HAS CHANGED YOUR LIFE.

10. HOW DO YOU FEEL ABOUT THE CHANGES THAT HAVE OCCURRED?

11. TELL ME ABOUT A TYPICAL DAY IN YOUR LIFE.

    a. Does there seem to be enough time to get everything done that you want to do?

    b. How do you manage so well?

Teaching Session Two: Information Giving and Interpreting.

Objectives:

A. When presented with a slide-casette constructed around a case study of the parents of a child with myelomeningocele, the parents will be able to:

    1. Identify information which was previously unknown to them.

    2. Identify similarities in the case presented and their experiences.

    3. Identify differences in the case presented and their experiences.

    4. Identify sources of aid and assistance which the family on the tape was unable to utilize.

    5. Analyze strengths in the family portrayed in the presentation.

    6. Analyze weaknesses in the family portrayed in the presentation.

B. During and following the discussion after the slide presentation and analysis the parents will be able to:

1. Examine a variety of viewpoints concerning medical treatment of severely malformed children.
2. Define and examine alternative possibilities for management of the affected child's condition.

Terminal behavior following second session:

Parents will begin to be able to extrapolate or extend beyond the situation given in the audio-visual presentation to explain the meaning of the implications, consequences, or effects inherent in the case presented and recognize possible implications for their own situation.

Method:

Presentation of slide-casette.

1. PLEASE SHARE SOME OF THE FEELING YOU WERE HAVING WHILE YOU WATCHED THE STORY. (If necessary, investigator might briefly and honestly share some of her feelings.)
   a. When do you remember being aware that spina bifida would have permanent effects and lifelong problems?
2. THE DIFFERENT TERMINOLOGY FOR THE CONDITION, MYELOMENINGOCELE, MENINGOMYELOCELE, SPINA BIFIDA CONFUSES SOME PARENTS. HOW DID YOU BECOME AWARE OF ALL THE NAMES?
   a. The names of all the persons caring for the spina bifida child--like the urologist, neurologist--all those sound so much alike confuses some parents. How did you learn these terms.
   b. Do you feel the explanation of what was being done to your baby--i.e. the back surgery, the shunt--was clear enough for you to understand?
3. THE PARENTS WERE CERTAINLY FRIGHTENED OF THE SURGICAL PROCEDURES. CAN YOU REMEMBER IF THIS WAS TRUE IN YOUR CASE?

4. SOME PARENTS ARE SURPRISED TO LEARN ABOUT THE DECREASED SKIN SENSITIVITY COMMON IN THE CHILD WITH SPINA BIFIDA. CAN YOU REMEMBER ANY TIMES WHEN IT WAS A PROBLEM TO YOU?

   a. Problems with casts?

   b. Problems with shoes?

   c. Hot water or concrete?

5. THE BLADDER AND BOWEL MANAGEMENT FOR THE CHILD WITH A SPINA BIFIDA IS CERTAINLY A CONCERN FOR MOST PARENTS. WHAT PROBLEMS ARE YOU ANTICIPATING THAT YOU MIGHT HAVE IN THIS AREA?

6. THE PARENTS AND PHYSICIAN DECIDED THAT THE BABY IN THE FILM SHOULD HAVE IMMEDIATE CLOSURE OF THE SPINAL DEFECT. HOW DO YOU FEEL ABOUT EARLY TREATMENT OF SPINA BIFIDA INFANTS?

   a. Do you believe the average family can cope with all the problems of the spina bifida child and come out all right?

7. IN MANY RESPECTS THE CHILD IN THE FILM WAS LIKE _____. COULD YOU TELL ME ABOUT THE SIMILARITIES YOU SAW?

   a. The differences...

8. HOW DID YOU FEEL ABOUT THE WAY THE DOCTOR AND NURSES ACTED IN THE SLIDES?
   a. Would such activities have been helpful to you?

   b. Who did you get most of your information from?

   c. What information would you have like to have right after _____'s birth?

   d. Did you have a public health nurse come to your home?

      1. What did you see the purpose of her visits to be?

      2. Was the purpose accomplished?

      3. Do you think home visits by a public health nurse would be of any benefit now?

9. WHAT DID YOU THINK THE FAMILY ON THE SLIDES HAD GOING FOR THEM?

   a. Could you see any strengths they displayed?

   b. They didn't always agree. How do you feel about that?

   c. Were they in any way like you and your husband?

10. WHAT WOULD HAVE BEEN THE MOST HELP TO THE FAMILY IN THE STORY?

    a. Is there anything the family members themselves could do?

    b. Is there anything outside agencies or persons could do?

11. WHAT WAS THE BIGGEST PROBLEM YOU HAD IN THE FIRST FEW MONTHS AFTER _____'s BIRTH?

    a. (If no response,--Some families believe the financial problems were greatest, some transportation, some lack of information concerning child and condition, some have problems with depression and worry. Did any of these happen to you?)

12. HOW DO YOU FEEL THE FAMILY ON THE TAPE WILL GET ALONG AS THE CHILD GROWS OLDER?

    a. Can you predict problems?

    b. Can you see sources of help?

Session Three: Review and Application.

Terminal objectives:

Parents receiving the experimental treatment will be able to verbally identify the problems directly relating to parents of children with spina bifida. They will be able to identify themselves as parents of a handicapped child and will be able to assess their family strengths, weaknesses, and potential problems.

Objectives:

The parents will:

1. Develop an awareness of the universality of many of the problems affecting parents of spina bifida children.
2. Develop an awareness of possible sources of help.
3. Be able to correctly use the appropriate terminology associated with spina bifida.

4. Demonstrate knowledge of areas of inadequate information or controversy in management of spina bifida.
5. Demonstrate a willingness to examine their own feelings and concerns related to the child with spina bifida.
6. Demonstrate an ability to build on past experiences.
7. Express satisfaction that can arise from giving good care to the child.
8. Be able to risk discussing possible future plans for child and family.
9. Express interest in seeking additional information concerning spina bifida.
10. Be able to feel a member of a group which can undertake solutions of common problems.

Method:

This session will start with a review of the pathology, etiology, treatment methods and main problems encountered by parents of children with spina bifida. A sample beginning would be:

WE HAVE SPENT TWO SESSIONS TALKING ABOUT THE CONDITON WHICH AFFECTS _____. I WOULD LIKE TO REVIEW SOME OF THE ITEMS WE HAVE DISCUSSED.

Spina bifida
- mild - occulta
- with no spinal cord involvement - meningocele
- spinal cord involvement - myelomeningocele or meningomyelocele

Terminology of health care workers
- urologist
- neurologist
- neurosurgeon
- pediatrician
- orthopedic surgeon
- social worker

Cause of spina bifida
    genetic considerations; prenatal diagnosis; multifactor cause

Defects involved
    vertebral
    muscles
    nervous tissue
    defect leading to hydrocephalus
    skin
    bones

Treatment plans
    no treatment - probable results
    conservative treatment
    aggressive treatment

Long term care considerations
    sources of help
        parents' groups
        clinics

LAST SESSION WE LOOKED AT SOME SLIDES OF A FAMILY WHOSE CHILD HAD SPINA BIFIDA, AND TALKED ABOUT HOW SOME OF THEIR PROBLEMS WERE LIKE SOME OF YOURS AND SOME WERE NOT.

1. FIRST OF ALL, IS THERE ANYTHING YOU WOULD LIKE TO DISCUSS FURTHER?

    a. Have you thought of any questions you would like to ask?

    b. Has anything happened this week that brings any fresh thoughts to your mind?

2. I WOULD LIKE FOR YOU TO SHARE WITH ME ANY REACTION YOU HAVE CONCERNING THE INFORMATION THAT HAS BEEN GIVEN TO YOU OR ABOUT OUR DISCUSSIONS.

    a. Were you surprised that there were so many other people in the same situation that you are in?

    b. Can you think of any of the information that was particularly interesting or useful to you?

3. PERHAPS YOU WOULD LIKE TO TALK ABOUT A SPECIAL OR UNUSUAL PROBLEM YOU OR YOUR FAMILY HAS?

    a. I remember on _____ that you mentioned _____. Would you like to say any more about that at this time?

    b. Do you see this relating to the problem that the family on the slide presentation had? How is it different?

4. I WOULD LIKE FOR YOU TO TRY TO PREDICT, IF YOU CAN, WHAT THE MOST CRUCIAL PROBLEM YOU SEE FACING YOU IN THE FUTURE THAT RELATES TO _____AND HIS CARE.

5. WOULD YOU PLEASE GIVE ME ANY REACTIONS YOU MIGHT HAVE TO THE SESSIONS WE HAVE HAD?

6. CAN YOU TELL ME WHAT YOU FEEL ARE YOUR GREATEST NEEDS AND CONCERNS AT THE PRESENT TIME?

   a. Do you see any possible sources of help or assistance?

   b. What would be of the most assistance to you, assuming that it could be made available?

STORY BOOK FOR THE AUDIO VISUAL PORTION OF INDEPENDENT VARIABLE

NARRATOR THE STORY YOU ARE ABOUT TO SEE AND HEAR IS ABOUT A FAMILY...IT COULD BE A FAMILY YOU KNOW...A FAMILY ACROSS THE STREET...OR, INDEED...IT COULD BE YOUR FAMILY. THERE IS ONE VERY SPECIAL THING ABOUT THIS FAMILY. TIMMY, THE YOUNGEST CHILD, WAS BORN WITH SPINA BIFIDA. THIS IS REALLY TIMMY'S STORY.

MARY AND GEORGE ROBRETSON WERE PLEASED WHEN MARY LEARNED SHE WAS PREGNANT. THEIR ONLY CHILD, JUDY, WAS THREE YEARS OLD, AND GEORGE AND MARY THOUGHT IT WAS A GOOD TIME FOR A SECOND CHILD. MARY'S PREGNANCY WAS ENTIRELY NORMAL, AND AS THE EXPECTED DATE DREW NEAR, MARY BECAME ANXIOUS TO BEGIN LABOR AND LEARN IF THE BABY WAS A BOY OR A GIRL. SHE WENT HAPPILY TO THE HOSPITAL WHEN HER LABOR BEGAN, LEAVING JUDY WITH GEORGE'S MOTHER.

LABOR LASTED ONLY FIVE HOURS, AND SHE BREATHED A SIGH OF RELIEF WHEN SHE HEARD THE BABY'S FIRST CRY.

MARY IS IT ANOTHER GIRL OR DID I GET MY BOY?

DOCTOR #1 MARY, YOU AND GEORGE HAVE A BOY, BUT WE ARE GOING TO HAVE TO HURRY HIM RIGHT INTO THE NURSERY. IT LOOKS LIKE HE WILL HAVE TO HAVE SOME SURGERY ON HIS BACK.

MARY WH-WHAT? WILL HE BE ALL RIGHT?

DOCTOR #1 MARY, TO TELL THE TRUTH, I'LL HAVE YOUR PEDIATRICIAN LOOK AT THE BABY RIGHT AWAY, AND THEN WE CAN TELL YOU MORE. RIGHT NOW, YOU JUST LAY BACK AND CONCENTRATE ON RESTING... WE'LL TAKE GOOD CARE OF YOUR BABY.

NARRATOR WHEN MARY WAS BACK IN HER ROOM AND GEORGE HAD ARRIVED, SHE RESTED FOR A FEW HOURS. DR. GREGORY, THEIR PEDIATRICIAN, AND ANOTHER DOCTOR THEY DID NOT KNOW, CAME INTO THE ROOM. LET'S LISTEN AS THEY TALK WITH THE NEW PARENTS.

DR. GREGORY MARY...GEORGE...THIS IS DR. PARKER...HE IS A SPECIALIST IN NEUROSURGERY. WE HAVE BOTH JUST COME FROM EXAMINING YOUR BABY...THERE IS NO WAY TO MAKE THIS NEWS EASY FOR YOU... THE BABY HAS A CONDITION THAT IS CALLED SPINA BIFIDA OR MYELOMENINGOCELE. I'LL EXPLAIN AS WELL AS I CAN WHAT THAT MEANS.

NARRATOR AS DR. GREGORY TALKED, HE MADE SOME SKETCHES ON A PAD OF PAPER HE HAD WITH HIM. WHAT HE TOLD THE PARENTS AND THE DRAWINGS HE MADE LOOKED SOMETHING LIKE THIS:

ON THE LEFT IS A PICTURE OF A NORMAL VERTEBRAL COLUMN...WE KNOW THAT AS OUR BACKBONE. ON THE RIGHT IS A NORMAL VERTEBRA...THAT'S THE BONY UNITS IN THE SPINE. NOTICE HOW THEY NORMALLY PROTECT THE SPINAL CORD FROM INJURY OR DAMAGE BY COMPLETELY SURROUNDING THE SPINAL CORD AND NERVOUS TISSUE WITH BONE. IN BABIES WITH SPINA BIFIDA, ONE OR MORE OF THE VERTEBRAE FAIL TO FORM CORRECTLY...SO THAT THERE IS AN OPENING IN THE BONY STRUCTURE, AND PART OF THE SPINAL CORD IS NOT COVERED WITH BACKBONE, BUT ONLY WITH TISSUE...IN VERY SIMPLE CASES OF SPINA BIFIDA, THE DEFECT MAY NOT EVEN BE NOTICED...THE SPINAL CORD IS NORMAL AND THE SKIN IS FULLY INTACT...

NARRATOR, CONTD. IN OTHER CASES, THERE IS A PROTRUSION, MUCH LIKE A HERNIA, OUT THROUGH THE OPENING IN THE VERTEBRA, AND A "SAC" DEVELOPES ON THE OUTSIDE OF THE BODY...COVERED ONLY BY THE MEMBRANES WHICH USUALLY, COVER THE SPINAL CORD. IF THE SPINAL CORD IS NORMALLY DEVELOPED AND NERVE IMPULSES CAN GET THROUGH, THIS IS CALLED A MENINGOCELE. SO BRIEFLY, IN A MENINGOCELE, WE HAVE:

A DEFECT IN THE VERTEBRA...

A SAC PRESENT ON THE OUTSIDE OF THE BODY

A NORMAL SPINAL CORD

NERVE IMPULSES ARE ABLE TO GET THROUGH AND THE DEFECT IS USUALLY MINIMAL.

OTHER TIMES THE SPINAL CORD IS MALFORMED AND THERE IS SPINAL CORD AND NERVOUS TISSUE INVOLVED IN THE SAC...ALONG WITH CEREBRAL SPINAL FLUID. THIS IS CALLED MYELOMENINGOCELE. THAT'S WHY THE PEDIATRICIAN ASKED DR. PARKER...WHO IS A SPECIALIST IN NEUROSURGERY, TO EXAMINE THE BABY. LET'S LISTEN AS DR. PARKER TALKS TO THE PARENTS.

DR. PARKER YOUR BABY'S DEFECT IS DOWN AROUND THE SMALL OF HIS BACK. WE CALL THAT A LUMBAR DEFECT. WE CAN NEVER BE ABSOLUTELY SURE JUST HOW EXTENSIVE THE DEFECT IS OR HOW MUCH CORD INVOLVEMENT THERE IS. THERE IS A SAC ON THE BACK FULL OF SPINAL FLUID...AND MY EXAMINATION HAS CONVINCED ME THAT THERE IS ALSO MENINGES AND ABNORMAL SPINAL CORD TISSUE...SO IN MYELOMENINGOCELE, IN ADDITION TO THE DEFECTIVE VERTEBRAE, AND THE SAC OF FLUID...THERE IS ALSO ABNORMAL SPINAL CORD...AND

DR. PARKER, CONTD. THE NERVE IMPULSES DO NOT GET THROUGH TO THE LOWER PARTS OF THE BODY. THIS WILL NEED ATTENTION LATER, BUT RIGHT NOW OUR BIGGEST PROBLEM IS TO PREVENT INFECTION...THE MYELOMENINGOCELE SAC IS NOT OPEN OR LEAKING, BUT IT'S LIKELY THAT IT WILL OPEN AND IF THIS HAPPENS, INFECTION RESULTS. MENINGITIS OR ENCEPHALITIS MAY ENDANGER THE BABY'S LIFE. ALTHOUGH THERE IS SOME DISAGREEMENT AMONG DOCTORS, MY EXPERIENCE HAS BEEN THAT THE BEST WAY TO PREVENT INFECTION IS TO SURGICALLY REMOVE THE SAC AS SOON AS POSSIBLE.

NARRATOR NO MATTER HOW HARD MARY AND GEORGE LISTENED TO WHAT WAS BEING SAID TO THEM, AND NO MATTER HOW HARD THEY TRIED TO UNDERSTAND, NONE OF IT MADE SENSE TO THEM, AND THEY FELT TERRIBLY CONFUSED. MARY STARTED TO CRY, AND ASKED THE QUESTION BOTH SHE AND GEORGE HAD ON THEIR MINDS.

MARY BUT AFTER YOU DO THE SURGERY, DOCTOR, HE'LL BE ALL RIGHT, WON'T HE? YOU CAN FIX IT, CAN'T YOU?

DR. PARKER BABIES WITH SPINA BIFIDA DO NOT HAVE MUCH CHANCE OF BEING COMPLETELY NORMAL...THERE IS A GOOD CHANCE TO SAVE THE BABY'S LIFE IF WE OPERATE SOON...ALTHOUGH I CAN'T EVEN PROMISE YOU THAT. IF WE <u>DON'T</u> OPERATE, HIS CHANCES OF SURVIVAL PAST INFANCY ARE LESS THAN 15%.

MARY WHAT DO YOU MEAN, "COMPLETELY NORMAL?" WHAT WILL BE WRONG WITH HIM AFTER YOU OPERATE?

NARRATOR BOTH DOCTORS ATTEMPTED TO EXPLAIN TO THE PARENTS SOME OF THE PATHOLOGY INVOLVED IN SPINA BIFIDA. THEY EXPLAINED HOW NERVES COME TO THE MUSCLES FROM THE SPINAL CORD AND

NARRATOR, CONTD. TRANSMIT IMPULSES FROM THE BRAIN. THAT IS HOW THE MUSCLES ARE ABLE TO CONTRACT AND RELAX...AND THE ARMS, LEGS, AND OTHER PORTIONS OR THE BODY ARE ABLE TO MOVE. THE BRAIN BECOMES AWARE OF HEAT, COLD, PAIN, AND TOUCH BY THE IMPULSES TAKEN FROM THE SKIN TO THE BRAIN BY THE SPINAL CORD...

IN MYELOMENINGOCELE, SOME OF THIS NERVOUS SYSTEM HAS NOT PROPERLY DEVELOPED. DEPENDING SOMEWHAT ON THE LOCATION OF THE SAC, AND THE AMOUNT OF NERVOUS TISSUE THAT IS INVOLVED, THE BABIES MAY NOT BE ABLE TO MOVE THE MUSCLES IN THEIR LEGS, THIGHS, OR FEET. THEY ALSO MAY BE UNABLE TO FEEL SENSATIONS SUCH AS HEAT OR COLD. HOWEVER, THE UPPER PART OF THE BODY IS USUALLY NORMAL. THE LACK OF SENSATION AND MUSCLE WEAKNESS USUALLY INVOLVES THE AREA BELOW WHERE THE SAC OF THE MYELO-MENINGOCELE OCCURS. SO THAT THE ARMS, CHEST, AND SHOULDERS, WITH PROPER TRAINING, CAN BE VERY STRONG. DR. GREGORY DIS-CUSSES THIS WITH MARY AND GEORGE.

DR. GREGORY THE BABY IS FORTUNATE IN AS MUCH AS THE LESION IS RELATIVELY LOW ON THE BACK. AND WE THINK WE DETECTED SOME MOVEMENT AND SENSATION IN THE THIGHS...THESE ARE GOOD SIGNS. THE FEET ARE CLUBBED AND WILL NEED SOME ATTENTION LATER. THAT'S QUITE COMMON IN SPINA BIFIDA CHILDREN...WITH SOME CASTING AND BRACING, SOME WILL WALK INDEPENDENTLY.

GEORGE ARE YOU SAYING HE MAY NEVER <u>WALK</u>?

DR. GREGORY THAT IS A POSSIBILITY. HOWEVER, WITH SOME MOVEMENT IN THE THIGHS, THERE IS A STRONG POSSIBILITY THAT WITH PROPER CARE AND TRAINING HE WILL WALK WITH SOME KIND OF BRACING OR CRUTCHES...IF WE CAN AVOID OTHER COMPLICATIONS.

GEORGE WHAT OTHER COMPLICATIONS?

DR. GREGORY THERE ARE TWO MAJOR PROBLEMS THESE CHILDREN OFTEN HAVE, AND WE WILL JUST HAVE TO WATCH CLOSELY AND TREAT THEM AS THEY DEVELOP...ONCE THE SAC HAS BEEN SURGICALLY REMOVED AND THE INCISION HEALED.

THE BABY HAS A STRONG POSSIBILITY OF HAVING BOWEL AND BLADDER PROBLEMS ALL HIS LIFE. BECAUSE OF THE LOSS OF SENSATION, A CHILD WITH SPINA BIFIDA NEVER KNOWS WHEN HIS BLADDER IS FULL, AND THE REFLEX ACTION WHICH MAKES TOILET TRAINING POSSIBLE DOES NOT OCCUR. THERE ARE SPECIAL DOCTORS CALLED UROLOGISTS TO HELP YOU WITH THESE PROBLEMS. AGAIN, THE SEVERITY OF THE PROBLEM VARIES WITH THE CHILD AND THE LESION, BUT IF IT IS A SERIOUS PROBLEM AND PROPER CARE IS NOT GIVEN, THE BLADDER MAY OVERFLOW AND LEAK MOST OF THE TIME. CONTINUAL PRESSURE CAUSES CHANGES IN THE KIDNEYS AND THE TUBES THAT CARRY THE URINE FROM THE KIDNEYS TO THE BLADDER. WHEN THE KIDNEY TISSUE IS DAMAGED, THE CHILD CAN BE IN SERIOUS TROUBLE. YOU'LL JUST HAVE TO SEE THAT THE BABY GETS VERY CLOSE MEDICAL SUPERVISION.

GEORGE MY GOD, IS THERE MORE?

DR. GREGORY GEORGE, I KNOW YOU AND MARY MUST BE COMPLETELY OVER-WHELMED BY ALL THIS...BUT THERE IS MORE THAT YOU NEED TO KNOW. DR. PARKER WILL EXPLAIN.

DR. PARKER A HIGH PERCENTAGE OF THESE BABIES...POSSIBLY 70-80 PER CENT, WILL DEVELOP HYDROCEPHALUS. YOU MAY KNOW THIS AS "WATER ON THE BRAIN."...THIS IS A CONDITION CAUSED BY A

DR. PARKER, CONTD. COLLECTION OF CEREBRAL SPINAL FLUID WITHIN THE HEAD...AND IT CAUSES RAPID EXPANSION OF THE HEAD SIZE BECAUSE THERE IS INTERFERENCE WITH THE CIRCULATION AND ABSORPTION OF THE FLUID. THE SPINAL FLUID IS PRODUCED IN THE BRAIN AND BECAUSE OF AN ABNORMALITY...IT DOES NOT DRAIN DOWN LIKE IT SHOULD AND IT IS TRAPPED THERE.

GEORGE HE'LL HAVE A BIG WATER HEAD?

DR. PARKER NO, NOT NECESSARILY. YOUR BABY'S HEAD IS QUITE NORMAL IN SIZE NOW. WE'LL JUST HAVE TO WATCH IT CLOSELY AND IF IT SHOWS ANY SIGNS OF INCREASING TOO FAST, WE HAVE SOME VERY SUCCESSFUL WAYS OF TREATING THIS. IT WOULD MEAN ADDITIONAL SURGERY, HOWEVER...THE QUESTION RIGHT NOW IS "DO WE DO SURGERY ON THE BACK AND TRY TO SAVE THIS BABY'S LIFE OR NOT?"

MARY WAIT,...I CAN'T THINK RIGHT NOW...WHAT IF THE SURGERY ON THE BACK IS NOT DONE?

DR. GREGORY AS WE SAID MARY, THERE IS A CHANCE THE BABY WOULD SURVIVE IF NO SURGERY IS DONE. THE SAC MAY HEAL OVER, AND WE MIGHT BE ABLE TO CONTROL THE INFECTION WITH MEDICATIONS ALONE. HOWEVER, THE CHANCE OF INFECTION WITHOUT SURGERY IS VERY GREAT...EVERY INFECTION REDUCES THE CHILD'S CHANCES OF LIVING...OR BEING A PRODUCTIVE HUMAN BEING IF HE DOES LIVE.

GEORGE AND WITH THE SURGERY, HE'LL BE A CRIPPLE ALL HIS LIFE, AND MAYBE HAVE THIS...HEAD PROBLEM AND KIDNEY PROBLEM?

DR. GREGORY THOSE ARE POSSIBILITIES, GEORGE...YOU HAD TO KNOW ABOUT THEM. THE TRUTH IS THAT THERE IS NO WAY OF KNOWING AT THIS MOMENT JUST WHAT THE POTENTIAL OF THE BABY MIGHT BE. SOME CHILDREN ARE MORE SEVERELY AFFECTED THAN ORIGINALLY THOUGHT. BUT IN SOME CASES, JUST THE OPPOSITE IS TRUE.

MARY CAN YOU LEAVE US ALONE FOR AWHILE NOW? I THINK WE WOULD LIKE TO BE ALONE...BUT DON'T GO AWAY...WE WILL HAVE MORE QUESTIONS, I'M SURE.

NARRATOR GEORGE AND MARY WERE LATER TO AGREE THAT THIS WAS THE MOST DIFFICULT DECISION THEY EVER HAD TO FACE. AT FIRST THEY SIMPLY SAT...DAZED. GEORGE WAS THE FIRST TO SPEAK.

GEORGE THERE MUST BE SOME MISTAKE. MAYBE THEY HAVE THE BABIES MIXED UP IN THE NURSERY. OUR LITTLE JUDY IS COMPLETELY NORMAL...HOW COULD A THING LIKE THIS HAPPEN TO OUR SON?

MARY I WONDER WHAT CAUSED IT...DID I DO SOMETHING THAT HURT THE BABY WHILE I WAS PREGNANT? I TRIED NOT TO SMOKE TOO MUCH...ONLY AT THE LAST...OH, THERE WAS THAT FALL I TOOK WHEN I WAS 3 MONTHS PREGNANT...GEORGE, DO YOU THINK THAT COULD HAVE DONE IT?

GEORGE MARY, IT DOESN'T MATTER NOW WHAT CAUSED IT. WHAT ARE WE GOING TO DO?

NARRATOR GEORGE AND MARY HAD NO WAY OF KNOWING AT THAT TIME THAT NOTHING MARY HAD DONE HAD AFFECTED THE CHILD. THE CAUSE OF SPINA BIFIDA IS NOT KNOWN. THERE ARE MANY DIFFERENT THEORIES, BUT THE BEST INFORMATION SEEMS TO INDICATE THAT A

NARRATOR, CONTD. COMBINATION OF FACTORS...GENETIC, ENVIRONMENTAL, POSSIBLY DIETARY...WORK TO RESULT IN SPINA BIFIDA. CASES OF TWINS HAVE BEEN RECORDED, ONE WITH SPINA BIFIDA, ONE NORMAL.

ON THE OTHER HAND, IT IS KNOWN THAT PARENTS, WHO HAVE HAD ONE SPINA BIFIDA CHILD, RUN AN INCREASED RISK OF HAVING ANOTHER. MUCH RESEARCH IS BEING DONE, AND MUCH IS STILL TO BE LEARNED. ONE THING IS CERTAIN, HOWEVER, THE DEFECT OCCURS SO EARLY IN PREGNANCY, PROBABLY DURING THE FIRST 4 WEEKS, THAT NOTHING MARY DID DURING PREGNANCY COULD HAVE CAUSED THE INFANT'S CONDITION.

SHORT MUSIC INTERLUDE

MARY THE HARDEST DECISIONS ARE THOSE WHERE THERE IS NO AGREED RIGHT OR WRONG. THIS IS NEARLY ALWAYS THE CASE WITH INFANTS WITH SPINA BIFIDA BECAUSE OF THE MANY, MANY UNKNOWN FACTORS INVOLVED WITH EACH CHILD, EACH DEFECT, AND EACH FAMILY.

IN TIMMY'S CASE, GEORGE AND I DECIDED TO PERMIT THE SURGERY ON TIMMY'S BACK, SETTING INTO MOTION A WHOLE CHAIN OF EVENTS WHICH WERE TO CHANGE THE LIFE OF OUR ENTIRE FAMILY. ONCE THE LESION WAS REMOVED FROM HIS BACK AND HEALING HAD BEGUN, I WAS ALLOWED TO HOLD AND CARE FOR TIMMY. BEFORE THEY LET US TAKE TIM HOME FROM THE HOSPITAL, HIS BACK WAS HEALED AND HE COULD BE PLACED ON HIS STOMACH OR BACK LIKE ANY OTHER BABY. IN FACT, THE NURSE EXPLAINED THAT IT WAS IMPORTANT THAT HE BE HANDLED AND LOVED AND CARED FOR LIKE ANY OTHER NEWBORN. I NEVER THOUGHT I COULD DO IT, BUT I DID.

NARRATOR THE DOCTOR SHOWED MARY SOME EXERCISES THAT SHE WAS TO DO WITH TIMMY'S FEET AND LEGS EVERY TIME SHE CHANGED HIS DIAPER. THIS WAS TO PREVENT ANY LOSS OF MUSCLE TONE, DUE TO TIMMY'S INABILITY TO MOVE HIS LEGS. LATER, A PHYSICAL THERAPIST WOULD HELP MARY WITH MORE COMPLICATED, BUT VERY IMPORTANT EXERCISES AND MOVEMENTS WHICH TIMMY NEEDED.

MARY WAS CAUTIONED BY THE NURSE TO BE VERY CAREFUL OF THE TEMPERATURE OF TIMMY'S BATH WATER, BECAUSE OF THE DANGER OF BURNING HIS INSENSITIVE SKIN. SHE WAS SHOWN HOW TO KEEP THE AREA OF THE BACK THAT HAD BEEN OPERATED ON ESPECIALLY CLEAN AND DRY. NOW LET'S LISTEN AS MARY TALKS ABOUT THEIR NEXT PROBLEM. (PAUSE)

MARY THE DAY SOON CAME THAT WE HAD BEEN DREADING. ON TIMMY'S SECOND ROUTINE CHECKUP, THE NEUROSURGEON SAID:

DR. PARKER I'M AFRAID THE BABY'S HEAD IS GROWING MUCH TOO RAPIDLY NOW. WE WILL HAVE TO DO SURGERY TO PREVENT DAMAGE.

MARY DR. PARKER SHOWED ME THE SOFT SPOTS ON TIMMY'S HEAD. THEY SEEMED TIGHT AND BULGING. HE ALSO SHOWED ME A CHART OF TIMMY'S HEAD GROWTH THAT COMPARED IT WITH THE NORMAL GROWTH OF A BABY'S HEAD...I WAS SO CONCERNED...I HAD TO ASK...WHAT WILL YOU HAVE TO DO TO HIM?

DR. PARKER WE'LL USE WHAT IS CALLED A SHUNTING PROCEDURE. WE WILL PLACE A TINY TUBE INSIDE THE BRAIN CAVITY AND BRING IT OUTSIDE THE SKULL UNDER THE SKIN AND BEHIND THE EAR, THEN IT WILL BE PLACED INTO A VEIN GOING TO THE HEART, OR INTO THE ABDOMINAL CAVITY. THIS SHUNT WILL ALLOW THE SPINAL

DR. PARKER CONTD. FLUID TO DRAIN FROM THE BRAIN WHERE MOST OF IT IS PRODUCED ...DOWN OUT OF THE HEAD AND INTO A PLACE WHERE THE BODY CAN ABSORB IT HARMLESSLY. EVERY BABY IS A LITTLE DIFFERENT AND SURGEONS PLACE THE TUBES WHERE THEY BELIEVE IT WILL DO THE INDIVIDUAL BABY THE MOST GOOD. I HAVE HAD THE MOST SUCCESS PASSING THE TUBES INTO A VEIN GOING TO THE HEART...I KNOW IT SOUNDS COMPLICATED...AND IT IS VERY DELICATE...BUT IT HAS BEEN DONE THOUSANDS OF TIMES ON CHILDREN JUST LIKE YOURS WITH GREAT SUCCESS.

NARRATOR AFTER GIVING THEIR PERMISSION FOR THE OPERATION, MARY AND GEORGE HAD MORE ANXIOUS HOURS OF WAITING FOR THE OUTCOME OF THE SURGERY. AFTER THE SURGERY WAS OVER, HOWEVER, TIMMY SEEMED JUST AS HE HAD BEFORE THE SURGERY, EXCEPT MARY COULD FEEL THE TUBE BEHIND HIS RIGHT EAR AND WAS SHOWN WHERE THE TINY VALVE WAS LOCATED THAT KEPT THE FLUID GOING FROM THE BRAIN TO THE HEART.

MARY NOW TELLS US OF HER FEELINGS AFTER TIMMY'S SURGERY.

MARY AT FIRST I WAS SCARED TO EVEN TOUCH TIMMY'S HEAD, AND TO TELL THE TRUTH, I GUESS I NEVER COMPLETELY GOT OVER MY FEAR OF HURTING HIM. BUT I ALSO BECAME QUITE PROUD OF THE WAY I CARED FOR TIMMY. WATCHING FOR THE DANGER SIGNS OF THE SHUNT NOT WORKING WHICH THE DOCTORS TAUGHT ME, JUST BECAME A ROUTINE PART OF TIMMY'S CARE.

NARRATOR: TIMMY'S STORY IS A SUCCESSFUL ONE. THE SHUNT WAS REVISED JUST ONCE, AND THE HEAD STAYED WELL WITHIN NORMAL LIMITS. DR. GREGORY RECOMMENDED A COORDINATED CARE CLINIC WHERE MARY AND GEORGE CONSCIENTIOUSLY TOOK TIMMY--SOMETIMES EVERY MONTH, SOMETIMES EVERY 2 OR 3 MONTHS. WORKING WITH THE SPECIALISTS INVOLVED WITH TIMMY'S CARE, MARY AND GEORGE SLOWLY BEGAN TO UNDERSTAND MORE FULLY TIMMY'S CONDITION AND THE PROBLEMS HE FACED.

THEY JOINED A SPINA BIFIDA PARENTS GROUP AND LEARNED, MUCH TO THEIR SURPRISE, THAT THERE WERE SEVERAL CHILDREN WITH SPINA BIFIDA IN AND AROUND THEIR OWN COMMUNITY. THEY ALSO LEARNED THAT WHILE CHILDREN WITH SPINA BIFIDA HAVE MANY COMMON AND SIMILAR PROBLEMS, EACH CHILD IS A SPECIAL INDIVIDUAL WITH UNIQUE PROBLEMS AND POTENTIALS. THEY HAVE LEARNED THAT THE DECISIONS TO TREAT EACH CHILD, AND THE DECISIONS ABOUT THE CARE OF EACH CHILD HAVE TO BE TAILOR MADE TO EACH CASE.

MARY AND GEORGE HAVE NEVER REGRETTED THEIR DECISION TO TREAT AND CARE FOR TIMMY, AND TIMMY'S DISABILITY IS MINIMAL. NOT ALL CHILDREN AND NOT ALL PARENTS OF SPINA BIFIDA CHILDREN ARE SO FORTUNATE...SOMETIMES, THEY DO STOP TO WONDER WHAT LIFE WOULD BE LIKE IF TIMMY HAD NOT BEEN A "SPECIAL CHILD."

APPENDIX C

LETTERS OF INTRODUCTION

AND CONSENT FORMS

N-605, School of Nursing
University of California
3rd. and Parnassus
San Francisco, California 94143

Dear Parent,

My name is Pat Scearse. I am a registered nurse and have for many years been doing public health nursing and teaching student nurses. Now I am a graduate student in Nursing at the University of California, San Francisco Medical Center.

I am very interested in the problem that affects your child, and the many problems that his condition may cause for you and your family. Unfortunately, not much has been written in the nursing textbooks about children with spina bifida and the particular problems they have. Much information is needed so that nurses and other professionals can better help the child with spina bifida, his parents, and family.

Because of my interest and because of the need for information, I would like very much for you to help me in a study I am doing as part of my school work. I have talked to the doctors who have treated _____, at_____ and they approve of my study and of your participation in it.

If you were to agree to help in the study, you would give me permission to visit you several times AT YOUR CONVENIENCE and would allow me to talk with you concerning some of your experiences and to interview you about some of the problems you may have had. We will have time to talk about any questions you may have about spina bifida, the care that is involved with the child, and to share some of the concerns you may feel.

You will be asked to take some simple tests which would be about spina bifida and about your attitudes toward family life...I would like to talk with you about this and answer all your questions concerning the study, so I will contact you by telephone very soon. Please think about doing this so that together we can collect some of the much needed information about the spina bifida child and his family.

Thank you.

UNIVERSITY OF CALIFORNIA
San Francisco
ACADEMIC SENATE

July 18, 1973

Patricia D. Scearse, R.N., PHN, M.S.
School of Nursing
631 D Nursing Building

Dear Ms. Scearse:

The Committee on Human Experimentation has approved your protocol, "A study to investigate the Effects of Instructional Nursing Intervention During Home Visits to parents of Spina Bifida Children" with the revised consent form and your letter of 17 July.

The number assigned this approval is 932701. This number should be included on all correspondence concerning this protocol and it must appear on all patient consent forms to be signed and on all patient charts involved.

The expiration date of this approval is July 18, 1974. If this project is to continue beyond that date, please submit an updated protocol in advance for the Committee's re-appraisal. If this protocol is used in conjunction with any other human experimentation or if it is modified in any way it must be re-approved for those special circumstances. In addition, the Committee requests prompt notification of any complications which occur during any experimental procedure.

Sincerely,

William K. Ehrenfeld, M.D.,
Vice-Chairman
Committee on Human Experimentation

ew

CC: Contracts and Grants

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

CONSENT TO ACT AS A RESEARCH SUBJECT IN A NURSING INVESTIGATION

932701
Title or ID Number

1. I agree to participate in a nursing investigation which has for its purpose obtaining information about the needs and problems of families with Spina Bifida children. I understand that the study will seek to learn whether parents can more readily and easily learn needed information concerning their child when it is presented to them in the privacy and comfort of their own homes. I understand that the study will seek to learn how the family is affected by the condition of the child.

2. It has been explained to me that my participation in the study will consist of allowing Mrs. Patricia D. Scearse, R.N., M.S., to come into my home for the purpose of interviewing me and to administer paper and pencil tests which will ask questions about Spina Bifida and about my opinions about family life and family adjustments which is a part of the study. I understand that if and when I give permission to do so, certain parts of the visits may be tape recorded.

   If I am assigned to the experimental group, I will allow Mrs. Scearse to come into my home for the purpose of providing information concerning the medical condition known as Spina Bifida. I understand that these sessions will consist of three home visits and that they will be scheduled with me at my convenience.

3. I understand that no physical nursing care will be given to my child by the investigator, and no testing will be done on my child by the investigator.

4. I understand that the information obtained in this study will be treated as confidential and used only for the purposes of this investigation. The families, clinics and participating physicians will be reported anonymously.

5. I understand that the procedures described in Section 2 above involve the following possible risks and/or discomforts:

   A. Although there is no known risk of increased knowledge and information, and no known ill effects to participating in testing of knowledge and adaptation, it is possible that individuals may experience depression or psychological harm when interviewed concerning highly emotional and sensitive issues. It is also possible that testing might cause embarassment and anger in some cases.

B. There are also the following possible benefits: 1) an increased understanding of my child's condition, 2) a lessening of guilt and threat evoked by the child's condition, 3) greater ability to recognize danger signals and act appropriately, 4) a greater acceptance of the child, and 5) increased ability to accept the present and to plan for the future.

6. I understand that participation in this investigation in no way affects the status of my child at the clinic or hospital which is providing medical care and supervision. I understand that I may withdraw from the study at any time by simply notifying the investigator and that withdrawal will not affect my child's care.

7. I understand that if I so desire, the investigator will return to my home and, at the completion of the study, make available any information which might be of value to me and which has been determined by the study.

8. The information in this consent was explained to me by Mrs. Pat Scearse, and I understand that she will answer any questions I may have concerning this investigation at any time.

9. I understand that there will be no payment for participation in this investigation, and that all expenses will be met by the investigator.

_____
Subject's Signature

_____
Date

I have read the above study and approve it.

_____
M.D., Attending Physician

_____
Date

CONSENT TO ACT AS A SUBJECT
OF A NURSING INVESTIGATION

APPENDIX D

PRETEST AND POSTTEST SCORES ON EXPERIMENTAL AND CONTROL GROUPS AND NONSIGNIFICANT STATISTICAL TESTS

APPENDIX D

TABLE D.1

UNDERSTANDING, SELF-CONCEPT AND ADJUSTMENT SCORES ON PRETEST IN ORDER OF FAMILY ADMISSION TO STUDY. ONE SAMPLE RUN TEST. N = 20

Family	Understanding Score	Position of Score with Respect to Median	Self-Concept Score	Position of Score with Respect to Median	Adaptation Score	Position of Score with Respect to Median
E_1	144	-	357	+	334	+
E_2	128	-	335	-	194	-
E_3	114	-	357	+	128	-
E_4	207	+	387	+	178	-
E_5	169	-	393	+	309	+
E_6	80	-	300	-	367	+
C_1	227	+	345	-	348	+
C_2	164	-	351	+	217	-
C_3	193	+	357	+	295	+
C_4	181	+	368	+	224	-
C_5	170	+	347	+	268	+
E_7	132	-	313	-	162	-
C_6	180	+	327	-	332	+
E_8	180	+	388	+	217	-
E_9	87	-	286	-	254	-
C_7	88	-	340	-	217	-
C_8	182	+	356	+	252	-
C_9	91	-	283	-	347	+
C_{10}	183	+	332	-	314	+
E_{10}	195	+	338	-	268	+
Median	169.5		346		261	

APPENDIX D

TABLE D.2

PRETEST AND POSTTEST SCORES WITH CHANGE INDICATIONS ON UNDERSTANDING EXPERIMENTAL GROUP AND CONTROL GROUP: $N_1 = 10$; $N_2 = 10$.

Experimental Group				Control Group			
Family	Pretest	Posttest	Difference	Family	Pretest	Posttest	Difference
E_1	144	178	+ 34	C_1	227	228	+ 1
E_2	128	161	+ 33	C_2	164	154	-10
E_3	114	150	+ 36	C_3	193	201	+ 8
E_4	207	223	+ 16	C_4	181	169	-12
E_5	169	186	+ 17	C_5	170	180	+10
E_6	80	192	+112	C_6	180	204	+24
E_7	132	167	+ 35	C_7	88	83	- 5
E_8	180	204	+ 24	C_8	182	176	- 6
E_9	87	142	+ 55	C_9	91	82	- 9
E_{10}	195	204	+ 9	C_{10}	183	162	-21
Median Scores	138	182			180.5	172.5	

APPENDIX D

TABLE D.3

PRETEST AND POSTTEST SCORES WITH CHANGE SCORES ON TENNESSEE SELF-CONCEPT CONTROL GROUP N = 10

	Total P			Personal Self			Family Self			Self Criticism		
Family	Pre	Post	Change	Pre	Post	Change	Pre	Post	Change	Pre	Post	Change
C_1	345	356	+11	68	64	- 4	69	75	+ 6	34	35	+ 1
C_2	351	348	- 3	69	69	0	79	78	- 1	29	29	0
C_3	357	351	- 6	67	64	- 3	72	71	- 1	33	33	0
C_4	368	391	+23	69	74	+ 5	86	87	+ 1	40	44	+ 4
C_5	347	344	- 3	81	80	- 1	71	70	- 1	38	38	0
C_6	327	334	+ 7	62	65	+ 3	65	69	+ 4	36	35	- 1
C_7	340	307	-33	67	59	- 8	73	65	- 8	31	37	+ 6
C_8	356	324	-32	71	63	- 8	74	68	- 6	28	42	+14
C_9	283	282	- 1	52	54	+ 2	57	57	0	45	47	+ 2
C_{10}	332	318	-14	64	61	- 3	71	62	- 9	32	34	+ 2
Median Scores	346	349		67.5	64		71.5	69.5		33.5	36	

APPENDIX D

TABLE D.4

PRETEST AND POSTTEST SCORES WITH CHANGE SCORES ON TENNESSEE SELF-CONCEPT EXPERIMENTAL GROUP N = 10

	Total P			Personal Self			Family Self			Self Criticism		
Family	Pre	Post	Change	Pre	Post	Change	Pre	Post	Change	Pre	Post	Change
E_1	357	355	- 2	57	65	+ 8	75	71	- 4	37	36	- 1
E_2	335	346	+11	64	68	+ 4	72	74	+ 2	27	28	+ 1
E_3	357	350	- 7	76	67	- 9	64	73	+ 9	28	29	+ 1
E_4	387	390	+ 7	76	75	- 1	85	82	- 3	29	24	- 5
E_5	393	400	+ 7	74	75	+ 1	81	82	+ 1	38	39	+ 1
E_6	300	311	+11	55	58	+ 3	65	67	+ 2	39	42	+ 3
E_7	313	326	+13	54	60	+ 6	70	70	0	34	36	+ 2
E_8	388	421	+33	82	87	+ 5	82	85	+ 3	30	35	+ 5
E_9	286	268	-18	54	48	- 6	65	56	- 9	39	44	+ 5
E_{10}	338	329	- 9	68	68	0	75	66	- 9	36	33	- 3
Median Scores	366.5	348		66	67.5		73.5	72		35	35.5	

APPENDIX D

TABLE D.5

PRETEST AND POSTTEST SCORES WITH CHANGE INDICATIONS ON FAMILY ADJUSTMENT TEST
EXPERIMENTAL GROUP: N = 10

	Total A			Interparental Friction-Harmony			Rejection of the Child		
Family	Pre	Post	Change	Pre	Post	Change	Pre	Post	Change
E_1	334	329	- 5	42	47	+ 5	49	49	0
E_2	194	228	+34	27	32	+ 5	25	27	+ 2
E_3	128	155	+27	17	17	0	17	23	+ 6
E_4	178	176	- 2	26	25	- 1	19	19	0
E_5	309	233	-76	29	22	- 7	41	36	- 5
E_6	367	341	-26	45	43	- 2	53	49	- 4
E_7	162	258	+96	25	38	+13	19	34	+15
E_8	217	207	-10	26	29	+ 3	32	23	- 9
E_9	254	310	+56	26	42	+16	38	44	+ 6
E_{10}	268	258	-10	34	35	+ 1	36	37	+ 1
Median Scores	235.5	258		26.5	33.5		34	35	

APPENDIX D

TABLE D.6

PRETEST AND POSTTEST SCORES WITH CHANGE INDICATIONS ON FAMILY ADJUSTMENT TEST
CONTROL GROUP: N = 10

	Total A			Interparental Friction-Harmony			Rejection of the Child		
Family	Pre	Post	Change	Pre	Post	Change	Pre	Post	Change
C_1	348	345	- 3	41	42	+ 1	54	52	- 2
C_2	217	222	+ 5	29	31	+ 2	27	27	0
C_3	295	292	- 3	34	32	- 2	44	41	- 3
C_4	224	249	+25	25	31	+ 6	29	31	+ 2
C_5	268	286	+18	30	35	+ 5	40	43	+ 3
C_6	332	325	- 7	36	38	+ 2	43	47	+ 4
C_7	217	213	- 4	30	28	- 2	32	32	0
C_8	252	265	+13	37	36	- 1	36	37	+ 1
C_9	347	347	0	47	47	0	52	54	+ 2
C_{10}	314	348	+34	43	44	+ 1	43	46	+ 3
Median Scores	260	289		35	35.5		41.5	42	

APPENDIX D

TABLE D.7

TOTAL ADAPTATION SCORES: KOLMOGOROV-SMIRNOV TEST. N = 20

	Cumulative Frequency Distributions on Change Scores						
	-76;-50	-49;-25	-24;-1	0;+23	+24;+48	+49;+73	+74;+98
Experimental Group N = 10	1/10	2/10	6/10	6/10	8/10	9/10	10/10
Control Group N = 10	0/10	0/10	4/10	8/10	10/10	10/10	10/10
$S_{N1}(X) - S_{N2}(X)$	1/10	2/10	2/10	2/10	2/10	1/10	0

$K_D = 2$

TABLE D.8

TOTAL FAMILY ADAPTATION: WILCOXON SIGN TEST. N = 10

Family	Posttest	Pretest	Difference	Rank
E_1	329	334	- 5	5
E_2	228	194	+34	8
E_3	155	128	+27	7
E_4	176	178	- 2	6
E_5	233	309	-76	1
E_6	341	367	-26	2
E_7	258	162	+96	10
E_8	207	217	- 10	3.5
E_9	310	254	+56	9
E_{10}	258	268	-10	3.5

Sum of Negative Ranks = 21

Sum of Positive Ranks = 34

APPENDIX D

TABLE D.9

INTERPARENTAL FRICTION-HARMONY SCORES: KOLMOGOROV-SMIRNOV TEST. N = 20

	Cumulative Frequency Distribution on Change Scores					
	-7;-4	-3;0	+1;+4	+5;+8	+9;+12	+13;+16
Experimental Group N = 10	1/10	5/10	6/10	8/10	8/10	10/10
Control Group N = 10	0/10	4/10	8/10	10/10	10/10	10/10
$S_{N1}(X) - S_{N2}(X)$	1/10	1/10	2/10	2/10	2/10	0

$K_D = 2$

TABLE D.10

INTERPARENTAL FRICTION-HARMONY SCORES. WILCOXON SIGN TEST. N = 10

Family	Posttest	Pretest	Difference	Rank
E_1	47	42	+ 5	7.5
E_2	32	27	+ 5	7.5
E_3	17	17	0	4
E_4	25	26	- 1	3
E_5	22	29	- 7	1
E_6	43	45	- 2	2
E_7	38	25	+13	9
E_8	29	26	+ 3	6
E_9	42	26	+16	10
E_{10}	35	34	+ 1	5

Sum of Negative Ranks = 10

Sum of Positive Ranks = 45

APPENDIX D

TABLE D.11

REJECTION OF CHILD BY MOTHER. KOLMOGOROV-SMIRNOV TEST. N = 20

	Cumulative Frequency Distribution on Change Scores				
	-9;-5	-4;0	+1;+5	+6;+10	+11;+15
Experimental Group N = 10	2/10	5/10	7/10	9/10	10/10
Control Group N = 10	0/10	4/10	10/10	10/10	10/10
$S_{N1}(X) - S_{N2}(X)$	2/10	1/10	3/10	1/10	0

$K_D = 3$

TABLE D.12

REJECTION OF THE CHILD BY MOTHER. WILCOXON SIGN TEST. N = 10

Family	Posttest	Pretest	Difference	Rank
E_1	49	49	0	4.5
E_2	27	25	+ 2	7
E_3	23	17	+ 6	8.5
E_4	19	19	0	4.5
E_5	36	41	- 5	2
E_6	49	53	- 4	3
E_7	34	19	+15	10
E_8	23	32	- 9	1
E_9	44	38	+ 6	8.5
E_{10}	37	36	+ 1	6

Sum of Negative Ranks = 15

Sum of Positive Ranks = 40

APPENDIX D

TABLE D.13

SPEARMAN Rho CORRELATION OF DEGREE OF DISABILITY OF CHILD WITH REJECTION OF CHILD BY MOTHER

LISTED IN RANK ORDER OF REJECTION OF CHILD (Subscale I). N = 20

Family	Subscale I	Rank	Degree of Disability	Rank	D Value
E_4	19	1	13	17.5	-16.5
E_3	23	2.5	9	4.5	- 2.0
E_8	23	2.5	12	15.5	-13.0
C_2	27	4.5	9	4.5	0
E_2	27	4.5	8	2	+ 2.5
C_6	31	6	13	17.5	-11.5
C_7	32	7	9	4.5	+ 2.5
E_7	34	8	7	1	+ 7.0
E_5	36	9	11	12.5	- 3.5
E_{10}	37	10.5	11	12.5	- 2.0
C_8	37	10.5	10	8.5	+ 2.0
C_3	41	12	15	20	- 8
C_5	43	13	11	12.5	+ 0.5
E_9	44	14	9	4.5	+ 9.5
C_{10}	46	15	10	8.5	+ 6.5
C_6	47	16	12	15.5	+ 0.5
E_6	49	17.5	10	8.5	+ 9.0
E_1	49	17.5	10	8.5	+ 9.0
C_7	52	19	11	12.5	+ 6.5
C_9	54	20	14	19	+ 1.0

t = .844. rho = 1 - .798 = +.202

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