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A study of families with stress related to the care of children with myelomeningocele

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AN ABSTRACT OF THE THESIS OF Janet L. Ferguson and Russel
Tweed for the Master of Social Work presented May 21, 1971.

Title: A Study of Families With Stress Related To The Care
Of Children With Myelomeningocele

APPROVED BY MEMBERS OF THE THESIS COMMITTEE:

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This was an exploratory-descriptive study of fifty children afflicted with myelomeningocele, ages one through six, who were known to the Myelomeningocele Clinic of the Crippled Children's Division. The study identified the degree of multiple physical, emotional, and environmental stress factors that families must be prepared to cope with.

The study identified eleven factors felt to play an important role in family dynamics and how they related to the families response to their child with myelomeningocele. The factors were tested and found to be valid by the use of a pre-test on ten case records.

Medical records were then obtained from the Crippled Children's Division for chart review purposes and the appropriate material was recorded. Scores were developed that indicated the degree of stress ranging from minimal involvement to maximum involvement.

The study found that a majority of the families in the sample live within commuting distance to needed medical services, have transportation available to them and generally utilize the necessary medical care appropriately. The remainder of the study showed, however, that families could be expected to face a variety of other problems that could only serve to increase family stress. Most of the families had limited financial resources. Over one-half of the families needed special education for their children. A majority of families had no medical insurance. Fifty-eight percent of the families were found to have additional stressful problems to cope with e.g., marital stress, sibling rivalry, additional ill members, etc.

Added to this was the information that the child with myelomeningocele was found to be greatly involved in a multiplicity of medical problems at many different levels of functioning, e.g., orthopedic, bowel, neurosurgical, etc., that would be expected to add to the already stressful family dynamics.

Among the recommendations developed was a plea for the expansion of the satellite clinic concept, development of parent groups on a geographical basis, development of educational programs for

educators and community service personnel, brief orientation programs for parents with the goal of helping them understand and integrate the health care system that they find themselves in.

A STUDY OF FAMILIES WITH STRESS RELATED TO
THE CARE OF CHILDREN WITH MYELOMENINGOCELE

by

JANET L. FERGUSON
and
RUSSEL TWEED

A thesis submitted in partial fulfillment
of the requirements for the degree of

MASTER OF SOCIAL WORK

Portland State University
1971

TO THE OFFICE OF GRADUATE STUDIES:

The members of the Committee approve the thesis of Janet L.
Ferguson and Russel Tweed presented May 21, 1971.

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CHAPTER I

INTRODUCTION

I. BACKGROUND OF STUDY

This thesis project was developed out of a field placement experience over a nine month period for student social workers at the Crippled Children's Division, University of Oregon Medical School. The students had been assigned to the Myelomeningocele Clinic (one of several different multiple discipline clinics within the Division) for the purpose of developing and improving social work skills. The children in this group are "at risk" many times in early life and have multiple, rather than single handicapping conditions. Personnel in helping professions, e. g. social workers, need to experience what it means to integrate multiple, fragmented services before they can teach parents how to do so effectively. The parents in this group were found to need constant consultation, advocacy, and intervention by social workers on their behalf if they were to be effective in the maintenance of a well planned, sustained, life-span care program. Doctors and others in helping professions need to understand family situations and stress related to the care of the child with myelomeningocele.

It was through this experience that interest was manifested in the problems of family stress and health care management as it related to the myelomeningocele population at the Crippled Children's Division.

One variable that influenced the decision to use the younger age group was the relatively recent organizational composition of the Multiple-Discipline approach practiced by the Crippled Children's Division staff. This approach grew out of the realization that this group of children, requiring constant medical supervision by a number of specialists needed to be seen as whole beings rather than as a series of problems unrelated to each other. In times past, the child was seen by the neurosurgeon following his hospital discharge if the possibility of developing hydrocephalus existed. He was referred to an orthopedist when necessary, but not routinely seen for urological studies. Some families thought that seeing specialists eliminated the need for a pediatrician or a general practitioner. No one integrated the services for the family or helped them maintain preventive treatment. Because of this, some parents were not aware of fecal or urinary incontinence until after the stage of normal toilet training was outgrown and they were dismayed to find that their child was excluded from most child care and public schools. In the Myelomeningocele Clinic, goals for these children are reviewed at appropriate intervals for more positive planning. These group conferences are followed by

conferences with the parents. The role of the social worker is one of implementation of treatment recommendations, being a liaison with the community and educational services and of providing continuous consultation to families between clinic appointments.

It was surprising and somewhat disappointing to realize that there was little recorded information about family emotional reaction when confronted with caring for a child with myelomeningocele. It was apparent, however, that there were many concomitant physical factors, such as kidney failure, hydrocephalus, etc., that affect the child with myelomeningocele and that identifying the stress factors affecting families with these children might be worthwhile. In the absence of subjective data related to this decision, it was decided to select or isolate factors which the students and the clinic personnel considered potentially stressful. It was known from experience that the stress for this group of families was great because of the multiplicity of handicapping conditions; because of medical complications in early life which are life threatening, and because of complications in the use of multiple, fragmented medical and community services and facilities. Although there was a paucity of information on the subject, an attempt was also made to assess how families functioned in using the service delivery system on behalf of their handicapped children.

Most children will grow and develop in relation to a pattern,

which, though personal for each, will be considered to be within a "normal" range. These children are able to take advantage of most of the social and cultural opportunities and ultimately to become independent, adaptable, and contributing members of society. However, there are in every community some children who are significantly "different" in their mental, emotional, physical and social characteristics to a degree that necessitates extra help in order to maximize their potential. It was the differences for the child with myelomeningocele, the difficulties that surround him, and the stress experienced by the family with which the students became concerned.

It is recognized that the birth of a child with a defect can produce stress within the immediate family. However, this birth can produce a series of disturbing events involving not only the child and his family, but the extended family, friends, community, and even society. Feelings of blame, shame, misunderstanding, and disappointment can disorganize family relationships. Gaps in services and absence of needed facilities as well as the chronic financial demands may intensify family problems.

Because of the seriousness and sometimes the multiplicity of the problems, most children with myelomeningocele require additional special services over and above the required treatment for this handicap. Availability of adequate medical resources are one of the primary problems faced by this group of handicapped children,

their families, and their communities.

Children with long-term chronic handicaps may require in addition to medical specialists, a broad range of community services that are often widely scattered among professional groups and under auspices of numerous public and private agencies located over large geographical areas. To integrate these diverse services in order to help handicapped children requires teamwork and an understanding that only through co-operation will a health care delivery system be effective.

II. DESCRIPTION OF THE AGENCY

The Crippled Children's Division is the designated agency for administration of federal-state programs for Crippled Children's Services. Theoretically, when a child with myelomeningocele is delivered, the attending doctor or pediatrician usually refers to a neurosurgeon immediately. Referrals of children born in other parts of the state are usually made to the Medical School Neurosurgery Department with hospitalization in Doernbecher and subsequently referred to the Crippled Children's Division for follow-up services. Families whose children are in private hospitals are usually referred by the attending neurosurgeon, particularly if the family needs financial help. Both private physicians and those on the Medical School staff want families to have the integrative services provided through

the Crippled Children's Division Myelomeningocele program and refer to it even though the treatment is continued under private care or in the Medical School Hospital and clinics.

It is important to understand the specific nature of the Crippled Children's Division and the role it takes in relation to handicapped children in the state of Oregon. The agency has a mandatory obligation to serve all areas of the state. The primary goal is to offer diagnostic services and treatment resources to the handicapped child. This is to insure that whenever possible, all handicapped children in the state of Oregon are given a chance to reach adult life and take their place in society as well adjusted and self-sustaining citizens. The age group served is from birth to twenty-one years of age. A unique and important component of service programs is the team evaluation and consultation to physicians and other personnel in the community. The makeup of the multiple discipline team varies depending upon the nature of the individual clinic. The professions include medicine, social work, speech pathology, audiology, psychology, nutrition, nursing, dentistry, physical and occupational therapy, and education.

The initial intent was to provide integrative help and consultation to Medical School staff involved in the treatment. As private physicians learned about the service, referrals were made with the request that the Crippled Children's Division provide periodic review

and integrative services. This, along with extended life span of this group of children resulted in an increased program. For an illustration of the complexity and inter-meshing of the medical care complex component, refer to Appendix A.

The Myelomeningocele Clinic within the Division assists with diagnosis and treatment planning for children with myelomeningocele and related disorders. Most children in this group need an integrated on-going plan of long-term medical care and rehabilitation. For most of the children, because of the nature of the impairment, there is no foreseeable time when a variety of medical and social services will not be needed. By helping the child and his family understand the totality of their needs and their role in following treatment recommendations, progress can eventuate. Some of the problems identified by the diagnosis of myelomeningocele are; orthopedic limitations, neurogenic bowel and bladder, kidney and bladder malfunction, and hydrocephalus. The intellectual capacity of the child will range from average to severe retardation. Institutional care may be the only alternative for a small number of patients.

The Myelomeningocele Clinic is an attempt to efficiently utilize multiple-discipline evaluations, consultations, and educational services to families, so that fragmented resources, family fears concerning the nature of the handicap, and concern for the future can be integrated into a sustained, intelligent care plan that can focus on each

child's needs.

III. DESCRIPTION OF MYELOMENINGOCELE

Myelomeningocele is based on a neurological impairment involving the brain, the spinal cord and the nerves that travel from the brain and spinal cord to the muscles, glands, and skin. The chronological development of the problem is very complex and occurs during pregnancy. Some of the bony, protective covering of the spinal cord will fail to develop fully. It is a matter of degree as to how much of the spinal cord will fail to develop. It is not unusual for some of the vertebrae to be slightly incomplete, leaving the spinal cord intact. (Spina bifida occulta). However, the condition that comes to the attention of the physician is that in which the vertebrae not only fails to develop completely, but the spinal cord fails to develop into a tube and instead forms a flat plate that protrudes from the back and, rather than being covered with backbone, is covered only with membranes that normally cover the spinal cord. This results in a sac like appearing protrusion on the infant's back. The physical problems stemming from this condition are those resulting from an interruption of the central nervous system control below the level of the lesion; e. g., fecal and urinary incontinence, paralysis, kidney infection, hydrocephalus and orthopedic malformations. See Appendix B for illustration.

The condition is, of course, visible immediately, and treatment can be started within hours. Perhaps the main reason for the lack of knowledge about the condition among the public is that until recently, most babies only survived for a few weeks and spent that time in the hospital. The parents usually never saw the infant nor were they advised as to what was wrong with it. Now, because of recent medical developments, an increase in survival rates of these children has been seen. Like many other diseases, there is probably a hereditary predisposition which is then triggered by some other factor or factors in the environment. The condition is more likely to reoccur in families, although physicians are not ready to claim that it is inherited, but rather, lean towards a poor genetic mating risk explanation.

Within the last ten years, many new medical procedures have been developed. The first surgery performed on the infant now is frequently a neurosurgical one to repair the myelomeningocele sac and by shunting procedures to ward off or minimize hydrocephalus. A common accompanying condition of myelomeningocele is hydrocephalus or cranial enlargement through pressure of fluid retention. Small plastic tubes, shunts, are inserted in the skull, which are sometimes seen behind the ears traveling down into the chest or other parts of the body. These tubes act as a pump to drain off the excess fluid.

CHAPTER II

REVIEW OF LITERATURE

It is with this background of experience and information that the literature concerning families with chronically handicapped children was reviewed. From this review, a plan was evolved to use an exploratory-descriptive format in an effort to develop an understanding of the stresses that families with children with myelomeningocele may encounter.

After completion of the literature review, three dominant themes were apparent; (1) purely medical aspect, (2) family crisis characteristics, and (3) treatment modalities.

Most experts now advise neurosurgical repair of the myelomeningocele within the first day of life, which is claimed to reduce the extent of orthopedic damage. Eckstein's (1966) descriptive analysis study has strongly suggested that early myelomeningocele repair can often ameliorate all orthopedic problems and that the inevitable urological problems can also be minimized.

Little information was found about how the news is broken to the parents about their child's defect. Parmalee (1962) stated that the way the physician sets the stage with the parent can influence how

he adjusts to the crisis and the successful use of occupational, physical, medical, and social services by the parents. How the parents are informed and how they are treated by both the doctor and the hospital staff are very important in this aspect. This is very difficult for the doctor because he has to initially admit that he is failing within his profession because he cannot heal the child. The parents can better accept their misfortune if the doctor can accept his inability to remove the child's handicap. Doctors may sometimes seem to come across as cold, blunt, or disinterested; when they are in reality very emotionally involved in their own helplessness.

The majority of the literature emphasized orthopedic and urological procedures to be used as the child develops. Depending upon the severity of the crippling, and the surgical procedures already performed, various methods are offered to ward off further deterioration and or to strengthen what physical resources the child does possess. This type of reporting in journals keeps specialists abreast of new, improved methods which may decrease the damage or deformity if employed. In the past, it was generally assumed that these children would not survive, but the literature stresses that it has been demonstrated that early and continued consistent treatment has extended the life span for some. No one can predict which children will survive and thus the effort is expended for every child.

In spite of family strengths, there are predictable areas and

periods of stress for the family when faced with the task of dealing with a chronically disabled child. Shotland (1964) offers general points that families experience when in this situation. The period of unknown prior to diagnosis usually finds the parents undergoing feelings of fear, guilt, suspicion, blame, and doubt. After diagnosis, anxiety and mourning for the lost "wholeness" that follows the "truth impact" is experienced. A third point of stress occurs when the child reaches the pre-school years and begins to physically fall behind his peers. When the child faces the elementary years and the experience of separation from family members, he enters into a world he finds difficult to understand; more stress is felt by the parents. During adolescence, the child and the parents must face the demands for a curtailed future and by adulthood, reality forces a coming to terms with the future for both the family and the off-spring. Again, it is pointed out that how families cope is largely dependent upon the emotional health of the family.

More specifically, Rapoport (1962) attempts to identify the coping patterns of families immediately after the onset of a stressful experience. She tells us that crisis time is limited during which the family will try to gain a state of equilibrium, with varying positive or negative results. (Heightened tension, attempts to solve the problem, depending on the results of the problem-solving attempts, and emergency mechanisms.)

Shotland (1964) dealt with the family stress in an extended time span and Rapoport (1962) dealt with it in the immediate stages. Both identified common family stress characteristics. There are definite feelings of guilt and ambivalence towards the child. Parents cannot project feelings of blame for the problems onto the child because this behavior is not socially acceptable. Schild (1964) discusses the anger about the narcissistic injury that most parents feel. No parent likes to be reminded that his child has a functional ceiling.

Olshansky (1962) discusses another response known as chronic sorrow. He points out that the condition is natural under most circumstances and that it is a natural response to a tragic event. Mandelbaum (1960) speaks about projection being one of the most commonly used defenses by parents coping with a defective child. Parents may look to other family members as the cause of the problem. The more intense this defense mechanism, the longer will be the duration and the greater the chances are that the child will become a part of the parents' psychological dysfunctioning. Parents with strong psychological adjustments seem better able to handle having a disabled child than those parents who were not able to gain a satisfactory adjustment in prior years. The use of denial by parents is a common mechanism, sometimes manifested in the activity of shopping around for medical care.

Giving birth to a child demands many basic adjustments. Our

society values high achievement, attractiveness, and intelligence. Parents faced with having to deal with the direct opposite often are overwhelmed by their own feelings and what they interpret as society's scorn. A disabled child will change the functioning of the family roles and relationships. Among families with myelomeningocele, Smith (1965) tells us that there are parental concerns over mental retardation, fears of having other children, the chronic financial burden that the family must face because of the long periods of hospitalization, and the cost of medical apparatus.

Reactions of guilt, self-blame, anxiety, denial, prejection, feelings of inadequacy, a sense of helplessness, myriads of questions about finances, education, and possibilities for such a child's marriage are all aspects that confront parents. Society adds to the pressure with its expectation of perfect off-spring.

Foreman (1967) feels that some parents have valid reason for bitterness. Because of tragic mis-diagnosis, the parents anticipate the child's eventual death which results in a gradual emotional detachment from the child or mourning in advance, only to become aware that the child is not going to die; but will continue to survive at a more involved level of handicappedness. There are some pregnancies which are undesired by the parents because of various marital or social crises, which are further complicated by the birth of a defective child. If the mother has either attempted or even wished for an

abortion, it is likely that she will link up these feelings with intensified guilt feelings. (In some way, she feels responsible for the handicap.)

Thomas (1965) refers to the various reactions of having produced a handicapped child. Guilt, fears of having other similar children, resentment, and doubts about their capacity to manage such children plague most parents. Sometimes, stresses within the family group, even with the best of intentions, such as the total devotion of an earnest mother towards the child's interest to the point of detriment of other siblings or the husband. On the other hand, the child may be the victim of complete disinterest of mentally ill-equipped parents.

Barsch (1968) traced child-rearing practices with handicapped children; including exhaustive research into courtship, marital, and social patterns.

The treatment modality theme was found to be mainly in social work publications. Some medical journals devoted perhaps a page or a few paragraphs to the treatment modalities in existence while working with the parents.

The social worker needs to have a clear understanding of the implications of the handicapping conditions related to family stress. The social worker is one of the family's first contacts in times of stress and acts as an advocate and an interventionist in helping to

arrange for the appropriate care. The social worker must help the parents assess symptoms in order to consult a physician about what is needed. Social workers must know the risks of delay or of getting to the wrong service. They must be conversant with the procedures in order to interpret them to the parents. To be a good consultant to families, physicians, and others involved in helping, social workers must know each patient individually and be familiar with his treatment plan.

In this area, a social worker's main concern should be with adding to the parental social functioning, which has the most direct effect on the child's social functioning. Almost all professionals, including physicians, recognize the need for skilled and expert experiences to work most successfully with these parents.

Social workers need to be aware of their own feelings if they wish to be supportive, rather than destructive. A social worker is naive if he does not realize that he is inherently relieved that this tragedy has not befallen him personally. Social workers are usually quite adept at diagnosing a problem and then devising an intervention plan that will, they are convinced, be the panacea for their client's problems. They are then decidedly impatient when their plans are not actualized or when psychological counseling does not dispel a parent's natural grief. Social workers should be aware that even if a parent can observe his plight on a conscious level, he cannot, nor

should he attempt to abandon his chronic sorrow. Parents have a life-time to work through their particular pain and there is no reason why it must be accomplished within the time span that a given social worker is intervening with counseling. The social worker is better able to help with parental desperation if he is able to control his own frustration and irritation with the parents and if he is able to accept his own guilt feelings in common with the parents.

The diagnostic study that is prepared is not a solution but a beginning and should encompass assessment of parental strengths as well as a medical diagnosis of the child. Social workers should accept the fact, as stipulated by Olshansky, Op. Cit., that parents of handicapped children suffer from reactions of chronic sorrow and that this is a natural, rather than an abnormal response.

Auerbach (1968) discusses the gains that parents can attain in discussion groups. Understanding children's needs at different stages of their development, examining what they expect of themselves as parents, gaining knowledge of the interaction which occurs between parent and child and siblings, and beginning to appreciate the external influences on the child and his family.

Wolfensberger (1967) urges that professions working in this area need to have positive attitudes towards the handicap, counseling competency, and an adept knowledge of the handicap, including services such as laws and resources. He feels that parents as a whole

have been misjudged, mishandled, and misunderstood by the majority of professionals. His approach is focused more on reality problems rather than on therapy-orientation. The offering of services should be made in the spirit and willingness to extend long-term and perhaps life-long resources to the family.

In conclusion, the primary idea that seemed to thread its way through the material concerning stress was that if a family has strong, balanced interaction among its members and is not involved in old, unsolved conflicts, unmet needs, or hostilities, the chances are great that they will be able to cope with a disabled child much more appropriately than if they find themselves enmeshed in interactional disputes.

CHAPTER III

METHODOLOGY

I. DESCRIPTION OF SAMPLE

The sample used in this study was a group of fifty children born between 1965 and 1970 chosen because the majority of children born before the neurosurgical advances of 1963 did not survive. This study was conducted on a chart review basis. The charts of children in the required age group were located by scanning a card index system compiled by the social worker assigned to the Myelomeningocele Clinic. The presentation of the data has been arranged in such a manner that it does not violate confidentiality.

II. DESCRIPTION OF WEIGHTING PROCEDURES

The weighting was designed with the purpose of indicating arbitrary problem complexity on a continuum from no problem to a problem of major complexity. More importantly, the weighting procedure was used to get away from the stereotyped thinking of only one aspect of the handicap. For example, more stress would be felt if a child was non-ambulatory than if he had a minor problem in gait control. In addition, however, it was thought that the weighting would

highlight the complexity of care which confronted families whose child had multiple handicapping conditions. For example, one child might have a minor orthopedic problem, but a severe problem urologically and/or neurosurgically. The degree of severity might be greater in all areas for some children. Complexity is due in large measure to what families have to do to maintain continuous treatment of multiple conditions.

Not all categories ranged from one to five, but the lower number reflected less severe involvement than the higher numbers, except in the mode of transportation and family-environment stress and additional illness or handicap categories. For example, one cannot say that a marital problem is more or less stressful than a delinquent family member. See the following table for a representation of the qualitative and quantitative values assigned to the sub-division alternatives.

III. DESCRIPTION OF INSTRUMENT DESIGN

The method of approach was of an exploratory-descriptive style. A one page form was devised in order to provide a scheme for presenting factors identified for the study as potential stress makers for the family-child system. This was accomplished by combining appropriate aspects of three previously used Crippled Children's Division chart review forms with pertinent information gathered from

TABLE I
RATINGS OF OUTCOME

Dimensions	Data	Weight	Meaning of Scale	Range
Living Situation	Natural Parents	1	Type of Residence wherein the population lived at the time of the study	1 - 7
	One Parent	2		
	Step-Parent	3		
	Relatives	4		
	Foster Home	5		
	Child Care Facility	6		
	State Institution	7		
Accessibility of Services	Pediatrician Neurosurgeon Orthopedist Urologist Hospital Out Patient Clinic Social Work Physical Therapy Occupational Therapy Public Health	1 for each of the ten services	The geographical distance from available needed services for children with Myelomeningocele	10-50
- 25 miles				
26- 50 miles				
51-100 miles				
101-300 miles				
301-500 miles				

TABLE I (Continued)

Dimensions	Data	Weight	Meaning of Scale	Range
Mode of Transportation	Automobile	1	Shows types of transportation available to the families in the sample	1 - 5
	Bus	2		
	Train	3		
	Commercial Plane	4		
	Charter Plane	5		
Financial	\$3000	5	Shows the financial status of the families in the study	1 - 5
	\$3000-5000	4		
	\$5000-7000	3		
	\$7000-9000	2		
	\$9000 +	1		
Insurance	Full Insurance	1	Shows the existence of insurance available to the families in the study	1 - 3
	Partial Insurance	2		
	No Insurance	3		
Family- Environment Stress	No Problem	1 for each	Shows the types of problems that can cause stress in any family in addition to having a handicapped child	—
	Marital Problem			
	Sibling Rivalry			
	Parent-Child			
	Behavior Management Problem			

TABLE I (Continued)

Dimensions	Data		Weight	Meaning of Scale	Range
Family - Environ- ment Stress (Continued)	Additional Ill Family Members Delinquent Members				
Educational Status	Private Pre-School		1	Shows the degree of educational needs that were identified in this sample, both present and anticipated	1- 5
	Regular Pre-School		2		
	Special School		3		
	Special Education		4		
	Home Instruction		5		
Intellectual Level	Average	109-84	1	Shows the degree of intellectual capacity identified within the sample	1- 5
	Borderline	83-69	2		
	Educable	68-53	3		
	Trainable	52-37	4		
	Custodial	-36	5		
Orthopedic Involvement	No Problem		1	Shows the degree of orthopedic complexity identified in the sample	1- 5
	Minor Problem		2		
	Ambulatory with braces		3		
	Ambulatory with crutches		4		
	Not Ambulatory		5		

TABLE I (Continued)

Dimensions	Data	Weight	Meaning of Scale	Range
Kidney-Bladder Involvement	No Problem	1	Shows the degree of kidney-bladder involvement identified in the sample	1 - 5
	Partial Control	2		
	External Collector	3		
	Surgical Intervention	4		
	Life Threatening	5		
Bowel Involvement	No Problem	1	Shows the degree of bowel complexity identified in the sample	1 - 5
	Control by Training	2		
	Manual Control	3		
	Total Incontinence	4		
	Colostomy			
Neurosurgical	No Problem	1	Shows the degree of neurosurgical complexity identified in the sample	1 - 5
	Arrested Spontaneously	2		
	Surgically Arrested	3		
	Revised	4		
	Neurosurgical complications	5		
Additional Illnesses or Handicaps	No Problem	1 for each	Shows the variety of miscellaneous conditions that can be present in addition to Myelomeningocele	_____
	Cardiac			
	Speech			
	Hearing			
	Other			

the thesis consultant and those categorical areas that had been found to be valuable from readings and experience. To test the research potentiality of the instrument design, a pre-test was run on the charts of ten ex-patients of the Myelomeningocele Clinic. The results of the pre-test indicated that the instrument was a feasible tool for the purposes of the study.

The instrument was divided into eleven main categories and seventy-five sub-categories. The complete instrument may be referred to in Appendix C.

The first main category dealt with Age and Sex. The second category dealt with the Living Situation. (Home, state institution such as Fairview Hospital and Training Center for severely mentally retarded patients, child-care facility such as Providence Child Care Center or the Waverly Children's Home, etc.)

The third area was Accessibility of Services. Ten services used by these families were identified, and these services were categorized according to the distance between the families' homes and these services.

The fourth category looked into the Modes of Transportation that are possible in public and private sectors.

The fifth category dealt with the Financial circumstances of the families.

The sixth category covered the existence and the extent of

Insurance Coverage. Full insurance refers to those families that were able to provide complete medical coverage for their child. Partial insurance identified the families whose insurance policies only included a percentage of the medical costs over the deductible. In such cases as these, supplementation from the Crippled Children's Service Funds was frequently needed. No insurance referred to those families who were unable to procure insurance of any kind because of insurance policies with exclusion clauses pertaining to birth defects.

Family Environment Stress was the seventh category. Marital problems referred to such items as separations, requests for counseling, etc. Sibling rivalry referred to both the handicapped child's relations with his siblings and their relationships with each other. Parent-child management problems refers to parent-child conflict, parental inability to provide appropriate structure for the child, etc. Additional ill members refers to any kind of pathology affecting members other than the handicapped child. (Physical and/or emotional). Delinquent members describes any siblings or parental acting-out in opposition to the established societal norms.

The eighth category involved Educational Status which refers to the type of educational structure usually required for this group of patients. Many private facilities will not accept multiply handicapped children. The cost of tuition and transportation are deterrents in using them. The regular pre-school refers to those children who may

be accepted for public supported pre-school environments. Special schools refers to those children whose physical limitations would preclude their functioning in public schools. Special education refers to provisions made in public school systems for those children who are additionally handicapped with intellectual limitations. Those who might need home instruction were identified as being physically unable to attend school or geographically isolated from educational resources, and or those who are temporarily too disabled to fit into the other four categories.

The ninth category dealt with Intellectual Levels. The Intelligence Quotient ratings were taken from the AAMD Classification system based on the WISC and Stanford-Binet. See Appendix D for a representation.

The tenth category described the area of Problem Multiplicity related to physical handicaps and included five identified areas of concern, e.g., Orthopedic, Urological, Bowel, Neurosurgical, and Additional Illnesses or Handicaps.

Minor problems in the Orthopedic section referred to minimal problems in mobility, etc. Ambulatory with braces and/or crutches referred to those children whose only prosthetic devices were bracing and/or crutches. Those children with check marks in both categories were ambulatory with the aid of both crutches and braces used simultaneously. Non-ambulatory referred to those who were

wheel-chair bound or bed ridden. All four categories referred primarily to mobility.

Urological problems included identification of those children with partial control (dribbling), using external collecting devices, surgical intervention such as ileal loops, and life threatening urological situations such as kidney failure.

Bowel problems include control by training, (timing and diet) manual control (suppositories) and total incontinency or no control at all.

Neurosurgical problems refer mainly to the hydrocephalic situation and the involvement of the shunt to facilitate the flow of cerebral fluid through the brain and to other parts of the body. Spontaneous arrest refers to the natural abatement of the condition. Surgical arrest (1-3 and 4 or more) refers to the surgical shunting procedures and the number of necessary revisions. Neurosurgical complications are life threatening such as meningitis.

Additional Illnesses or Handicaps that were identified included cardiac problems, speech problems, hearing problems, and other miscellaneous anomalies.

The Use of Medical Services category was the eleventh main category. There were eleven subjective descriptive statements of family functioning that were identified by the Crippled Children's Myelomeningocele Clinic staff as being related to a family's

management capabilities.

A composite Problem Multiplicity score was derived by combining the four weighted sections of Orthopedic, Kidney-Bladder, Bowel, and Neurosurgical levels to arrive at an involvement description for each child.

IV. STATISTICAL METHOD USED

Means and standard deviations were computed on the Weighting values that were assigned to the sub-division choices. The goal was to compare the distributions and to analyze a pattern of stress situation intensity.

Modes were identified on the unweighted sections of Family Environment Stress, Method of Transportation, and Additional Illness or Handicap in the Problem Multiplicity sections to analyze similar patterns.

CHAPTER IV

FINDINGS

Out of a total population of fifty it was found that fifty-six percent of the sample were male and forty-four percent of the sample were female. Sixty-four percent lived with their own families and the remainder resided in other living situations. It was found that ninety-six percent were Caucasians with Chicanos being the only minority group represented. Ninety percent had an automobile available (see Tables III, IV, V).

TABLE II
AGE AND SEX DISTRIBUTION

Years	Male	Female	Percent
- 2	1	0	02
2 - 3	10	7	34
3 - 4	5	4	18
4 - 5	8	5	26
5 - 6	4	6	20
Total	28	22	100

N = 50

TABLE III
DISTRIBUTION BY RACE

Category	Total	Percent
Caucasian	48	96
Black	0	00
Chicano	2	04
Oriental	0	00
Other	0	00
Total	50	100

N = 50

TABLE IV
LIVING SITUATION

Category	Total	Percent
Natural Parents	32	64
Step Parents	0	00
Foster Home	4	08
One Parent	5	10
Relatives	2	04
Child Care Facility	6	12
State Institution	1	02
Total	50	100

N = 50

TABLE V
METHODS OF TRANSPORTATION

Category	Total	Percent
Automobile	45	90
Bus	4	08
Train	0	00
Commercial Plane	0	00
Charter Plane	1	02
Total	50	100

N = 50

I. ACCESSIBILITY OF SERVICES CATEGORY

A scoring range from ten to fifty was established with the lowest number indicative of easy accessibility to needed medical services. The mean was 14.9, s.d. 8.49. This shows that two-thirds of those families who utilize the needed medical services for their children live within twenty-five miles of the available service. Even though a majority of the families were in an optimistic relationship to services, the review of case material and discussion with clinic staff indicated that critical problems could develop around getting to appropriate services. For example, whenever a trip must be made, other children usually must be cared for. Some families must plan to stay for more than a day for clinic and hospitalization. If the husband

cannot get time off (usually with loss of pay) another adult must accompany the mother if the patient is an infant. If the patient is in a one-parent family and the parent is employed, there is a threat to the job if time must be taken frequently to accompany the patient to his appointments. Our study showed that a few families (6) lived as far as 300 to 500 miles away from appropriate health care services for a child with myelomeningocele. Table VI will show the accessibility of services for families found in the sample.

II. FINANCIAL CATEGORY

In this category the scoring range was from one to five with the number one indicating an income of \$9000 or more and the number five indicating an income of \$3000 or less. The mean was 3.06, s. d. 1.22, indicating that there was a predominance of low income families within the sample. With a lack of financial power it can be anticipated that the family will be unable to manage the chronic medical care that myelomeningocele children must live with. Lack of funds implies a dependency relationship for the family that can result in increased stress. See Table VII for the financial information.

TABLE VI
ACCESSIBILITY OF SERVICES

Category	-25 Miles %		26-50 Miles %		51-100 Miles %		101-300 Miles %		301-500 Miles %	
Peditrician	46	92.0	2	04.0	1	02.0	0	00.0	1	02.0
Neurosurgeon	31	62.0	6	12.0	7	14.0	5	10.0	1	02.0
Orthopedist	31	62.0	5	10.0	7	14.0	6	12.0	1	02.0
Urologist	32	64.0	8	16.0	4	08.0	5	10.0	1	02.0
Hospital	34	68.0	6	12.0	4	08.0	6	12.0	0	00.0
Out-Patient Clinic	36	72.0	5	10.0	4	08.0	5	10.0	0	00.0
Social Work	34	68.0	6	12.0	4	08.0	5	10.0	1	02.0
Physical Therapy	36	72.0	4	08.0	4	08.0	5	10.0	1	02.0
Occupational Therapy	35	70.0	5	10.0	5	10.0	5	10.0	0	00.0
Public Health Nurse	48	96.0	2	04.0	0	00.0	0	00.0	0	00.0

N = 50

TABLE VII
FINANCIAL DISTRIBUTION

Category	Total	Percent
\$9000 - up	7	14
\$7000 - \$9000	5	10
\$5000 - \$7000	15	30
\$3000 - \$5000	11	22
\$3000 - down	12	24
Total	50	100

N = 50

III. INSURANCE CATEGORY

This category used the range from one to three with the number one indicating those families with full insurance and the number three indicating those families with no insurance. The mean was 2.38, s. d. .43 indicating a high degree of families were without insurance. Numerically twenty-four families out of fifty were not covered by any insurance whatsoever. The inability to take care of unforeseen medical crises can increase the anxiety and stress threshold that families have even though the Crippled Children's Division has helped those families who have partial or no insurance at all.

TABLE VIII
INSURANCE DISTRIBUTION

Category	Total	Percent
Full Coverage	3	06
Partial Coverage	23	46
No Coverage	24	48
Total	50	100

N = 50

IV. FAMILY ENVIRONMENTAL STRESS CATEGORY

This category did not use a qualitative scale as it was impossible to determine for this study that one type of family stress held more value than another type of family stress. The objective of this category was to indicate what other stress factors the family may have besides the stress of raising a child with myelomeningocele. Fifty-eight percent of the families were found to have additional stressful problems. The wider a family must spread its ability to cope with stress, the greater the chances are its effectiveness will decrease. Tables IX and X will show other categories of stress that were identified.

TABLE IX
FAMILY ENVIRONMENTAL STRESS:
NUMBERS OF FAMILIES WITH
ADDITIONAL IDENTIFIED
STRESS FACTORS

Category	Total
No Additional Stress Factors	21
Marital Problems	11
Sibling Rivalry	6
Parent-Child Management Problems	14
Additional Ill Family Members	14
Additional Delinquent Family Members	3

TABLE X
INCIDENCE OF STRESS FACTORS

Category	Number of Families
No Additional Stress Factors	21
One Additional Stress Factors	21
Two Additional Stress Factors	7
Three Additional Stress Factors	1

V. EDUCATIONAL STATUS

A scoring range from one to five was established with the number one indicating those children who would be expected to function adequately in a pre-school and the number five indicating those children who would need home instruction. The mean was 2.74, s.d. .93. This shows us that most children in the population would be expected to use the Special School services. This has strong implications for educational services in the community. If these services are not available when the child reaches school age further stress will face the family. Lack of community based educational resources and a lack of understanding on the part of many educators can be tragic for the child with myelomeningocele who has shown progress right up to the time he must enter an educational program. It was felt by the staff that generally speaking only the schools in the urban areas can provide varied resources for multiply handicapped children and even these are seldom willing to enroll a child who is incontinent of urine and feces.

TABLE XI
EDUCATIONAL STATUS

Category	Total	Percent
Private Pre-School	3	06
Regular Pre-School	13	26
Special School	10	20
Will Need Special Education	19	38
Will Need Home Instruction	5	10
Total	50	100

N = 50

See page 26 for a definition of educational categories.

VI. INTELLECTUAL LEVEL CATEGORY

Results of this assessment indicated that the majority of the population fell into the Borderline designation. The scoring range was from one to five with the number one identifying those with average intelligence and the number five indicating those children who could be expected to need custodial care. The mean was 1.98, s. d. 1.17. The title of the category (Borderline) emphasizes the fact that these children run the risk of being arbitrarily dealt with by the educational system. Consultation with clinic staff has indicated that, depending on the school district, the child may be placed in a mental retardation program or in a regular school program. The label of

mental retardation can only compound the stress with which the family is faced. See Table XI.

TABLE XII
INTELLECTUAL LEVEL

Category	IQ	Total	Percent
Average	(84 - above)	24	48
Borderline	(69 - 83)	11	22
Educable	(53 - 68)	7	14
Trainable	(37 - 52)	4	08
Custodial	(36 - below)	4	08
Total		50	100

N = 50

VII. USE OF MEDICAL RESOURCES

This category was designed to give a quantitative impression of how the available resources were utilized by the families in the sample. The results for this assessment were determined by interviewing the staff social worker who was assigned to the Myelomeningocele Clinic at the time of the study. There were eleven questions asked concerning the ability of the family to appropriately use the necessary medical care. All questions were equal in value with the total score indicating how well the family used the medical resources.

The mean was 6.44, s.d. 2.30, indicating that almost one-half of the sample population could effectively use the medical services that were available to them. Although there are some broad common characteristics that families experienced when reacting to stress or crisis, families could be very individualistic when trying to manage chronically critical medical problems. Some families would never notify the Clinic when they moved. Only one family in the sample was constantly good at keeping appointments. Many families seem to use resources only at the times of crisis. The actual management of appointments at the Clinic does not require family participation. Physicians determine when a child should be seen, then send notices to the families. Few families take it upon themselves to call if they feel that their child should be seen.

In the subsections of the Problem Multiplicity Category the following results were found:

VIII. ORTHOPEDIC INVOLVEMENT

In this category the scoring range was one to five with one meaning no problem and five meaning not ambulatory. The mean was 3.80, s.d. 1.96. The results indicate that a majority of the children in the sample were strongly involved with orthopedic problems. The lack of mobility and the visibility of orthopedic problems can be traumatic to a growing child. The degree of visibility of the orthopedic

condition can effect the self-concept of the child and the parents. Schools again play an important role because many are not prepared to deal with the child who uses braces, crutches or a wheelchair to move around. Time is an important thing because the family must understand the long range plans that orthopedic problems require. Natural growth will provide the opportunity for important changes to take place as the child progresses. Families must learn to face long periods of inactivity waiting for their child to reach to next stage of progress.

TABLE XIII
INCIDENCE OF ORTHOPEDIC INVOLVEMENT

Category	Total	Percent
No Problem	7	14
Minor Problems	4	08
Ambulatory With Braces	9	18
Ambulatory With Crutches	11	22
Not Ambulatory	19	38
Total	50	100

N = 50

IX. KIDNEY BLADDER INVOLVEMENT

The scoring range was from one to five with the number one

meaning no problem and the number five meaning a life threatening situation. The mean was 2.86, s. d. 1.16. Kidney Bladder involvement appeared to be affecting a little over one-half of the children in the sample. Inability to control the bladder is one of the primary reasons for excluding a child with myelomeningocele from the school room. Continual wetness can also produce sores and irritation that must be continually managed by the parent. As the child grows, clothing for some one who is always wet becomes hard to find. Possible kidney failure is a life threatening situation that families must cope with continually.

TABLE XIV
INCIDENCE OF KIDNEY-BLADDER INVOLVEMENT

Category	Total	Percent
No Problem	7	14
Partial Control	13	26
External Control	16	32
Surgical Intervention	13	26
Life Threatening	1	02
Total	50	100

N = 50

X. BOWEL INVOLVEMENT

The scoring range went from one to five with number one indicating no problem and number five indicating the need for a colostomy. The mean was 1.84, s. d. .90. This indicated that approximately two-thirds of the patients managed to control their bowel activity through training. It should be noted that even though bowel involvement was not considered consequential for this pre-school sample it will keep children out of school programs if it cannot be controlled.

TABLE XV
INCIDENCE OF BOWEL INVOLVEMENT

Category	Total	Percent
No Problem	23	46
Control By Training	15	30
Manual Control	11	22
Total Incontinence	0	00
Colostomy	1	02
Total	50	100

N = 50

XI. NEUROSURGICAL INVOLVEMENT

The range for this category was from one to five with the number one meaning no problem and the number five meaning neurosurgical complications. The mean was 2.78, s. d. 1.46. The majority of the population appeared to have undergone surgical intervention to prevent the possibility of hydrocephalus at least three times. Each intervention is a life threatening situation that the family must learn to cope with. Twenty-four children in the sample had undergone surgical intervention one to three times. Eight had been involved with surgical intervention four or more times.

TABLE XVI
INCIDENCE OF NEUROSURGICAL INTERVENTION

Category	Total	Percent
No Problem	15	30
Arrested Spontaneously	1	02
Surgically Arrested 1-3 Times	24	48
Surgically Arrested 4-more Times	8	16
Neurosurgical Complications	2	04
Total	50	100

N = 50

XII. ADDITIONAL HANDICAP INVOLVEMENT

This category identified other medical problems that the child with myelomeningocele was involved with in the sample. Individual medical conditions were not given values as no attempt was made to determine whether one condition produced more stress than another. Sixty percent of the sample was involved with medical problems other than those that have already been discussed. This means that even more disciplines will be involved with some families. If services are fragmented and the family is unable to manage the integration of the health care resources, the family will suffer; the child with myelomeningocele will suffer.

TABLE XVII
INCIDENCE OF ADDITIONAL HANDICAPS

Category	Total
No Additional Handicap	20
Cardiac	4
Speech	2
Hearing	2
Other (visual handicaps, multiple anomalies, obesity, etc.)	26

XIII. PROBLEM MULTIPLICITY CATEGORY

This category attempted to bring together the four sub-categories pertaining to medical aspects discussed above. The goal was to determine from the sample the average range of medical involvement that a child with myelomeningocele may be faced with. The range for this category was from one to five with the number one meaning a minimum amount of involvement and the number five meaning a maximum amount of medical involvement. The mean was 2.99, s. d. 1.00. This shows us that the majority of the sample fell within a range from two to four, indicating a high degree multiple medical involvement. To exemplify this further it was possible to find a child with myelomeningocele in the sample with only minimal medical involvement e. g. partial control in the Kidney-Bladder Category and with no problems in the remaining three categories. However, it was statistically easier (over 50%) to find a child with myelomeningocele in the sample who had identified problems in all of the four sub-categories e. g. was not ambulatory, used an external collector, had neurosurgical complications, and controlled his bowels by training.

It is clear that parents with children with myelomeningocele will have an unusual amount of potentially stressful situations with which to deal with during their child's life span. The fact that three children

have died since the collection of material for this study began exemplifies the stress and anxiety that families with children with myelomeningocele must face.

CHAPTER V

COMMENTS AND CONCLUSIONS

An assessment of the findings indicates that a majority of families with children with myelomeningocele found in the sample live within commuting distance to needed medical care, have transportation available to them and generally utilize the necessary medical care appropriately.

The remainder of the categories show, however, that families with children with myelomeningocele could be expected to face a variety of other problems that could only serve to exacerbate family stress. Most families were identified as having little financial power. A majority of the families had little or no medical insurance. Over one-half of the families must seek special educational resources for their children. Fifty-eight percent of the families in the sample were seen as having additional stressful problems to cope with e.g. marital problems, sibling rivalry, additional ill members. Coupled to this, the child with myelomeningocele was found to be greatly involved in a multiplicity of medical problems at many different levels of involvement e.g. orthopedic, bowel, neurosurgical, that would be expected to add to the already stressful family dynamics.

How a family responds to a child with myelomeningocele can be anticipated in the writings of Leonard Shotland. Feelings of fear, guilt, blame and doubt are usually experienced at the time between birth and diagnosis. After diagnosis feelings of anxiety (about the future) and mourning for the loss of "completeness" will appear when the reality of the diagnosis is felt. How the family learns about the child is also a contributing factor. The literature indicates (Hare) that how parents are made aware of the condition of their child is an important factor in alleviating family stress. Staff at the Myelomeningocele Clinic related a story of how a parent was told that their newborn child would die. The family arranged for the funeral, but the child continued to survive. Another parent in a parents' group related that she and her husband had been told that their child would be a vegetable and that he should be placed in an institution. Today the child is able to be at home and is far from being a vegetable. The chronic sorrow that parents experience can be identified in their child rearing patterns. Some will react by infantilizing the child as he grows e. g. one mother with a child in a wheelchair had cared for her to the extent that the youngster could not use her hands in any way. Other parents will respond by treating the child as though he had no handicap at all, "we treat him just like one of the kids". The child's reaction to the parents response to his handicap can often be seen in a loss of self esteem, dependency, and childhood depression.

The study shows that the composite stress factors can be an important point of pressure for families. Examples from the sample include a Chicano family, geographically isolated and with a language barrier who are unable to grasp the importance of proper health care for their child. Marriage relationships appeared to be threatened under the pressure of the feelings that developed after the birth of their handicapped child e. g. guilt, blame. Family roles and relationships seemed to change when the handicapped child entered the family. Concerns about mental retardation, finances, having other children became important. With one-parent families the loneliness of being the only one to manage the care for their handicapped child often produced periods of depression for the parent.

The study clearly indicates that families with children with myelomeningocele and the affected child himself face a wide range of stress factors, emotionally, environmentally and physically. How well the family responds to these stresses will effect the progress of the child. The Myelomeningocele Clinic, in its capacity as a diagnostic center, can play an important part in relieving some of that stress by helping families cope with the multiple problems that they will face.

The coordination and continuity of health care is essential for the progress of the child. For example, the Crippled Children's Division has a satellite clinic in Eugene, Oregon in order to respond

to the handicapped child in the southern part of the state. This can relieve some of the pressure of geographical isolation for those families that are not within commuting distance to the Crippled Children's Division clinics in the metropolitan Portland area. In a negative sense, all of the services for treatment of myelomeningocele are not available in one place and at one time. Families are usually referred by their private physician to the Crippled Children's Division for diagnostic services. If the child continues his contacts with a specific clinic, it will be for periodic team evaluation and recommendations (not treatment). Some families will use specialists in private practice while others utilize the University of Oregon Medical School facilities where they must deal with separate and autonomous outpatient clinics for treatment. A hospitalized patient is under medical supervision for the specialty for which he was admitted. Special arrangements are required for consultation and/or treatment by another specialist. The frequency of hospitalization varies but one is aware of the traumatic effects on the young child and the stress that develops from separation within the family. If treatment becomes fragmented, the family can easily lose track and will have difficulty in maintaining perspective about the rehabilitation goal for the child.

Please see Appendix A for examples of the differences in the use of medical services. Diagram A shows a family utilizing the private care system and the involvement it finds itself in concerning

transportation, finances, between specialists and management of appointments. Diagram B shows a family as it uses the facilities available at the medical school. The successful integration of health care services allows the patient and family to understand what is happening. If the family has confidence that they are actively involved in the progress of their child, the greater the likelihood that rehabilitation goals can be reached. The Myelomeningocele Clinic offers a foundation where the family can learn to understand and integrate the necessary services for their child.

I. SUGGESTIONS FOR CHANGE

To increase the effectiveness of the Myelomeningocele Clinic, a more formalized orientation to the medical care system that the child will be involved with should be developed. The goal would be to help the parents learn about the system so that they can use it to their advantage. This program could be the first step in helping the families develop skills in coping with the multiple stresses of raising a child with myelomeningocele.

In the area of health care accessibility, the extension of the use of satellite clinics to other areas of the state as the population warrants it would be to the advantage of the family. As population increases in the western half of the state, the development of additional satellites would be possible.

An orientation program for personnel in education and other community services could be planned to provide understanding about the services of the clinic and the child with myelomeningocele. Through the use of seminars and involvement with children with myelomeningocele a better idea of his capacities and needs can be developed. With more awareness, hopefully more resources in education, day care and community services can be developed.

A health care program (similar to the one for the General Practitioner) should be developed for the physician with the goal of reorienting him to the impact on family dynamics when a handicapped child is diagnosed.

A program for the social work staff could include curriculum designed to increase skills in educational activity for both the parent and the community. An increase in social work staff would allow for concentration in these activities.

Families that have participated in the myelomeningocele parents group that would meet at the clinic when their child was brought in for periodic evaluations have indicated an interest in having some type of newsletter developed so that information could be shared regarding the care and management of their child e. g. where to get appropriate underwear for growing children who are incontinent.

The parent group itself served as an educational experience for some parents. It was usually made up of different parents each

time it met, but the opportunity was there to share experiences and observe the individual differences of other children with myelomeningocele. The suggestion here is that these groups be allowed to continue and that individuals be encouraged to form new parent groups that are geographically related. The size of the groups throughout the state could serve as a measure of when and where to plan another satellite clinic.

To provide a more complete picture of the child's capacities a parental management scale should be developed and included in the records.

To increase the understanding of myelomeningocele a subscription to the English Spina Bifida Association magazine may prove to be helpful. Much of the review of literature was English in origin, leaving the impression that they were deeply involved with helping families come to terms with raising a child with myelomeningocele.

The review of literature indicated that a family that had successfully coped with crises prior to the birth of a handicapped child would have a better response to that crisis than a family that had failed to develop healthy mechanisms to combat crises. The above suggestions are hopefully designed to facilitate the families ability to face and manage the chronic medical care that comes with raising a child with myelomeningocele.

II. IMPLICATIONS FOR FURTHER RESEARCH

The study has raised a number of questions that may be useful for further research. These questions are:

1. Recent literature (Hewett) has suggested that feelings of guilt on the part of the parent may be exaggerated because we (counselor, physician) imply that they have every reason to feel guilty. Research into just how much the family with a handicapped child deviates from the norm is needed.
2. What are the financial implications of the myelomeningocele disability for the child, family, and community?
3. Which area of the problem-multiplicity group appears to be most severe to the family (external, visible handicap or internal handicap)?
4. What management techniques can be developed to facilitate a patient-centered medical service system/

The overwhelming multiplicity of stress factors identified in this study clearly shows us that further study utilizing contacts with the actual families is needed in order to understand the complete involvement of myelomeningocele with the patient, the family, the community and the health care system.

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APPENDIX A

DIAGRAMS OF SYSTEMS INTERACTION

MEDICAL CARE SYSTEM A

MEDICAL CARE SYSTEM B

An example of the possible degree of interaction that a patient with Myelomeningocele can be faced with. Integrating the use of these resources will facilitate the progress of the patient.

APPENDIX B

ILLUSTRATION OF MYELOMENINGOCELE

FIG. 1. The diagram on the facing page illustrates the vertebral column and spinal cord of the baby shown here. *A*: a cross-section of the normal upper part of the spine. *B*: a cross-section of the lower part of the spine showing incompletely developed vertebrae and spinal cord.

APPENDIX C

SAMPLE OF THE INSTRUMENT

AGE AND SEX	-2 years	2-3 years	3-4 years	4-5 years	5-6 years
Male					
Female					

LIVING SITUATION	Nat. Parents One Parent	Step-Parent Relatives	Foster Home	Child Care Facility	State Institution
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ACCESSIBILITY of SERVICES	-25 Miles	26-50 Miles	51-100 Miles	101-300 Miles	301-500 Miles
Pediatrician or GP					
Neurosurgeon					
Orthopedist					
Urologist					
Hospital					
OP Clinics					
Social Work					
Physical Therapy					
Occupational Therapy					
PHN					
School					

MODE OF TRANSPORT	Automobile	Bus	Train	Commercial Plane	Charter Plane
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FINANCIAL	\$9000+	\$7000-\$9000	\$5000-\$7000	\$3000-\$5000	-\$3000
INSURANCE	Full Ins.	Partial Ins.	No Ins.		

FAMILY-ENVIRONMENT STRESS	No problem Marital Probs	Sib. Rivalry	P-C Behavior Man. Probs.	Add'l Ill Members	Delinquent Members
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EDUCATIONAL STATUS	Private Pre-School	Regular Pre-School	Special School	Will Need Spec. Educ.	Will Need Home Instruct.
INTELLECTUAL LEVEL	Average 84-109	Borderline 83-69	Educable 53-68	Trainable 37-52	Custodial -36

PROBLEM MULTIPLICITY					
Orthopedic	No Problem	Minor Problem	Ambulatory with Braces	Ambulatory with Crutches	Not Ambulatory
Kidney-Bladder	No Problem	Partial Control	External Collector	Surgical Intervention	Life Threatening
Bowel	No Problem	Control by Training	Manual Control	Total Incontinence	Colostomy
Neurosurgical	No Problem	Arrested Spontaneously	Surgically Arrested 1-3	Revised 4 or More	Neurosurgical Complications
Additional Illness or Handicaps	No Problem	Cardiac	Speech	Hearing	Other

USE OF MEDICAL RESOURCES

- _____ Aware of multiple problems, doesn't focus on one to the exclusion of others.
- _____ Seems to understand relationship between Crippled Children Clinics and treatment resources required for patient.
- _____ Assumes responsibility for sustaining treatment, for requesting and keeping appointments with private physicians and/or Medical School clinics.
- _____ Does not need direction and/or reminders by Crippled Children's Division team in order to maintain integration and continuity.
- _____ Notifies when authorizations are needed and/or financial circumstances or phone and address change.
- _____ Sufficiently conscious of hazards of decubiti.
- _____ Voluntarily seeks consultation with Public Health Nurse.
- _____ Uses social work services for integration of fragmented services.
- _____ Uses social work services for educational planning.
- _____ Uses social work services for emotional support.
- _____ Uses social work services for information about community services.

APPENDIX D

CLASSIFICATION OF IQ SCORES

<u>IQ RANGE</u>	<u>STANFORD-BINET</u>	<u>WECHSLER</u>	<u>NEW STANFORD-BINET</u>
Above 140	Genius or near-genius	Very superior	Very superior
130-139	Very superior	Very superior	Superior
120-129	Very superior	Superior	Superior
110-119	Superior	Bright normal	High average
90-109	Normal	Normal or average	Normal or average
80-89	Dullness	Dull normal	Low average
70-79	Borderline deficiency	Borderline	Borderline defective
Below 70	Definite feeble-mindedness	Mental defective	Mentally defective
50-70	Moron		Educable
20-50	Idiot	(30-50)	Trainable
Below 20	Imbecile	(Below 30)	Custodial

AAMD CLASSIFICATION

	<u>WISC</u>	<u>S-B</u>	
-1 to -2 SD	85-70	84-68	Borderline
-2 to -3 SD	70-55	68-52	Mild
-3 to -4 SD	55-40	52-36	Moderate
-4 to -5 SD	40-25	36-20	Severe
-5 to -6 SD	25	20	Profound