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Uncertainty, coping, social support, and family functioning in parents of children with spina bifida

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UNCERTAINTY, COPING, SOCIAL SUPPORT, and FAMILY FUNCTIONING in PARENTS of CHILDREN with SPINA BIFIDA: A DESCRIPTIVE CORRELATIONAL ANALYSIS

by

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Dedicated with love to
my mother and the
memory of my father.

Preface

The number of people who helped me with this project is so great that I could not begin to list them all. First, I would like to thank my mother, who supported and encouraged me in every way possible. Next, I would like to express my gratitude and respect to my committee members, Dr. Holaday, Ms. Lynch, and especially Dr. Ferketich, for spending hours critiquing and helping me to rework this project in order that it attain its fullest potential. I would like to thank my advisor, Mary Tesler, who never failed to give me support and encouragement along the way. Special thanks goes to Steve Paul for his help with the statistics. Finally, I would like to thank the San Francisco Bay Area Chapter and the Stanford Chapter of the Spina Bifida Association, especially Diana Wright, Ken Holmes, and Char Meese, for supporting my work and for helping to facilitate the data collection process.

Uncertainty, Coping, Social Support and Family Functioning in Parents of Children with Spina Bifida: A Descriptive Correlational Analysis

Marilyn D. Miller

Congenital anomalies such as spina bifida often exacerbate feelings of uncertainty in parents. This may affect levels of coping, social support and family functioning. Measures of such concepts are few and have not been frequently used in families of children with congenital anomalies. The purposes of this study are to: (1) assess the reliability of the Parents' Perception of Uncertainty Scale in parents of children with spina bifida, (2) describe the degree of parental uncertainty, coping, social support, and family functioning in this population, and (3) describe the relationships among these variables using the Behavioral Systems Model. Twenty-eight subjects were obtained through two chapters of the Spina Bifida Association. The sample consisted of primarily white, middle class, married, mothers of children with myelomeningocele. Subjects were given the Parents' Perception of Uncertainty Scale, the Ways of Coping Checklist, the Inventory of Socially Supportive Behaviors, and the Family APGAR Scale. Results indicated that all tests except the Ways of Coping Checklist were reliable for this population. Average levels of uncertainty and social support were lower for this population than for populations of families of hospitalized or chronically ill children respectively. Family functioning levels were similar to those of healthy populations. A strong relationship was indicated between perceived social support and family functioning ($r = .67$, $p \leq .001$), indicating limited support for the Behavioral Systems Model. The number of surgeries experienced by the child was negatively related to social support ($r = -.52$, $p \leq .005$) and family functioning ($r = -.56$, $p \leq .04$).

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CHAPTER 1 PROBLEM AREA

Introduction

Congenital anomalies such as spina bifida, often exacerbate feelings of uncertainty in parents because outcomes are frequently ambiguous and unpredictable (Butani, 1984; Solnit and Stark, 1961; Lorber, 1971). Parental uncertainty may, in turn, affect coping styles, family functioning, and need for social support networks (Holaday,1984; Strauss, 1975; Lazarus,1966; Barrerra,1981; Smilkstein,1980). The Behavioral Systems Model of Dorothy Johnson may be useful in describing the relationships between these variables. The Behavioral Systems Model views man as being comprised of eight interrelated subsystems that constitute human behavior (Grubbs, 1980). Each subsystem is founded upon a series of sustenal imperatives (functional requirements) that protect, nurture, and stimulate that particular subsystem. If a sustenal imperative is weakened, then the strength of the entire subsystem is compromised. For example, coping may be described as a sustenal imperative of the achievement subsystem. If uncertainty caused by a child's illness decreases a parent's ability to cope then that parent is unable to achieve a desired goal. Similarly, social support and family functioning are sustenal imperatives of the affiliative subsystem. If uncertainty about a child's illness weakens parents' social support networks or hinders family functioning, that, in turn, affects the parents' ability to affiliate or connect with others. However, these interpretations are purely theoretical since limited research has been generated on the concept of uncertainty and its relation to coping, social support and family functioning in families of children with congenital birth defects. Few studies have also been conducted on specific sustenal imperatives of the Behavioral Systems Model. This study will discuss the relationship of uncertainty to coping, social support, and family functioning in families of children with spina bifida using the Behavioral Systems Model.

Spina bifida occurs relatively frequently, 16 in 10,000 births in the U.S. (Greenberg et al, 1982), and results in complications such as paralysis, hydrocephalus, and possible death. Treatment varies and has ethical implications. Lorber (1971), in a classic but controversial study, maintains that treatment should depend on the severity of the lesion. The most severe cases should not be treated at all since the quality of life would be poor (Lorber, 1971). Although other studies have shown that certain children with severe lesions do well when treatment is initiated early , multiple surgeries are often required and complications may not be resolved until after the age of five or six (McLone, 1985). Because most physicians believe that surgical closure of the sac should be done within forty-eight hours after birth, the amount of time given to parents for decision making regarding treatment options is minimal (McLone, 1985). Thus, it is not surprising that multiple complications associated with spina bifida at birth, combined with the limited time for critical decision making, the possiblity of long-term complications, and the potential death of the child, all serve to increase the level of parental uncertainty. As a result, the effects of spina bifida on the family can be severe. The illness, as well as the possible uncertainty it creates, may affect coping styles (Hayes and Knox, 1984; Hymovich, 1976,McCubbin, 1984). In addition, the need for multiple surgeries may deplete a family's financial resources, increase the need for social support, and alter family functioning (Dorner, 1975).

Although uncertainty has been mentioned in many studies, the literature reveals that few researchers have measured it or recorded the process of its resolution. In several laboratory experiments uncertainty has been considered an independent variable (Nomikos et al,1968; Monat et al, 1972). Others have discussed uncertainty indirectly in connection with variables such as stress, control, and information processing (Suls and Mullen,1981; Miller and Mangan, 1983). Some research has measured different aspects

of the concept of uncertainty. For example, lack of information and ambiguity have been associated with the stress of coping with stimuli whose outcomes are threatening and uncertain (Lazarus, 1966). Only Mishel (1981, 1983, 1984) has directly studied uncertainty in hospitalized patients, their families, and subjects with chronic diseases using instruments specifically designed to measure it. Little is known, however, about parental uncertainty associated with birth defects such as spina bifida.

Uncertainty and its relationship to coping has not been fully explained. Some researchers have found that uncertainty decreases one's ability to cope with illness (Hymovich, 1976; Lewandowski, 1980; Lazarus, 1966). Others have maintained the opposing view, that uncertainty may be used as a coping mechanism (Miller, 1981; Miller and Mangon, 1983). The relationship between uncertainty and social support has not been determined in the research literature, and has only been mentioned on a theoretical level. Likewise, no research has supported a relationship between uncertainty and family functioning.

Purpose

The purposes of this study are to: (1) assess the reliability of Mishel's Parental Perception of Uncertainty Scale in this population, (2) describe the degree of parental uncertainty, coping, social support and family functioning with a child's diagnosis of spina bifida, specifically myelomeningocele, and (3) discuss the relationship between perceptions of uncertainty, methods of coping, levels of social support, and family functioning using the Behavioral Systems Model.

Significance

Spina bifida is the second most frequently occurring birth defect in the United States, present in sixteen out of every 10,000 births (Greenberg, et al, 1982). Regionally, the Southeast has the largest occurrence rate with eight per 10,000 births. The Western

states have a rate of four per 10,000 births (Greenberg, et al, 1982).

Because there is no cure for spina bifida, patients and their families must learn to adapt to the limitations placed on individuals by this condition. Due to the immaturity of the central nervous system at birth, the full functional status of the child may not be known until toddlerhood (Menke, 1985). Often spina bifida patients are subjected to a series of corrective surgeries (Lorber, 1971). Since many health care professionals may be involved in the care, patients and their parents could receive conflicting and ambiguous information.

Clinical nursing practice as well as the larger theoretical body of knowledge can be enhanced by better understanding the phenomenon of uncertainty. Knowledge development regarding uncertainty may contribute to nursing theory particularly in relation to the Behavioral Systems Model. New coping strategies may be needed in order for the patient and family to attain a sense of mastery over illness. Increased levels of social support and improved family functioning might be additional resources worth developing. In addition to to examining the impact of uncertainty on coping, social support, and family functioning, this study will also provide baseline information about the particular level of uncertainty experienced in parents of children with a neurological condition. It will also show how social support and family functioning are also affected by chronic illness, an area largely unexplored in the research.

Assumptions

This research was based on several assumptions. First, man is a behavioral system comprised of eight subsystems which are goal directed (Johnson, 1980). Second, illness is interpreted as an environmental stressor that results in changes in the subsystems for successful adaptation. Third, uncertainty is considered to be a major variable affecting adaptation to illness. Fourth, nursing's role is to stimulate patients to achieve an adequate

level of control over life and illness (Johnson, 1980).

Definitions

Spina Bifida (myelomeningocele): a congenital anomaly that occurs when there is a failure of the caudal end of the neural tube to close early in embryonic life causing a sac containing spinal nerves, meninges, and cerebral-spinal fluid to form and protrude through the opening. Lesions may appear at any cord level. Hydrocephalus may be a concurrent problem.

Uncertainty: a condition that exists when a person (parent) is unable to assign values to an illness, in this case the child's spina bifida and/or is unable accurately to predict the outcomes of that illness (McIntosh, 1974; Mishel, 1983, 1984). Uncertainty was measured using Mishel's Parents Perception of Uncertainty Scale (PPUS).

Coping: Methods used for dealing with a threatening situation (Lazarus, 1975). It was measured by the Ways of Coping Checklist (Folkman and Lazarus, 1980).

Social support : "Support accessible to an individual through social ties to other indiviuals, groups, and the larger community (Lin, 1979, pp. 109)." The Inventory of Socially Supportive Behaviors was used to measure social support in this population.

Family Functioning: A situation that occurs when members of a family " have a commitment to nurture each other emotionally and physically. The commitment is one to share resources such as time, space, and finances, and is made between two or more adults with or without children and single adults with children (Smilkstein, 1980, pp. 223-224)." Family functioning was measured by the Smilkstein's Family APGAR Scale (1980).

Child: any child born with myelomeningocele regardless of sex, or ordinal position between the age of 2-18.

Parent: any biological or adoptive mother of a child born with myelomeningocele regardless of race, religion, color, sex, or creed over the age of 21.

Limitations

Limitations arise from the small sample size and from the measurement scales. The small number of subjects makes generalizability difficult because variables such as ethnicity, education, and socio-economic status cannot be controlled. Since the subjects are members of the Spina Bifida Association, the population may be skewed in the direction of increased social support.

Mishel's test has limitations as well, because factor analysis shows that factor II (lack of clarity) was less able to distinguish between parents of children admitted for medical versus surgical reasons. Factor analysis indicated stronger support for the other three attributes (ambiguity, lack of information, and unpredictability). That particular critical attribute may not withstand further testing in varied populations. The coping and social support scales were not developed for this population so there may be some risks to validity.

Risks to the subjects involve the time needed to complete the questionnaire. Because four tests will be administered subject fatigue may affect the response rate. Questions may cause some subjects to associate them with previous stressors and this may be anxiety producing for the subject. Although the strictest confidentiality will be maintained, loss of privacy remains possible.

Summary

Uncertainty may play a major role in adaptation to chronic illness, affecting coping, social support and family functioning. These relationships have not been researched in families of children with spina bifida. Spina Bifida is a serious birth defect with many chronic side effects (McLone, 1985). Treatment consists of numerous surgeries and procedures. Families need to adapt to this illness in order to cope successfully with the side effects. Because the complications may not be resolved until the child is older,

outcomes for quality of life may be uncertain (McLone, 1985). This, in turn, may affect parental coping, perceived social support and level of family functioning. These variables need to be examined in order to determine if a relationship exists. Results will be explained in terms of the Behavioral Systems Model focusing on the relation of uncertainty to the sustenal imperatives of coping, family functioning, and social support which are part of the achievement and affiliative subsystems. Results from this study will have implications for further nursing research in terms of patient/ family education, assessment, and interventions of coping, social support, and family functioning.

CHAPTER 2 CONCEPTUAL FRAMEWORK

The conceptual framework for this study will provide a method of describing the phenomena of uncertainty, coping, social support, and family functioning. The main theories of each phenomenon will be briefly discussed in order to provide a basis for consideration in conjunction with the Behavioral Systems Model. The Behavioral Systems Model will provide the main framework for analysis of the current literature and for analysis and interpretation of the results of this study.

Uncertainty

Uncertainty has been recognized by philosophers as something that man must continually address by virtue of possessing a finite mind. Since man is not capable of knowing everything, some things remain unknown or uncertain. Uncertainty is often related to health -illness situations because knowledge in the field is limited and many times professionals are not able to provide clients with adequate information (Light, 1979). Two theories of uncertainty and illness exist. The first views uncertainty as a source of stress for patients that must be resolved in order for successful adaptation to occur (Mishel, 1981, 1983, 1984). The second views uncertainty as a buffer to stress. Patients may seek uncertainty as a refuge from threatening diagnoses and prognoses (Miller and Mangon, 1983).

The view of uncertainty as a source of stress has been postulated by a variety of researchers (McIntosh, 1974; Mishel, 1981). Mishel holds that uncertainty must be resolved if the patient is to cope with the illness. Uncertainty is a source of stress because patients are unable to assign meaning to events and are unable to predict outcomes accurately (McIntosh,1974;, Mishel, 19891). Mishel (1981) ascribes four interrelated attributes to uncertainty. Multi-attributed ambiguity pertains to a variety of meanings that can be applied to a situation. Lack of clarity refers to the confusion that may be present

when information is given to patients. Lack of information occurs when knowledge in the field is limited. Unpredictability is the inability to predict outcomes of illness. The impact of each of these attributes on uncertainty-induced stress may vary among situations.

The second opinion holds that uncertainty is a buffer to stress, rather than a source of it (Miller and Mangon, 1983). Some patients may find it easier or less stressful to cope with uncertainty rather than with a threatening diagnosis or illness. Often, not knowing the outcome allows for the element of hope that accompanies an unknown situation. Uncertainty in this case is a coping mechanism that allows the individual to address the threat.

Miller and Mangon (1983) showed that approaches to uncertainty vary with coping styles of individuals. Some prefer to resolve the uncertainty because it is viewed as an added source of stress. Other individuals use it as a stress buffering device. Both interpretations need to be considered in this study because the literature supports both findings.

Coping

Coping is a phenomenon which has been extensively researched. It is necessary for individuals to cope with the stresses of life. Lazarus (1966) believes that stress is caused by a threat and that coping is the means to deal with the threat. There are levels of awareness for coping and these levels may vary for several reasons: "details of the stimulus, properties of the psychological system that make the stimulus threatening; the relationship between the psychological system and the stimulus; the contingencies and the constraints involved in coping with the stress; and the emotion reaction itself (Lazarus, p.84, 1966)." Coping styles will vary according to individuals. Cultural backgrounds, religious beliefs, and societal norms will affect how individuals cope with stress. Ambiguous, unpredictable situations make coping more difficult (Lazarus, 1966). Illness

has been described as a source of stress and it requires successful coping in order for the individual to adapt to it. According to Folkman and Lazarus (1980) coping can be divided into two categories, emotion-focused and problem-focused. Emotion-focused coping occurs when the primary response to stress is emotional. For example, when a parent learns that his/her child has a chronic illness, that person may become depressed for an extended period. Problem-focused coping refers to taking action to adapt to the situation. In this case, a parent of a chronically ill child may cope by joining a parent support group to voice concerns and fears. It must be noted that there is no one correct way to cope with stress. Whether coping is effective or ineffective depends on the result of the coping strategy for that individual. Depression in the early stages of chronic illness is to be expected and may be an effective early strategy. When the depression becomes so severe that the person can no longer function in society, it becomes an ineffective coping strategy.

Coping in relation to uncertainty differs according to the two views of uncertainty. If uncertainty is viewed as stress producing, effective coping would be indicated by efforts to remove the uncertainty (Mishel, 1983). Coping would, therefore, be more problem-focused. When uncertainty is viewed as a stress buffering device, it becomes a coping mechanism (Miller and Mangon , 1983). In this case, there would be no efforts made to alleviate the uncertainty, on the contrary, the uncertainty would be supported. Coping would be emotion focused, when the fears of the illness, as well as the illness itself, become the primary sources of stress (Miller and Mangon, 1983). Thus coping styles vary according to a person's response to uncertainty in relation to the illness.

Social Support

Social support networks provide individuals with overall social communication and assistance. Since society is made up of indivduals who agree to live in relation to each

other and to take responsibility for each other, social support is a product of society. The basic support network of most individuals has been recognized as the family, but friends in neighborhoods, churches, and work environments, as well as in the larger society, also have mutual access to the individual network (Kaplan,1974; Barrera and Ainlay, 1983). During times of crisis, such as illness, social support networks are crucial to individuals. By providing the individual with varying amounts of assistance, social support networks can serve to buffer the stress of the situation.

Social support is the tangible, familial, and community assistance that a patient or family receives during the course of an illness. Barrera and Ainlay (1983) identify four sources of social support. Directive guidance refers to informational instructional forms of support that aid the individual in problem solving (Barrrera and Ainlay, 1983). Non-directive support consists of the emotional and caring aspects of support (Barrera and Ainlay, 1983). Positive social interaction refers to diversional, distracting activities, and it also allows for elements of reciprocity in the social environment (Barrera and Ainlay, 1983). The final source is tangible support which consists of financial aid, material support, and task sharing (Barrera and Ainlay, 1983). Research has shown that individuals, who have a support network that provides support in several areas, are better able to buffer stress and meet the challenges of illness (Barrera, 1981; Schaefer, 1981; Norbeck and Tilden, 1983; Ferrari, 1986).

Family Functioning

The family has long been recognized as the basic unit of society. However the family in our society has undergone many changes. No longer is the large extended family the main unit. Increased mobility of individuals has placed more emphasis on the smaller nuclear family. When a chronic illness such as spina bifida occurs, a family may not be able to rely on extended family members for support. Family functioning refers to the emotional

and physical support given among members (Smilkstein, 1982). The needs of the child with spina bifida may place increased demands on other famiy members and will add to the overall stress the family is experiencing. (Tew et al, 1974). Whether the family remains intact during this crisis depends on the level of family functioning prior to it (Martin, 1975; Dorner, 1975). Families who are united with strong membership support usually remain intact, while those that are unstable dissolve (Martin, 1975; Dorner, 1975). Smilkstein et al (1982) has associated stressful life events such as illness with changes in family functioning. Illness, according to Smilkstein et al (1982), increases the amount of intrafamilial and societal resources used by a family. These resources enable the family to cope successfully with the illness. When the resources are not present, the family enters a crisis phase which may result in maladaptation (Smilkstein et al, 1982). Smilkstein et al (1982) identifies the family as the main source of social support for individuals.

Behavioral Systems Model

The relationships between uncertainty, coping, social support and family functioning may be described by the Behavioral Systems Model of Dorothy Johnson. Uncertainty is an environmental phenomenon that affects coping styles, social support and family functioning. In the following paragraphs, the basic defintions and assumptions will be discussed, followed by a review of the eight behavioral subsystems. Each subsystem is composed of five components: goal, set, choice, action, and sustenal imperatives (Auger, 1976). The sustenal imperative component provides the key to understanding how uncetainty relates to coping, social support and family functioning. Lastly, the instruments will be discussed in relation to the sustenal imperatives.

As was previously stated, Johnson views man as a collection of behavioral subsystems that interrelate to form a whole person or behavioral system (Grubbs, 1980). Human behaviors are organized, complex, overt actions that are purposeful and functional to the

individual (Grubbs, 1980). These actions are to maintain the stability and balance of man and his environment. Man is composed of eight behavioral subsystems each one of which has a set of specific goal related functions. These subsystems are interrelated and thus a disturbance in one can affect the others (Johnson,1980). A person's behavior is also affected by the environment and by others in the community. Instabiltiy occurs when there is an imbalance in the subsystems that is caused by a stressor.

The eight subsystems are: achievement, affiliative, aggressive/protective, dependency, eliminative, ingestive, sexual, and restorative (Grubbs, 1980). The achievement subsystem enables one to attain mastery or control over the enviornment (Grubbs, 1980). Education, job promotion, and acquisition of technical skill are considered part of this subsystem. The affiliative subsystem involves the need to relate to others in order to achieve intimacy and inclusion in social groups (Grubbs, 1980). An individual also has an aggressive/ protective subsystem which seeks to protect self or others from threatening situations (Grubbs, 1980). Self-assertion, for example, plays a vital role in this subsystem (Grubbs, 1980). The dependency subsystem helps to support environmental resources needed to gain trust and feelings of reliance (Grubbs, 1980). Johnson recognized that although everyone strives to be independent, society is sustained by the interdependence of its members. The eliminative subsystem removes biologic waste from the individual (Grubbs, 1980). Some scholars maintain that release of tension is also part of the eliminative subsystem. The ingestive subsystem provides the nutritive requirements of the individual from the environment (Grubbs, 1980). Grubbs maintains that achievement of a pleasure state is also part of this subsystem. The sexual subsystem is associated with procreation as well as sexual gratification needs (Grubbs, 1980). Finally, the restorative subsystem counters fatigue and provides replenishment (Grubbs, 1980).

The structure of every subsystem is comprised of five parts: goal, set, choice, action,

and sustenal imperatives (Auger, 1976). Since sustenal imperatives are essential to this research, they will be discussed separately. As for the remaining four components, goal is the objective behind each behavior (Auger, 1976). Set consists of the pattern of behaviors that the individual usually resorts to in similar situations and thus develops over time (Grubbs, 1980). Choice refers to all other available behaviors that can be used in the situation apart from set (Grubbs, 1980). (Distinguishing between set and choice is difficult and requires in-depth knowledge of the individual.) Action refers to the behavior that is currently being exhibited (Grubbs, 1980).

Each subsystem is based on a foundation of sustenal imperatives or functional requirements which protect a person from noxious stimuli, nurture adaptative behavior, and stimulate the individual in order to elicit new responses (Fawcett, 1984). As regulating mechanisms, they help maintain stability by adjusting behavior or changing conditions. They can be either learned or unlearned and consist of biophysiological, sociological and psychological mechanisms (Grubbs, 1980). Auger (1976) states that a " deficiency in any or all of these sustenal imperatives threatens the life of the system as a whole, as well as the effective functioning of the particular susbsystem with which it is directly involved (Auger, 1976; p. 43)." The behaviors exhibited by each susbsystem, as well as, the nursing interventions that are derived from the theory are often based on sustenal imperatives. (For a model depicting the theory see figure one.)

Figure 1

The Behavioral Systems Model

	Achievement Subsystem <-------> Affiliative Subsystem
Function	mastery or control over the envir. achieve intimacy and social group
	Action- observed behavior
	Choice- all behaviors possible
	Set- usual pattern of behavior
	Goal- objective
	Sustenal Imperatives- basis for subsystem
Coping	Social Support; Family Functioning

Although Johnson states that the model would fail without these sustenal imperatives because they are essential for subsystem balance, it is this portion of the theory that is least described. Johnson did not discuss the effect of the imperatives on the subsystems in detail and, critics of the Johnson theory have cited this as one of the model's major weaknesses. Since the relationships between uncertainty, coping, social support, and family functioning can best be described by sustenal imperatives of the achievement and affiliative subsystems of Behavioral Systems Model, these will be the focus of this study.

Sustenal imperatives of the achievement subsystem include: educational methods, rewards and punishments, grades, increased autonomy and responsibility (Auger, 1976). Achievement of mastery over events as well as adaptation to them are also parts of the subsystem. Coping may be interpreted as a method of adaptation to a particular situation

(Grubbs, 1980). Successful coping allows the individual to attain a level of mastery over stress. Because coping styles are learned and refined in order to allow individuals to deal with threatening stressors (Lazarus, 1966), they are considered to be part of the sustenal imperatives of the achievment subsystem. An individual's repetoire of coping styles is developed early in life and is evoked whenever stressful situations occur (Lazarus, 1966). New styles that are often based on the previous mechanisms will be created in order to cope with new stimuli (Lazarus, 1966). Once coping mechanisms have been learned, they become part of the set and are behaviors that are often called upon. The individual's action of coping is based on the set. New coping styles offer the individual with a choice. If the individual chooses, the new style may be added to the established set of behavioral patterns. Limited coping styles result in a narrow set, confining the range of behavioral responses to threatening situations.

Sustenal imperatives of the affiliative subsystem are related to development of trust, kinship, mutual relationships, self-esteem, communication, and interpersonal relationships (Auger, 1976). Social support is a sustenal imperative of the affiliative subsystem because it allows an individual social ties to other individuals, groups, and the society at large (Lin, 1979). Social support is the amount of inclusion into society an individual experiences. It refers to intimate support of family members as well as government support for individuals in need. Family functioning is a measure of one social group. The family is an individual's main source of intimacy and group inclusion. It is, therefore, a nurturant sustenal imperative of the affiliative subsystem. When chronic illness affects a family, outside support and resources supply these nurturant imperatives, thus enhancing the family's ability to cope. Nurturant imperatives expand the set of behavioral responses. They also offer the individual a variety of choices in selecting a course of action. Limited sustenal imperatives in the affiliative subsystem result in a narrow

choice and set, thus limiting a family's resources for dealing with illness.

Uncertainty, as defined by research, is the inability to predict outcomes accurately and/or the inability to assign values to events (McIntosh, 1974; Mishel, 1983). If one is unable to assign values or meaning to events, one will not understand the total implications of an event (McIntosh, 1974; Mishel, 1981). Thus, one has little control over the event or the effects of the event on one's life. An uncertain environment affects the sustenal imperatives that support certain subsystems. For example the sustenal imperatives of the achievement susbsystem are related to education and individual autonomy (Auger, 1976). Education is interpreted as information given to individuals as well as formal education. Uncertainty may be due, in part, to a lack of available information, thus diminishing an individual's perception of control over the environment. This may affect coping styles by introducting additional stress which compounds the already exisiting stressors.

In terms of the affiliative subsystem, uncertainty may also affect social support and family functionining. Since information is related to both social support and uncertainty, a deficiency in the amount of information an individual receives from the support network may cause a rise in uncertainty (Dimond and Jones, 1980). Sociologists have also indicated that social support may act as a buffer to stressful situations (Barrera, 1981). When stress is increased by uncertainty, social support networks may be essential in supplying the individual with resources necessary to cope with stress. In short, uncertainty is an environmental phenomenon that may be produced by illness. It has a negative effect on the sustenal imperatives of the achievement subsystem thereby causing a deficit. Because the subsystems are interrelated, the affiliative subsystem will respond to the deficit in the achievement subsystem by providing an increase in the supportive services available to the individual. These services, in the form of increased

family functioning and social support, provide essential resources needed by the individual to cope with stress.

In this study spina bifida will be present in all subjects. Here, spina bifida will be the stressor and uncertainty will be viewed as an additional stressor to the environment. These two factors will input into the behavioral system of the parents, thus affecting the sustenal imperatives of the achievement and affiliative subsystems. Since there is little research on uncertainty, coping, social support, family funcitoning, and spina bifida the direction or strengths of the relationships cannot be predicted. Johnson's theory states that the subsystems are interrelated, and thus, there is support for determining the relationships between uncertainty, coping, social support and family functioning.

The uncertainty measured by the Parent's Perception of Uncertainty Scale will be correlated with the Inventory of Socially Supportive Behaviors (social support), the Ways of Coping Checklist (coping) and the Family APGAR Scale (family functioning). In this way, the relationship between the variables may be assessed. These relationships will be described in terms of the sustenal imperatives of the susbsystems, and from assessment of these imperatives nursing diagnoses and interventions will be determined. This research will also give support to Johnson's idea of sustenal imperatives and their importance in the behavioral system model.

REVIEW OF THE LITERATURE

Pertinent literature regarding spina bifida, uncertainty, coping, social support and family functioning is discussed in this review. The major themes in the research literature are presented as well as the indirect relationships between certain variables. The Behavioral Systems Model is used to critique the studies in terms of sustenal imperatives of the achievement and affiliative subsystems. The pathophysiological manifestations of spina bifida are presented along with the familial responses to the illness. The concept of

uncertainty is critiqued both as a stress inducer requiring resolution, and as a means of buffering stress. Coping pertains to problem-oriented styles that either reduce the stress of uncertainty, or emotion-focused methods that use it counteract stress. Since the literature is divided on the subject, both viewpoints are described. Research in the social support and family functioning literature has linked each of these concepts to spina bifida. Most families of children with spina bifida usually have increased social support needs. Family functioning is shown through the research to reflect to the pre-illness state of the family. No research has directly correlated the variables, although relationships are suggested (Dorner, 1975; Martin, 1975).

Spina Bifida

Spina bifida is one of the most common chronic disorders of childhood and may be responsible for many pathophyisological as well as psychological and social effects. Numerous sequelae including paralysis, incontinence, and scoliosis may also be present. In the child's early years, outcomes for improved quality of life may be dependent on the need for numerous surgeries. Families of a child with spina bifida have to adjust to having a chronically ill member. It can be hypothesized that the defect may cause alterations in coping, social support and family functioning. Research has not determined a relationship between coping, and social support in these families, and whether family functioning is altered is controversial. Tew et al (1974) maintain that spina bifida may have an effect on family functioning, wheras others (Martin ,1975; Dorner, 1975) maintain that no relationship exists. Levels of uncertainty related to the severity of the defect may have an effect on these variables.

Spina bifida is caused by the failure of the neural tube to close early in embryonic life (Bahinson,1982). Primary neural development consists of formation of the neural plate from the embryonic ectoderm. The neural plate curves to form the neural tube on day 18

of gestation (Menkes, 1985). The neural groove will then close to form the neural tube. By day 26, the neural tube closes to form the primitive structure of the central nervous system (Menkes, 1985). If the rostral end of the neural tube fails to close, anencephaly will result, and if the caudal end remains open, spina bifida occurs. Three types of spina bifida are known: occulta, meningocele, and myelomeningocele. Spina bifida occulta is an opening of the spinal column under the skin (the word occulta meaning hidden) (Bahinson, 1982). Meningocele is a sac-like formation of the meninges and cerebral-spinal fluid which occurs through an opening in the spinal column either anteriorly or posteriorly (Bahinson,1982). Myelomeningocele (meningonmyelocele), the most serious type of the disorder, is a sac containing the meninges, cerebral-spinal fluid, and the tissue of the spinal cord (Bahinson, 1982). In this type, the exposed nerve endings are damaged and neurological deficits will occur depending on the level of the lesion. Over 80% of the cases with myelomeningocele involve hydrocephalus. (McLone, 1985). Hydrocephalus is caused by structural anomalies in the brain that obstruct the flow of cerebrospinal fluid. The most severe cases of hydrocehalus are seen with Arnold Chiari malformation (Menkes, 1985). The highest incidence of mortality are associated with Arnold Chiari malformation, in which the brainstem is displaced into the cervical spinal canal, compressing it and resulting in death of this structure (McLone, 1985). In cases with hydrocephalus, death may be caused by ventriculitis from an infected shunt (McLone, 1985; Bahinson, 1982). Myelomeningocele has been associated with bowel/bladder incontinence, knee/feet defects, scoliosis, and paraplegia, resulting from subsequent damage to the spinal nerves (McLone, 1985).

Because the severity of the side effects varies, there are several treatment options. In 1971, Lorber reported a radical treatment program where the most severely affected children would not be treated at all, but rather allowed to die since their survival rates with

treatment were poor. Lorber proposed a system of degrees of severity of illness which would indicate who received treatment. The study had two sample groups. The first had 323 infants treated between 1959 and 1963. 50% of these children survived after one year. In 1967-1968 another 201 infants were observed. Of these, only 64% survived (Lorber, 1971). All the infants in both groups were treated in the first day of life. Factors such as increased head circumference (61% mortality), extensive paralysis (65%), extreme kyphosis (55%), and mulitple congenital anomalies (90%) were associated with poor survival (Lorber, 1971). Lorber maintains that since the mortality rates were so high even with treatment, why treat at all if it is going to be unsuccessful. Although Lorber used large samples, they were selected from personal experience. Lorber did not describe the selection process in detail, and it is difficult to determine who constituted the sample. The two groups were matched according to residua. Descriptive statistics were used to analyze the results, but no correlative statistics were used. Lorber's idea was met with skepticism in the U.S. because of its ethical implications. McLone (1985) has shown that with early treatment most of these defects can be corrected or compensated for by medical, surgical, and therapeutic methods.

McLone(1985) studied 200 consecutive newborns with spina bifida. All were treated within 24 hours of birth. 37% showed improvement in motor function over time, and by school age, 80% were community ambulators (McLone, 1985). Overall mortality rates for the children in this sample was 2%, most commonly associated with Arnold Chiari malformation. In 90% of the population, urinary continence was attained wih intermittent straight catheterizations by the age of 5-9 (McLone, 1985). Part of the success of McLone's efforts relates to advances in medical science since Lorber's study. Charney et al (1985) studied the course of 110 infancts who had early (within 48 hrs), delayed (3-7 days) and late (1 week - 10 months) surgery for sac closure. Respective survival rates were

92%, 94%, and 100% (Charney et al, 1985). The authors maintained that delayed or late surgery could be successful, thus allowing parents more time for decision-making. Upon review, it should be noted that the three groups were not of equal in size, with the largest group undergoing early treatment. Survival rates among the three groups might have been coincidental. Of the sample only 29% had hydrocephalus and 54% had no adverse criteria (Lorber's Criteria) that would indicate poor prognosis (Charney et al, 1985). Thus from the sample, good prognosis would be indicated with early treatment. Because the group had good prognostic indicators, changing the sac closure time may or may not have affected the success rates. It could be postulated that children with poorer prognostic indicators may require early treatment.

Because of the many physiological side effects, children with spina bifida have various needs depending on the severity of the lesion. Since parents are often the primary caretakers, time and energy that may have been directed toward the rest of the family is used to care for the ill child (Litman,1974). These children place an increased demand on the families' resources (Smilkstein, 1982). Families must adapt to the child's special needs and, as a result, family dynamics and role expectations may be altered . Parental concerns first involve the issue of decision making (Charney et al, 1985). Because treatment is intiated relatively early, little time for decision making is permitted (Charney et al, 1985). Often the shock of the illness along with the grieving process for the loss of the perfect child may make decision making very difficult (Butani, 1984).

Questions of uncertainty arise at the same time decisions have to be made. Many residua are not apparent at birth, and often the total extent of the defect is not known until the child begins to miss developmental milestones (Bahinson, 1982). For the first year, health care professionals may not be able to predict the course of action. Uncertainty bout the ability of the child to adapt to the world may also be a parental concern that persists

from birth to adolescence (Dorner, 1975). How parents cope with this defect varies from parent to parent. Often coping is related to the amount of received social support and level of family functioning. Uncertainty regarding issues such as quality of life also arises. No research has considered this question, nor have coping strategies or social support needs been examined. However, issues surrounding family functioning have been considered frequently in this population. These will be discussed further in the section on family functioning.

Spina bifida is a very complicated disorder and has many effects on children and families. It is important to remember that the numerous disabling effects may also impact on the levels of perceived uncertainty, coping styles and social support needs of these particular families. However, no research has directly studied these concepts in these families. The research on family functioning in parents of children with spina bifida is divided. Tew et al (1974) maintain that spina bifida may cause a decrease in overall family functioning. However, more recent research holds that that spina bifida has no significant impact on family functioning (Dorner, 1975; Martin, 1975). Because of the controversy in the literature, more research is needed to determine the actual relationship between spina bifida and family functioning.

Uncertainty

Uncertainty has been studied in many dimensions by psychologists, sociologists, and nurses. It has been defined as the inability to assign values to events and/or the inability to predict outcomes (McIntosh, 1972; Mishel, 1981). Mishel described four critical attributes of uncertainty: (1) multi-attributed ambiguity, (2) lack of clarity regarding information that is presented, (3) lack of general information, and (4) unpredictability Several ideas regarding the concept of uncertainty have arisen out of this research. For example, some maintain uncertainty has a synergistic effect on stress (McIntosh,1974; Shalit, 1977 ; Folkman,

1984 ; Lazarus, 1966). Others believe uncertainty is a coping mechanism, that must be fostered in order to buffer stress (Miller, 1979 ; Miller and Mangon, 1983). Uncertainty may also be interpreted as an environmental stressor that affect the sustenal imperatives on the achievment and affiliative subsystems. Each researcher has used a different definition of uncertainty in the research designs. The work of each approach will be critiqued on the basis of its contributions and limitations. Since this study will be replicate of the work done by Mishel in part, her work will be reviewed in greater detail. The Behavioral Systems Model will serve as a means of critique for the remaining studies.

The most complete paper on uncertainty was done by McIntosh (1974). He theorized about uncertainty in patients with cancer, in terms of how patients are given and /or not given information. After an extensive review of the literature, he defined uncertainty as that which occurs "when the decision-maker is unable to assign definite values to events and/or is unable to accurately predict outcomes" (McIntosh, p.170, 1974). McIntosh (1974) recognized that the degree of uncertainty in cancer patients varied due to the specific diagnosis. This recognition led him to distinguish between two types of uncertainty, clincal and functional. Clinical uncertainty pertained to a lack of knowledge in the field, whereas functional uncertainty refered to a physician's deliberately withholding of information from the patient. McIntosh (1974) viewed clinical and functional uncertainty as something that patients needed to control in order to cope with their disease. Interestingly, patients who were not given complete information sought knowledge from other sources, for example, the person in the next bed, friends, relatives, the media. etc. Because cancer describes many different diseases, patients would often assign the wrong meaning to their signs, symptoms, and prognoses. Johnson's theory can be used to describe this phenomenon. The patient in view of an uncertain situation is trying to obtain information for the purposes of trying to achieve successful adaptation to illness. McIntosh

(1974) recognized the necessity of communication in helping to alleviate uncertainty. He suggested that more research be done in physician-patient communication, informal data gathering, and uncertainty in chronically ill patients.

In another review of the literature, Light (1979) described the training of medical personnel in relation to uncertainty. Two situations were linked to uncertainty . The first was the lack of knowledge in the field about the disease, and the second involved having to make a decision without proper knowledge of the patient or the disease. The first pertained to lack of available knowledge regarding specific diseases, diagnoses, prognoses, and treatment. The second refered to emergency situations when decisions have to be made quickly without knowledge of the patient or his disease. Light (1979) also noted that at times uncertainty was used by physicians as a means of controlling patients. Uncertainty arises from the environment because it results in a lack of information either as a deficiency in the field of medical knowledge or in a deliberate witholding of information by professionals. The lack of information prevents a person from achieving a sense of mastery and control over a situation and it is difficult to attain balance in the achievement subsystem.

Suls and Mullen (1981) studied uncertainty, control, and the onset of illness in 119 undergraduate volunteers. Both sexes were equally represented in the sample. Subjects were asked fill out demographic questionnaires, a recent illness inventory, and a recent life events scale. No mention was made of reliability and validity of the instruments used. Results showed no correlation between between life events and onset of illness ($r = .07$ and $p \leq .21$) (Suls and Mullen, 1981). However, when the results were computed for controllability in relation to life change and onset of illness, a different perspective emerged. "The life-events/illness relationship was stronger for undesirable life events of uncertain controllability ($r = .42$) than for uncertain uncontrollable events ($r = .23$) (Suls and

Mullen, 1981, p. 32)". The difference between the two groups was significant at $t_{16} = 2.38$, $p \leq .01$ (Suls and Mullen, 1981). From this finding the authors concluded that uncertainty had a synergistic effect on stressful events (Suls and Mullen, 1981). The lack of information on scale reliability and validity was problematic. It must also be noted that these findings were derived from a healthy population. No conclusions could be drawn about persons who are ill.

Psychologists such as Lazarus et al studied the relation of uncertain and/or ambiguous events on stress as well as the effect of anticipation and control on stress. Certain studies have looked at the element of the unexpected (Nomikos, Opton, Averill, and Lazarus, 1968). 52 college students were randomly assigned to one of two groups, referred to as "short anticipation" and "long anticipation." (Short and long anticipation refer to the length time between the suggestion of a threat and its occurrence.) Physiological measurements of vital signs and skin conductance along with a battery of psychometric tests that measured self-reported stress, mood changes, tension, and overall stress were administered. Each group viewed two versions of a stressful movie (consisting of three vignettes) that were identical except for the anticipatory periods. Analysis of skin conductance data revealed that long-term anticipation was found to be more stress-provoking than short-term anticipation. Analysis of covariance between initial time of anticipation and the actual impact of the accident showed a significant increase in skin conductance in the long anticipatory group during two of the vignettes ($F = 6.68$, $p < .02$ and $F = 4.66$, $p < .05$) (Nomikos, Opton, Averill, and Lazarus, 1968). Graphs of the physiological indicators revealed that the anticipatory period was more stressful than the accident itself, however correlations and levels of significance between the physiological data of the two groups were not listed (Nomikos, Opton, Averill, and Lazarus, 1968). This ommission is important because the reader is unable to determine if signifcant

physiological differences actually existed. No description of the reliability and validity statistics was provided. This study was completed on healthy inividuals and therefore must be used with caution when discussing phenomena common to the ill. According to the Behavioral Systems Model, uncertainty may be explained as an environmental stress that inhibits the protective sustenal imperative of the achievement subsystems. When this happens, an individual no longer has power over a situation.

Nursing research has also measured levels of stress in relation to anticipatory events. Eberly et al (1985) studied stress in parents whose children were unexpectedly admitted to the PICU. Two groups of parents were studied. 233 parents who had children with planned admissions to the ICU and 262 parents of children who had unexpected ICU admissions, but sampling type was not indicated. Parents were given the Parent Stressor Scale and the State-Trait Anxiety Scale. The Parent Stressor Scale is a 62 item, five-point Likert scale that measures seven dimensions of stress, while the State Trait Anxiety Scale is a 20 item test. Results showed that parents of children with unexpected admissions had higher scores on the State Trait Anxiety Scale, $F_{(1, 492)}= 10.87$ with $p<.001$ (Eberly et al, 1985) Mean scores on the parent stressor scale were high for both groups but, again, the unexpected group had the higher scores. This indicated that unexpected or unpredictable admissions increased parental stress (Eberly, 1985). However, there are major weaknesses in the study. First, the sample consisted primarily of mothers (66%), most of whom were white (87%), and almost half of whom had greater than a high school education (46%). Only 14 % of parents in the planned group and 27% of the parents in the unplanned group thought their child's condition was severe (Eberly et al, 1985). No reliability and validity indices of the test were given. Because of the limitations, results cannot be generalized to include a wide variety of people. It was also noted that inadequate, confusing, or unclear information was the third highest source of

stress (Eberly, et al, 1985). Thus, the relation between uncertainty and stress was supported through the factor of unpredictability in this study. Uncertainty was not described directly but two of its attributes, lack of information and ambiguity are related to stress. Based on the Behavioral Systems Model uncertainty is interpreted as an environmental stessor that results in deficiencies in the sustenal imperatives of the achievement and affiliative subsystems. Decreased information and increased ambiguity prevent the parent from sucessfully achieving a level of mastery over the child's illness. The affiliative subsystem may be affected by the inability of the parent to protect the child from noxious stimuli.

While Eberly et al (1985) studied the effects of stress in an acute situation, Hayes and Knox (1984) completed a qualitative research project on the stress parents with children with long-term disabilities undergo. In-hospital, unstructured interviews were obtained from 40 parents of chronically ill chidren. A convenience sample was obtained and data were analyzed according to constant comparative analysis and results were printed verbatim from the interviews (Hayes and Knox, 1984). Statistical analysis was not used in this study. Results cannot be generalized to a large population because of the nature of the methodology but nevertheless the study provides certain insights. Hayes and Knox (1984) showed that hospitalization of chronically ill children caused increased stress in this particular sample of parents. Parents reported that a major cause of stress was not being able to fully understand the nature of the child's disease, i.e. uncertainty regarding their child's illness. Parents were the main interpreters for their child, and felt frustrated when they did not know enough information to tell the child. Parents stated that until they had complete information regarding their child's disease, they had difficulty coping with it. Hayes and Knox (1984) felt that communication of clear accurate information was paramount in parental understanding. According to the Behavioral Systems Model,

accurate information would nurture autonomy and control in the achievement subsystem.

Although the two previous studies have generated questions about the effects of unpredictability (Eberly et al, 1985) and lack of information (Hayes and Knox, 1984) on uncertainty, Mishel has done the most comprehensive work on uncertainty to date. Describing uncertainty as being unable to assign values to events and/or being unable to predict outcomes accurately, Mishel began by studying uncertainty in adult patients (Mishel, 1984; McIntosh, 1974). One hundred medical patients were chosen from a VA hospital. Uncertainty was measured by the Mishel Uncertainty in Illness Scale (MUIS). Stress was measured by the Hospital Stress Rating Scale (HSRS), and seriousness of illness was determined by the Seriousness of Illness Rating Scale (SIRS), (Mishel, 1984). The results showed a strong correlation between hospital stress and uncertainty, with the ambiguity factor rating stronger than the unpredictability factor. According to Mishel, lack of information had the strongest relation to uncertainty ($p \leq .001$), (Mishel, 1984). Uncertainty was also associated with isolation, separation from family and financial problems. Mishel concluded that "correlational analysis indicated a strong relationship between uncertainty and stress suggesting that it was vagueness, lack of clarity, and lack of information about events that accounted for their evaluation as stressful, rather than the event itself" (Mishel, p. 169, 1984). She also found that when uncertainty ceased or decreased, stress also decreased.

Earlier, in 1983, Mishel conducted another study that sought to link uncertainty to specific diseases or stressful procedures in adults. Six disease/treatment categories were chosen: cardiac catheterization; cardiovascular disease; gastro-intestinal disease; lupus; rule-out symptoms; and cancer (Mishel, 1983). Four critical attributes of uncertainty were described and listed as factors: multi-attributed ambiguity (factor I), lack of clarity regarding information that has been given to patients or families (factor II), lack of information

regarding diagnosis, prognosis, and treatment (factor III), and unpredictability with regards to patient outcomes (factor IV). Using the same conceptual framework, Mishel studied uncertainty relationships in patient groups by using disease specific versions of the Mishel Uncertainty Scale. Results clustered around various aspects of each factor. Responses related to ambiguity centered on treatment concerns; severity, state and controllability of illness; and meaning of symptoms. Lack of clarity pertained to information provided by health professionals and effectiveness of treatment on disease and symptoms. Responses concerning seriousness of illness and diagnosis were associated with lack of information. Unpredictability responses clustered around course and outcome of illness. The cardiovascular group focused on two groups: ambiguity and complexity. The lupus group had three clusters: ambiguity; absence of information; and unpredictability. The cancer population also had two clusters: ambiguity and controllability. The cardiac catheterization had three clusters: ambiguity, complexity, and lack of information. The symptom group clustered around four variables: ambiguity, complexity, lack of information, and unpredictalbility. Only the gastro-intestinal group did not cluster. The results show "the closeness of fit between the data and clinical use of the findings" (Mishel, p. 368, 1983). By using diagnostic specific tests, was strengthened.

The final study to be critiqued is Mishel's research on parents' perception of uncertainty with respect to their hospitalized child. Mishel again used the same definition of uncertainty and conceptual framework. The sample consisted of 272 parents: 126 were parents of surgical patients; 96 were parents of medical patients; and 50 were parents of children receiving a diagnostic work-up. The parents were then given the Parent Perception of Uncertainty Scale (PPUS), a test developed from the MUIS (Mishel, 1983). Parents were also given a subjective seriousness of illness question. The purpose of the study was to examine the reliability and validity of the test. The four critical attributes of

uncertainty: multi-attributed ambiguity (I); lack of clarity (II); lack of information (III); and unpredictabiltiy (IV) were factored. One-way analysis of variance results showed that the medical group differed from the surgical group on two of the four factors, III and IV (p=.001) (Mishel, 1983). The medical group also differed from the diagnostic group on factor III (p=.001) The study showed minimally significant relationships among the three groups and seriousness of illness (Mishel, 1983). Mishel also recommended that further research be done on the topic of parental uncertainty.

All of Mishel's work can be interpreted according to the Behavioral Systems Model. In each study uncertainty is an environmental stressor produced by the illness which results in deficiencies in the achievment subsystem. These deficiencies prevent the patient from nurturing autonomy and control.

Research on the concept of uncertainty has produced varying results. Through the work of Nomikos (1968), Eberly et al (1985) and others a relationship between uncertainty and stress has been determined. However, the research has been done in controlled laboratory situations which do not replicate reality or in qualitative interviews that generate but have not tested theory. Each work has highlighted a different aspet of the concept but no study has been replicated. A large portion of the literature is found not in research articles but in theoretical papers. McIntosh (1974), for example, reviewed the literature extensively, and developed defintions based his review, but his ideas were not supported by research until Mishel's work. Mishel's findings, although greatly significant in the adult population, had statistical limitations in the pediatric setting. Lack of clarity was not strongly supported statistically and this may pose difficulties for future use of Mishel's test. If lack of clarity cannot withstand testing, certain questions should be revised, or it may have to be dropped from the instrument altogether. Also in the pediatric setting, Mishel's work was used solely to develop a tool. She did not attempt to identify populations at risk, nor

has the parental uncertainty tool been used in a disease specific population of parents. This research needs to be replicated in a specific population and thus provide support for use of the instrument. In theoretical terms, the Behavioral Systems Model may be applied to the uncertainty literature. Uncertainty may be perceived as an environmental stressor that results in deficiencies in the sustenal imperatives of the achievment subsystem. Parents are not able to achieve a sense of mastery and control over their child's illness because of difficulty assigning meaning to events and inability in predicting outcomes accurately. Autonomy and mastery nurture the achievement subsystem.

Uncertainty and Coping

Uncertainty is related to coping but research is divided about the nature of that relationship. It is viewed as either a stimulus or a response. One set of studies shows that as uncertainty increases, ability to cope will decrease (McCubbin, 1984; Comaroff and Maguire, 1984; Lewadowski, 1980; Hymovich, 1984; Shalit, 1977). Uncertainty acts as the stimulus to ineffective coping. The other set of views indicates that the ability to cope increases with uncertainty and that uncertainty is a response to environmental events (Monat, et al, 1972; Miller and Mangan, 1983). The main tenants of these viewpoints will be presented and discussed in this section.

Uncertainty associated with illness may be a source of stress that requires effective coping. This opinion is supported by Lewandowski(1980) who studied coping patterns of parents of acutely ill children. The sample consisted of 59 parents who had children undergoing open heart surgery and requiring a subsequent stay in an Intensive Care Unit. Interviews and observations revealed that parents experienced shock and stress regardless of how well they had been prepared (Lewandowski,1980). Coping strategies used by these parents included attaining information necessary to understanding the child's prognosis and treatment (Lewandowski,1980). Based on the findings, it appears

that relief from uncertainty may improve coping.

While Lewandowski studied coping in parents of children in an ICU, most of the research has revolved around parents of chronically ill children. McCubbin et al (1984) studied coping strategies of100 families of children with Cystic Fibrosis. They were given open-ended interviews which yielded 80 specific items of coping behavior (McCubbin, 1984). The sample was drawn from a larger population of 208. Attrition consisted of refusal and time limitations. Intact families comprised 90% of the sample and 85% were in the original marriage union. Median length of marriage resulted in a score of 12.6 years (McCubbin, et al 1984). Ages for parents were a median score of 35-37 years for fathers and mothers respectively. Finally, 49% of mothers were fulltime houswives with no outside employment. Test items were subjected to descriptive and factor analysis, and three groups of strategies emerged: maintenance of family integrity, maintenance of social support systems and self-esteem, and comprehension of the child's situation through communication with the health care team. Cronbach's alpha were respectively .79, .79. and .71 indicating good test reliability. McCubbin et al (1984) noted that positive coping correlated with overall health of the child, $r = .20$, $p \leq .05$ for mothers and $r = .23$, $p = .05$ for fathers (McCubbin et al, 1984). Although these results indicate a positive direction of the relationship, the low correlation indicates that the relationship is weak and may be inconclusive. Therefore, further support must be obtained. From McCubbin's work, one may conclude that comprehension of the child's situation helps a parent develop a positive coping strategy. Conversely, a lack of understanding might increase stress. Comprehension of the child's illness and the ability to predict outcomes may be viewed as providing autonomy and, therefore, supporting the achievement subsystem.

Comaroff and Maguire (1984) observed coping patterns of families of 60 leukemic children through the use of open-ended interviews. Results, reported by case study,

indicated that uncertainty related to difficulty coping with leukemia (Comaroff and Maguire, 1984)."...the experience of uncertainty and the search for meaning were *the* characteristic features of the impact of the disease upon sufferers and their families " (Comaroff and Maguire, p. 115, 1981). Only a description of the population was done. No inferential statistics were provided. Like most qualitative research, this study provided a foundation. It showed that uncertainty can be an environmental source of stress that inhibits coping.

Hymovich (1984) studied the coping patterns of 63 parents of chronically ill children. A convenience sample was given an open-ended questionnaire. Content analysis revealed four categories of stressors and seven coping strategies that pertain to families of chronically ill children. Knowledge deficit is a source of stress, which could be resolved by receiving education pertaining to the child's illness (Hymovich, 1984). Hymovich (1976) held that one of the most important tasks of the family is to understand the nature and prognosis of the disease. By attaining an adequate level of understanding, parents and other family members have an easier time coping with the disease (Hymovich, 1976). Three elements: information, guidance, and support constitue parental understanding (Hymovich, 1976). Information according to Hymovich (1976) should be specific and accurate. Problems with this work revolve around the lack of hypothesis testing and descriptive statistics which results in incomplete interpretation of the results. More statistical anlysis needs to be done to support the findings.

These studies describe the relation between uncertainty when viewed as a stressor and coping patterns. Results indicate that uncertainty has a negative effect on coping, and in order for effective coping to occur, uncertainty must be resolved. Uncertainty is interpreted as an environmental stressor that requires resolution for successful coping to take place. Successful coping provides the achievement subsystem with the nurturing,

protecting, and stimulation imperatives that allow for autonomy and mastery over events.

Other studies emphasize the role of uncertainty as a coping strategy. Monat et al (1972) studied stress and coping under conditions of uncertainty using a quasi-experimental design. Twenty college male subjects were randomly selected and randomly assigned to four groups, each having different probabilities of receiving an electric shock: 100% time known, 50% time known, 5% time known, and 0% time known. The sample size was small and therefore, not generalizable. Also, this study was accomplished on healthy subjects, and therefore, correlations with ill populations may or may not be possible. Finally, the sample consisted of all males. Perhaps the findings would be different in a female population. Psychological questionnaires, subjective ratings, and physiological monitoring were used to measure signs of stress and coping. Results showed that in the 100% time unknown group, " avoidance like thoughts" occurred before and after the shock. Monat (1972) concluded that "uncertainty about when a harmful event will occur seems to encourage avoidant-like coping strategies with the passage of time", and that subjects were likely to use uncertainty as a coping mechanism (Monat et al, 1972, p. 244). Uncertainty, in this case, is a coping strategy that protects the self from the threat of a noxious stimuli. In Johnson's terms uncertainty is a protective sustenal imperative.

The interpretation of uncertainty as a coping mechanism was supported by Miller and Mangan (1983) who studied the relation between coping styles and the amount of information provided prior to a procedure. The design was quasi-experimental. 40 volunteer gynecologic patients were grouped according to coping style, blunters (n=20) or monitors (n=20). Members of each group were randomly assigned to two groups: one receiving copious amounts of information about the test (colposcopy) and the second receiving minimal amounts of information. Patients were subjected to various

psychological tests such as, Spielberger Trait Anxiety Test, Multiple Affect Adjective Check List, and the Repression Sensitization Scale, as well as other subjective and physiological measures of discomfort and arousal. Results were obtainted before, during, and after the colposcopy. The research indicated that the low information group had overall less arousal and better coping ability than the high information group. Analysis of variance indicated a significant relationship between: information and tension, $F_{(1, 36)} = 5.71$, $p \leq .02$; information and expected pain, $F_{(1, 36)} = 2.95$, $p \leq .1$; and information and depression, $F_{(1, 36)} = 4.03$, $p \leq .05$. Also it was noted that the particular coping style had an important impact. Monitors who cope with threats by seeking out information coped better in the high information group. Blunters who cope with aversive stimuli by distraction and avoidance fared better in the low information group (Miller and Mangan, 1983). "This is indicated by a significant interaction between coping style and information on change scores from initial pulse rate to final pulse rate, $F(1, 36) = 7.09$, $p \leq .01$ (Miller and Mangon, 1983, pp.229-30). Through these findings it was established that uncertainty could be a source of stress as well as a coping mechanism depending upon the situation. In Johnson's terms, it could be a source of stress or a source of protection for the achievement subsystem. When it is a source of stress, it is part of the environment and affects the system as a whole. When it is a sustenal imperative, it protects the achievement subsystem from a greater threat or fear (namely that of outcomes of illness). Because of the dual role uncertainty can play, the researchers suggest that coping styles of individual patients be considered before presenting them with preliminary information about procedures.

Since research is unclear about the relationship of uncertainty to coping, additional work needs to be done in order to develop a basic understanding of the two concepts. McCubbin (1984), Hymovich (1976), and others maintained that uncertainty or certain

aspects of it, change coping styles and increase coping behaviors. This is due in part to the positive relationship betwen uncertainty and stress (Eberly et al, 1985). These researchers studied the attributes of uncertainty and coping. Lack of information, they asserted, increased coping mechanisms or changed the current style of coping so the individual could adapt to the situation (McCubbin, 1984; Hymovich, 1984). In addition, ambiguity affected coping styles by making it more difficult for the individual to cope (McCubbin, 1984; Hymovich, 1984). Some researchers did not study uncertainty as a concept with all of its attributes contributing to the situation, rather, the individual attributes were studied separately. However, in the work of Miller and Mangon (1983) and Monat et al (1972), uncertainty was studied as a concept in and of itself. Uncertainty functioned as the independent variable and its effect on other variables such as stress, anxiety etc. was measured. This body of research indicated that uncertainty may be used as a coping strategy and that too much information will increase a subject's stress. In summary, the research on uncertainty is divided on whether to consider uncertainty as a stressor or a result. In certain situations uncertainty functioned as a coping mechanism; however, in other situations, it increased a subject's stress.

Uncertainty and Social Support

No research has been done relating the concepts of uncertainty to social support. However there are aspects of social support that may relate to the attributes of uncertainty. Social support has four attributes: positive communication, social integration, instrumental behavior, and reciprocity (Dimond and Jones, 1980). Information sharing is considered to be a part of positive communication. Lack of information is a crucial attribute of uncertainty. If a lack of information persists, it may indicate a malfunctioning social support network. Light (1979), in studying uncertainty, noted that sometimes information is manipulated by health professionals. Lack of clarity of received information, an attribute

of uncertainty, may indicate an inadequate support network. For example, perhaps the health care team is supplying the family with confusing information. Therefore, it is necessary to consider uncertainty in relation to social support. Social support is a sustenal imperative that provides nurturance and protection to the affiliative subsystem and stimulation to the achievement subsystem. Individuals may rely on a support network to protect them from threatening events, such as illness. A support network may stimulate the individual to develop new coping strategies and approaches for dealing with threatening events. In the following pages, the literature on social support networks during times of illness will be reviewed, in order to assess if a relationship beteween uncertainty and social support has been established.

Research has shown that levels of social support often affect the response of a subject to illness or changes in health status (Barrera,1981; Norbeck and Tilden, 1983; Lin et al, 1979). Social support has been negatively linked to stressful life events and illness. Lin et al (1979) studied this relationship in a representative sample of 170 Chinese-Americans selected from a master list of 550 names. The sample was primarily male (N =121), with greater than high school level of education. Social support was negatively related to the appearance of psychiatric symptoms ($r = -.37$). Although the direction of the relationship was indicated by this result, analysis shows a weak relationship. Level of significance is not given. Levels of social support were concluded to be predictors of illness . However, it is recognized that this was only a preliminary study, and that findings in a Chinese-American sample may not be generalizable to other populations. Further research into the relationships between social support, stressful life events and illness is recommended. The Behavioral Systems Model interpretation of social support as a protective sustenal imperative is supported by the results.

In a study by Schaefer et al (1981), stressful life events, psychological symptoms ,

morale, and physical health were related to social network size and tangible, emotional, and informational support. From a subject pool of a larger study, 109 subjects (9 later dropped out of the study) between 45-64 years of age were randomly selected. All subjects were white and either Protestant or Catholic indicating possible sample biases (Schaefer et al, 1981). The 100 subjects were given a battery of six tests that measured, social support, social network, life events, psychologic symptoms, morale and health status. Internal consistency for emotional and informational support was obtained (A = 0.95 and 0.81 respectively), but vacillated with respect to tangible support (A = 0.31). Results showed that "low tangible support and emotional support in addition to certain life events were independently related to depression and negative morale; informational support was associated with positive morale (Schaefer, et al, 1981, pp. 381)". Thus decreased social support failed to nurture the affiliative subsystem (low emotional support) and decreased stimulation (low tangible support) negatively affected the achievement subsystem, resulting in decreased morale . The authors concluded that further research in the area was needed to refine the concept of social support.

Norbeck and Tilden (1983) studied the relationship between social support, life stress and emotional disequilibrium during pregnancy. They hypothesized that (1)" negative life events would be positively related and social support would be negatively related to emotional disequilibrium and (2) high life-stress, low social support, and high emotional disequilibrium would be positively related to complications of pregnancy (Norbeck and Tilden, 1983, pp. 33)". The sample consisted of 170 women who were experiencing a non-complicated pregnancy and who were between 12-20 weeks of gestation. Subjects were given a battery of tests that measured life stress, anxiety, depression, social support and self-esteem (Norbeck and Tilden, 1983). The study showed that life stress explained 21.4% of the variance (B =.44) of emotional disequilibrium, while social support resulted

in 6.5% of the variance (B = -.23) of emotional disequillibrium. Thus, the first hypothesis was supported with a positive relationship between life stress and emotional disequillibrium and a negative relationship between life stress and social support. However, caution must be used when applying the findings to other populations. Hypothesis 2 was only partially supported, although high life stress was related to overall complications of pregnancy. Because R^2 = .21 for life stress and .07 for social support the relationship is weak, therefore the authors recognize the need for further research.

The preceeding research address social support issues in adult populations, and care must be taken when applying these results to families with ill children. In a recent study, Ferrari (1986) described the perception of social support between parents of healthy and chronically ill children. The sample consisted of 148 adults (74 married couples) that volunteered to be in the study. There were at least two children per family. All participants were married. Subjects were matched and assigned to three groups: two groups of families of chronically ill children (diabetic and autistic) and a group of families of healthy children. Subjects were given the Inventory of Socially Supportive Behaviors. Results showed that parents of healthy children perceived higher levels of social support than families of either chronic illness group. Mean social support scores were 97.3, 89.1, and 83.1 for the healthy, autistic and diabetic groups respectively (Ferrari, 1986). Findings in this study may be biased towards the sample and results may vary within a population of single parent families. The results indicated only that the healthy group had more perceived social support than the autistic and diabetic groups. The range of scores, whether high or low, is not reported.

In summary aspects of social support have been related to stressful events and to psychological equilibrium, however the results are often vague because social support is such a broad concept. Research reported in which the specific attributes of social

support are identified may be more helpful. Uncertainty and social support have not been related in the research literature, however, it has been established that both are related to stress. The question is would increased social support act as a buffer to the effects of uncertainty on stress? There also seems to be a relationship between some of the individual attributes of each concept. Lack of information in an uncertain situation could have a hypothetical effect on overall social support. In any case the relation between uncertainty and social support needs to be further researched. Social support has been shown to relate to stressful life events, psychological symptoms and morale (Schaefer et al, 1981; Norbeck and Tilden, 1983). The Behavioral Systems Model would interpret social support as a protective sustenal imperative that aids in successful adaptation to a stressor. No research has described this relationship in parents of children with spina bifida. Because there are weaknesses in the literature, no statistically strong relationships were indicated. Thus, the need for further research is supported.

Uncertainty and Family Functioning

Uncertainty and family functioning are two concepts that have not been studied in relation to each other. There may, however, be a relation between these two phenomena; and both have been studied in relation to stressful environements such as illness. Family functioning has been shown to be altered in families with chronically ill children (Pless et al, 1972). In terms of the Behavioral Systems Model, family dynamics is the main sustenal imperative of the affiliative subsystem. The individual's relation to the family is the main source of protection, nurturance, and stimulation for the individual. Illness and uncertainty that results from it may increase family disequilibrium. Family functioning must be defined and then discussed in relation to the family with the chronically ill child. Finally research must be conducted in order to determine if there is a relationship between uncertainty and family functioning.

The main unit of society is the family, and most of the support that individuals in crisis receive is through family members. Smilkstein (1980) defines a functioning family as one in which the members "have a committment to nurture each other emotionally and physically (Smilkstein, 1980, pp. 223)". This refers to social integration as well as sharing of time, resources and space (Smilkstein, 1980). Chronic childhood illnesses often may have devastating effects on a family. The sick child requires more of the family's resources, materially and emotionally (Smilkstein, 1980; Litman,1974). Familial roles are often altered especially when the child is hospitalized. These families may require more social support from outside sources than other healthy families (Smilkstein, 1980). Research has indicated that stress will cause imbalances in the family that may lead to a breakdown in family functioning (Smilkstein, 1980; Pless et al. 1972; Tew et al, 1974). Tew et al (1974) conducted a ten year longitudinal study of 59 families of children with neural tube defects in the United Kingdom (UK). He compared the results of these families with those of a matched control group followed for the same period. At time of birth, both groups had a marital satisfaction rate of 70%. At the end of the study, 46% of the families of handicapped children considered their marriages to be satisfactory, while in the control group the rate was 79% (Tew et al, 1974). Seven of the marriages in the study group ended in divorce which, when extrapolated, was a rate almost twice the national divorce rate. Interestingly enough, the families of a child with a mild handicap had a similar rate of marital problems (including divorce) to those with a severly handicapped child, 37% to 31% respectively, while the familes of a moderately handicapped child had the lowest rate of problems, 9% . Although this study provides some interesting findings, it must be remembered that only 59 families were studied, therefore, the results cannot be generalized. Cultural differences between the UK and the USA also make generalizabilty difficult. Finally, the causes of marital breakdown might be related to other factors.

Further research in this area is required in order to determine the effects of spina bifida on family functioning.

Dorner (1975) studied the families of 63 adolescents with spina bifida in the U.K. in order to determine if there were any indications of decreased family functioning caused by the effects of long-term illness. Factors of social isolation and depression of both children and parents were closely studied through interviews. Most of the parental respondents were mothers. Social isolation of the adolescent was directly related to the presence of urinary and mobility complications from spina bifida. Periods of depression were experienced by 31% of the girls and 15% of the boys in the study. Parents' degree of social isolation was related to the mobility of the child, yet 57.5% claimed they had no restrictions on their social lives. 22.5% needed to make arrangements for respite care in order to leave the home environment. Mothers of spina bifida children were found to be more depressed than those with normal children, yet when questionned further these mothers attributed the depression to bereavement, menopause, or other normal causes of depression. Spina bifida was rarely identified as the source of depression. Dorner (1975) found that the incidence of marital breakdown was no different than that in the general population which directly refuted the findings by Tew et al (1974). Dorner (1975) recognized that these mothers were "more vulnerable" and therefore more likely to experience depression. The social isolation and depression experienced by the patients were considered as the main detriments to adequate family functioning. According to the Behavioral Systems Model, the social isolation and depression causes a decrease in stimulation of the affiliative subsystem resulting, in impaired functioning of that subsystem.

Martin studied 34 American families of children with spina bifida as part of a larger project. The main purpose of the study was to assess the level of family functioning.

Contrary to the findings of Tew et al (1974), Martin (1975) also found that families of handicapped children had no greater divorce rate than families of normal children. However it was noted that many of the spina bifida children did not live with their natural parents. This may indicate that a breakdown in family functioning occurred immediately following the birth of a handicapped child. Martin (1975) recognized the need for early evaluation and support services for both biological and adoptive parents.

The changes in family functioning caused by chronic illnesses are still under debate. Research has shown that affiliative subsystem deficiencies may or may not occur. All researchers maintained that a breakdown was more likely to occur in a family with already strained relations (Tew et al, 1974; Dorner, !975; Martin, 1975). Research has indicated that in order for normal functioning to occur in times of chronic illness, the family must be willing to undergo change. Some families are better able to accept changes and thus can begin to resume effective functioning. The question for research remains: would an increase in uncertainty, increase the stress of a family enough to cause changes in family functioning?

Summary

Limitations are present in the current literature. In most psychological studies, uncertainty was neither clearly defined nor measured. Although Mishel did provide a working defintion of the concept, there are limitations to her studies. Factor II (Lack of clarity) reached minimally significant results, however Mishel (1983) admitted that the factors might not reach levels of significance with future testing. Likewise, the construct validity measures for the PPUS need to be repeated (Mishel, 1983). Mishel (1983) began to consider the relation of specific dieases to uncertainty, but only in connection with adult patients. No research has been done linking parental uncertainty with specific birth defects, or particular chronic childhood illness. Research on the relationship

between uncertainty and coping yielded various results, and must further refine the direction of that relationship. Although the literature indicates relationships between uncertainty, stress, and coping, no research has been done describing the relationships between uncertainty, social support, and family functioning. The Behavioral Systems Model has been used to critique the studies. Uncertainty in terms of this model may be interpreted either as an environmental stressor or as a protective sustenal imperative of the achievement subsystem. Problem-focused and emotion-focused coping strategies are viewed as protective, nurturing or stimulating imperatives of the achievement subsystem. Social support and family functioning, however, are sustenal imperatives of the affiliative subsystem since they protect, nurture and stimulate an individual's ability to function in social relationships. To date, no research has used the Behavioral Systems Model to describe these relationships. Thus, the body of literature on uncertainty and related concepts is deficient, and requires future studies to address these issues.

CHAPTER 3 RESEARCH METHODS

Design

A correlational descriptive design was used to gain information about perceptions of parental uncertainty with their child's diagnosis of spina bifida. Although previous research indicated there was a relationship between uncertainty and other variables, this research was limited in scope and did not address the questions of this study. Therefore, additional information about the relationships between social support, coping and family functioning with uncertainty was sought. Parents were mailed the packet of instruments and asked to fill them out at their convenience.

Research Setting

Subjects were obtained from two Bay Area chapters of the Spina Bifida Association. Because of financial and time limitations only two chapters could be used. All questionnaires were filled out by the subjects in their homes.

Sample

A convenience sample of 28 mothers of children between 2 and 18 years with myelomeningocele was obtained. Mothers were used because research has shown that they are often the principal caretakers of the child (Litman,1974). Only mothers of children with myelomeningocele were selected because that is the type of spina bifida asociated with chronic complications. Criteria for inclusion in the study were the same as those used by Mishel (1983), that is, mothers had to be able to read and write English, be the primary caretaker of a child, and could not have a disability that would prevent them from filling out the forms. These criteria were selected because it enabled the largest number volunteers to be included in the study. Since the number of spina bifida families in any given geographical area is small, time and financial allottments require that the easiest, most cost efficient method of sampling be used to ensure appropriate sample

size. Committee on Human Research guidelines were used in order to protect the privacy and rights of the subjects. Parents were informed that they have the right to refuse participation at the beginning or at any time during the research. There are limitations to the study because of this sample size. Results can only be interpreted in view of this particular sample.

Procedure

Recruitment was conducted in accordance with the policy of the two participating chapters of the Spina Bifida Association. First, advertisements for the study were placed in chapter newsletters which had a combined circulation of 500. Of these, approximately 300 were parents of children with myelomeningocele. Potential subjects were given thirty days to respond to the ad by telephone call. Ten subjects responded to the advertisement, but only seven completed the forms. Because the initial response was inadequate, the chapters agreed to a second recruitment approach. Consent forms were mailed by the chapters to the 300 approximate families. They were sent introductory letters from the investigator and the chapters involved along with two copies of the consent form and the Subject's Bill of Rights. If they chose to participate, they were instructed to sign both copies of the consent form and return one to the researcher. After initial contact was made and consent obtained, each subject was sent a packet containing the questionnaires, and a demographic data sheet. An hour and fifteen minutes was the estimated time to complete the packet. No special instructions for filling out the forms were given aside from the original instructions for each test. Subjects were allowed fifteen days to complete and return the packets. If no response was received within fifteen days, a follow-up letter was sent. The subject was then allowed an additional thirty days to return the packets. If no response was obtained by this time, the subject was to be dropped from the study. Of the 300 consent forms mailed by the chapters, thirty-six

subjects responded. Of these, only twenty-one met the criteria. Both phases yielded a total sample size of twenty-eight.

Instruments

Parents' Perception of Uncertainty Scale(PPUS)

Subjects were mailed the Parents' Perception of Uncertainty Scale (PPUS) and asked to fill them out at home. The Parents' Perception of Uncertainty Scale was developed in 1983 by Mishel and was derived from her work on uncertainty on adult patients. It is the only instrument that measures uncertainty in parents of hospitalized children. The PPUS is a 34-item Likert scale that uses the four attributes of uncertainty as subscales. Reliability was determined by internal consistency measurements of coefficient alpha. Criteria included: coefficient alpha >.70, item subscale correlation r=.40, and subscale-subscale correlation between r = .30 and r = .70 (Mishel, 1983). Standardized alpha was equal to .91 (Mishel,1983). Table one shows subscale internal consistency measurements. Reliability coefficients for factors I (ambiguity) and II (lack of clarity) were solid and those for factors III (lack of information) and IV (unpredictability) were acceptable for a new test.

Table 1

Initial Reliability Analysis of The PPUS

Factor	Standard Alpha	Item Subscale Correlation
I	.87	.40 - .70
II	.8	.46 - .65
III	.73	.41 - .56
IV	.72	.42 - .60

Note: Table 1 is adapted from "Parents' Perception of Uncertainty Concerning their Hospitalized Child" by M. H. Mishel, 1983, Nursing Research , 32 (6), pp. 324-330.

Factor analysis consisted of principle axis factoring with rotation. A four factor solution resulted (Mishel, 1983). Factor loading occurred at .38 or above. Of the original 34 items, three did not load at all and were dropped (Mishel,1983). Orthagonal rotation revealed that of the remaining 31 variables, 29 loaded significantly on only one factor. Two variables required theoretical considerations for placement. Intercorrelations between individual factors and the total score were all positive with r=.50 to .89, indicating that different factors measured different aspects of uncertainty (Mishel, 1983).

Construct validity was assessed by testing the hypothesis that there would be no difference in uncertainty across groups. Total results indicated: $F_{(2,269)}= 7.45$ at $p \leq .001$. Parents of medical patients differed significantly from parents of surgical patients, and the parents of surgical patients differed significantly from those in the

diagnostic group ($p \leq .001$). However, only a minor difference was noted between parents of medical and diagnostic patients. Parents of medical and diagnostic patients felt " less able to construct a picture of the symptoms and treatment , that less information had been given to them, and, therefore, a greater sense of unpredictability was present (Mishel, 1983, p. 328)." Construct validity was assessed by testing the relation of uncertainty with subjective perceived seriousness of illness. A weak correlation supported the alternative hypothesis and, thereby, gave some support to construct validity ($r= .16$, $p. \leq .004$).

The PPUS is the only available tool that measures parental uncertainty. Because it was used only in its initial development study, there are several limitations with the test. The results for factor II (lack of clarity) showed that this variable did not correlate with treatment groups or with seriousness of ilness.

" There was no difference in the lack of clarity subscale among treatment groups. In this analysis only Factor II failed to distinguish between groups. Also on the correlation with seriousness of illness, the lack of clarity factor was the only factor that did not correlate with the external variable (Mishel, 1983, pp. 329)."

Further limitations of the PPUS is that it has never been tested in a disease specific population, only in general with parents of medical and surgical patients. Use of the test with specific populations is the next step in test development. Mishel (1984) did this with the Mishel Uncertainty Scale, which is in a more advanced stage of development. Continuous use of the PPUS will either support or reject test reliability by the obtaining of consistent results. Finally, correlating the test results with those obtained by instruments that measure other variables will support the construct validity of the tool.

Ways of Coping Checklist

Coping was measured by the Ways of Coping Checklist (WCC). Developed in 1980

and revised in 1985 the instrument measures problem-focused and emotion-focused coping. Eight subscales of coping behavior (confrontive coping, seeking social support, self controlling coping, planful problem solving, distancing, escape-avoidance, positive reappraisal, and accepting responsibility) were developed to measure problem- and emotion-focused coping. Because various methods of coping were measured, the WCC may be used to determine how families are coping with uncertainty. If a parent is using uncertainty as a coping mechanism, one would expect that person to exhibit an emotion-focused coping style such as distancing. However, if uncertainty functions as a source of stress, coping may be viewed as problem-oriented since the person is trying to eliminate uncertainty through a more confrontive coping style. The original instrument had two parts: a descriptive narrative and a questionnaire. It was developed to measure coping in normal individuals with varying amounts and types of stress. The descriptive narrative was the account of a particular stressful event. The responses on the checklist were then related to that particular event. In this study only the checklist was used and subjects were asked to relate the questions to their child's spina bifida. Thus spina bifida served as the stressful event. This method was decided upon because it is easier for the subjects and because the investigator is interested in general coping patterns in these families not the coping patterns related to a specific event. As a result coping styles cannot be related to specific stressful events. Although the WCC has been used in many studies, only the results from the original study will be discussed in relation to reliabilty and validity assessments.

The WCC was developed by Folkman and Lazarus to measure coping patterns of normal individuals in specific stressful situations. In the original study, 100 respondents between the ages of 45-64 participated in the study. Subjects were sampled fron a previously studied population (Folkman and Lazarus,1980). The instrument consists of

68 items that describe a broad range of coping strategies divided into two categories problem-focused and emotion-focused. Validity was supported in various ways. First, an interrater reliability of 91% agreement among 10 people familiar with the theory being tested was obtained. Secondly, factor analysis using a varimax rotation showed that 78% of the problem-focused items correlated with the first factor and 68% of emotion focused items correlated with the second factor. Reliability was assessed by use of Coefficient alpha. The result for two administrations of the problem (P) scale was .80, and for the emotion (E) scale, .81. This was done by randomly selecting two administrations and treating them separately. However, coefficient alphas for the subscales were lower: confrontive coping, a=.70; distancing, a = .61; self-controlling, a=.70; seeking social support, a=.76; accepting responsibility, a=.66; escape-avoidance, a=.72; planful problem solving, a=.68; and positive reappraisal, a= .79 (Folkman and Lazarus, 1985).

The WCC has not been used in families of children with spina bifida, nor has it been correlated with the variables of uncertainty, social support , and family functioning. Since this is a new population for this test, reliability will need to be assessed. This may be difficult since the initial reliability coefficients for the subscales were low. However, correlations with the above variables may add new knowledge to the coping literature.

Inventory of Socially Supportive Behaviors (ISSB)

The Inventory of Socially Supportive Behaviors (ISSB) was developed by Barrera in 1981 to quantitatively measure perceived social support. The ISSB has been used successfully with parents of chronically ill children and,for this reason, was chosen for this study (Ferrari, 1986). Originally, the ISSB was a five-item Likert scale that measured social support via four subscales which correspond to the four attributes of social support (guidance, emotional, tangible, and social interaction). Subsequently, the ISSB has been

used many times, but only the results from the original study will be discussed here. In addition, another study that measures social support in fathers of chronically ill children will be reviewed.

The orignal sample for the ISSB study consisted of 86 pregnant teenagers selected from three clinics (Barrera,1981). Subjects were given the social support scale along with a maladjustment scale, a negative life events scale. The scale consisted of 40 items. Internal consistency was initially obtained through a test-retest of the same population at two different time intervals. Coeffiecient alphas were analyzed at .92 and.94 respectively, thus indicating a high internal consistency. Construct validity correlations between stressful life events and social support were positively related with $r=.41$, $p\leq.001$. Stressful life events were positively correlated with support need $r= .36$, $p\leq.001$ and negatively correlated with support satisfaction $r=-.38$, $p\leq.001$. Finally, the role of social support as a stress buffer was examined by regression anlysis of each symptom measure. "Support variables, negative life events, and their interactional support were poor indicators of anxiety and somatization... In regression on the depression subscale scores, significant stress x social support interactions were shown for two support variables : total network size ($F_{1, 82} = 4.00$, $p\leq.05$) and unconflicted network size ($F_{1, 82} = 4.21$, $p\leq.05$) (Barrera, 1981, pp. 84)". Therefore it may be concluded that depression may be influenced by both the degree of stress experienced and the amount of social support perceived.

The ISSB was used by Ferrari (1986) to measure social support in parents of chronically ill versus healthy children. Results showed that parents of healthy children had higher levels of social support (group mean = 97.29) than parents of autistic or diabetic children (group means = 89.13 and 83.13 respectively) (Ferrari, 1986). Interestingly, mothers reported higher levels of social support than did fathers with

$F(1, 136=15.32, p\leq.001)$. This study supported for the use of the ISSB in research on parents of children with chronic illnesses. Because it was able to measure the differences among the three groups (normal, autistic, diabetic) the reliability of the tool was supported.

The ISSB has been used in many research situations. It has successfully measured perceived levels of social support as well as the four critical attributes of social support in these populations. Recent literature (Ferarri, 1986) supports the use of the test in families of chronically ill children such as those with spina bifida. This study will add to overall reliability of the test. In addition, the literature will be increased by describing the correlation between social support and other variables.

Family APGAR Scale

The Family APGAR Scale will be used to determine the level of family functioning in this study. The Family APGAR Scale was devloped in 1978 by Smilkstein as a family functioning screening tool for family practice physicians. It was conceptually based on the neonatal apgar scale. The instrument is a two-part test but only the first part, an indicator of family functioning, will be used. The Family APGAR Scale was selected because it is administered easily and it has high reliability and validity indicators. Results will be correlated with the responses on the other tests. The Family APGAR Scale has not been used in this type of research, but its author has used it extensively in the family practice literature (Smilkstein, 1980,1984; Smilkstein et al, 1982).

The Family APGAR Scale is a five-item Likert scale consisting of five responses per item. The responses are given points on a scale of 0-4. The highest possible score is 20 while the lowest is zero (Smilkstein et al, 1982). Space is left for personal comments under each item. In an initial study of 528 first and second year college students, the Family APGAR Scale achieved a Cronbach's alpha of .80 (Smilkstein et al, 1982). In

another study with 100 Tawainese college students, test-retest reliability achieved a coefficient of .83 (Smilkstein et al, 1982). Initial validation was determined by correlating responses on the Family APGAR Scale with responses on the Pless-Slatterwhite Family Function Index with r= .80 . Validity was indicated by positive responses in married students (mean = 8.24) , a group in which high scores would be expected, and low results in mental health patients (mean = 5.89), a group in which low results would be expected. By using the Family APGAR Scale in this study, reliability will be obtained through replication. Construct validity will be obtained in correlations with other variables.

PROPOSED DATA ANALYSIS

Data analysis consisted of descriptive and inferential statistics. Frequency distributions as well as point estimates were generated on demographic as well as instrument data. Estimates of reliability for all instruments were assessed by using Cronbach's alpha as a measure of internal consistency. Pearson's correlation coefficients and non- parametric measures of association were used, as appropriate for the data, to examine relationships among demographic and study variables. Tests which examine differences between sub groups of the population such as T- tests, ANOVA or their non-parametric equivalents may also be appropriate.

Each research question was answered through appropriate statistical analysis

What are the psychometric properties of the Parental Uncertainty Scale in this population?

Reliability was determined by Cronbach's alpha prior to any descriptive or inferential analysis.

What is the relationship between parental uncertainty and spina bifida?

Descriptive statistics including the mean and standard deviation of the test scores were used for the initial analysis. Correlational statistics were then used to identify the

relationships between the instruments. Finally correlational relationships between the various residua from spina bifida and the overall scores were analyzed.

What is the relation between parental uncertainty, methods of coping, levels of perceived social support, and levels of family functioning?

Descriptive statistics including mean and standard deviation along with Pearson's Correlation coefficients were used to analyze overall test results as well as the individual subscale item relationships when appropiate. Differences between groups were assessed by T-tests, ANOVA , or their non-parametric equivalents.

CHAPTER 4 RESULTS

Introduction

Statistical analysis consisted of sample description, and analysis pertinent to the purposes of the study. In order to determine the reliability of the instruments, Cronbach's alpha coefficients were used on the four instruments as well as their subscales. To describe the levels of perceived uncertainty, social support, family functioning, and methods of coping, computation of the mean, standard deviation, and the range was conducted. Finally, Pearson's Correlation Coefficient was used to discuss the relationships between uncertainty, coping, social support and family functioning. Correlational analysis was used to determine relationships among the total scores, the subscale scores, and the responses to the demographic data. Analysis of variance was used to examine group differences on major variables.

Sample

The sample consisted of 28 mothers of children with myelomeningocele. Most of the mothers were white, middle class, married, and fairly well-educated. Parents ranged in age from twenty-nine to fifty. Family size consisted of about three children (including the child with spina bifida) per family. Table 2 lists the pertinent demographic statistics.

Table 2

Demographic Statistics

Variable	Freq.	%	Variable	Freq.	%
Race-			Annual Income-		
White	24	85.7	5-10,000	1	3.6
Black	1	3.6	10-15,000	3	10.7
Hispanic	4	10.7	15-20,000	1	3.6
Marital Status-			20-30,000	5	17.9
Married	25	89.3	30-50,000	10	35.7
Divorced	3	10.7	50-70,000	6	21.4
Education-					
Graduate	4	14.3			
College	15	53.6			
H.S.	9	32.0			

	Mean	S.D.	Range	Max	Min
Age of Parent	36.5	5.97	21.00	50	29
No. of Children	2.82	1.61	7.00	8	1
Age of Child with S.B.	6.7	5.24	15.00	17	2

Note: N = 28

Since severity of spina bifida varies in each case, it is important to describe the group

of children with spina bifida in terms of sex, age, past surgeries, and presence of side effects. Of the twenty-eight children with spina bifida, 42.9% (n=12) were boys and 57.1% (n=16) were girls. Ages of the children ranged between two to eighteen years with a mean age of 6.89 years (S.D.= 5.24). The total number of surgeries related to myelomeningocele ranged from 2 to greater than 9 with a mean of 5.25 (S.D. = 2.22). Most of the children experienced incontinence of the bladder, while approximately three-quarters also had incontinence of bowel. Hydrocephalus was present in three quarters of the children. Finally, a large percentage of children required the use of ambulation-assistance devices such as braces and crutches. Table 3 lists the occurrences of side effects related to spina bifida.

Table 3

Presence of Side Effects of Spina Bifida

Variable	Freq.	%
Incontinence of bowel	22	78.6
Incontinence of bladder	27	96.4
Paralysis	19	67.9
Hydrocephalus	21	75.0
Braces	23	82.1
Crutches	11	39.3
Wheelchair	13	46.4
Scoliosis	9	32.1
Knee Problems	7	25.0
Foot Problems	15	53.6
Learning Disabilities	7	25.0
Mental Retardation	0	0

Note: N = 28

Reliability

The first purpose of the study was to determine the reliability of the Parents' Perception of Uncertainty Scale with parents of children with myelomengocele. In this section, reliability coefficients for each of the instruments are reviewed

Parents' Perception of Uncertainty Scale

The total score of the Parents' Perception of Uncertainty Scale (PPUS) had a

Cronbach's alpha of .94, supporting that the test was reliable for this population. Table 4 lists the reliability coefficients of the PPUS and its subscales.

Table 4

Reliability Coefficients of the PPUS

Scale/subscale	No. of items	Stand. alpha
PPUS	31	.94
Lack of Information.	5	.63
Lack of Clarity	9	.88
Multi-attributed Ambiguity	13	.89
Unpredictability	4	.68

Note: N = 28

Thus, reliability of the instrument in this population was supported with an alpha of .94. Two of the subscales, lack of clarity and multi-attributed ambiguity, were reliable for this population with alphas of .88 and .89, respectively. The other two attributes, lack of information and unpredictability, achieved alphas of .63 and .68 which indicated low reliability on these subscales. However, since uncertainty is comprised of all four elements, and since each contributes to the level of perceived uncertainty, the total score coefficient is more indicative of overall test performance.

Ways of Coping Checklist

The Ways of Coping Checklist (WCC) does not have a total score so each of the eight subscales must be assessed individually. Cronbach's alpha measurements were

conducted on all the subscales but only accepting responsibility (a = .78) demonstrated an acceptable level of consistency for a previously developed instrument (Nunally, 1978) Table 5 lists the reliability coefficients for the WCC.

Table 5

Reliability Coefficients of the WCC

Scale/subscale	No. of items	Stand. alpha
Confrontive Coping	6	.68
Distancing	6	.69
Seeks Social Support	6	.63
Escape/Avoidance	8	.64
Accepts Responsibility	4	.78
Self Controlling	7	.63
Positive Reappraisal	7	.69
Planful Problem Solving	6	.28

Note: N = 28

Since the subscale, accepting responsibility, was the only one with a coefficient alpha greater than .70, reliability for this population was not supported.

Inventory of Socially Supportive Behaviors

Support for the reliability of the ISSB was indicated by a Cronbach's alpha coefficient of .96. The subscales had high coefficients as well. Table 6 lists the reliability coefficients for the ISSB.

Table 6

Reliability Coefficients of the ISSB

Scale/subscale	No. of items	Stand. alpha
Total ISSB	40	.96
Tangible Support	12	.84
Guidance Support	14	.92
Emotional Support	11	.95
Social Interaction	3	.87

Note: N = 28

The ISSB was reliable for the population as indicated by the total reliability score of .96. The individual subscales all had reliability coefficients of .84 or greater, indicating strong reliability for each of the subscales.

Family APGAR Scale

The total score on the Family APGAR Scale had a Cronbach's alpha coefficient of .89 indicating reliability in this population. Since the test has only five items, subscale analysis was not possible.

In summation the PPUS, the ISSB and the Family APGAR Scale all attained adequate reliability coefficients for this out-patient population. Only the WCC did not achieve high reliability coefficients, therefore, hampering further analysis with this instrument.

Degrees of Uncertainty, Coping, Social Support and Family Functioning

The second purpose of the study was to determine the degree of perceived uncertainty, social support, family functioning, and methods of coping,in parents of children with myelomengocele. In order to achieve this objective descriptive analysis, the standard deviation and the range were generated from the total scores and the subscale scores of each instrument (see Tables 7,8, and 9).

Uncertainty

The level of perceived uncertainty in this population was determined by comparison of the mean, standard deviation, range, and kurtosis of the PPUS. The mean of the total score equaled 68.09. In a normal distribution, such as this, the mean is the best estimate of the level of uncertainty of the group. Comparison with the mean of the total score in studies done by Mishel (1983) indicates that this group of parents experienced less uncertainty than parents of hospitalized children (means = 80-92). Although some members exhibited a great deal of uncertainty, others reflected very little. Table 7 indicates the results for the Parents' Perception of Uncertainty Scale.

Table 7

Degree of Parental Uncertainty (PPUS)

Scale/subscale	No. of items	Mean	S.D.	Total Possible	Maximum	Minimum
PPUS	31	68.09	19.40	155	109.00	39.46
Lack of Information	5	9.002	64	25	15.00	5.00
Lack of Clarity	9	20.57	7.14	45	36.00	9.00
Multi-attributed Ambiguity	13	29.31	9.12	65	49.00	14.91
Unpredictability	4	9.20	2.99	20	17.00	4.55

Note: N = 28; Scoring range per item: 1-5

Coping

Due to its low reliability the WCC must be assessed carefully. The subscale planful problem solving had the lowest reliability coefficient. In spite of the low reliability, positive reapraisal appeared to be the method described as being used the most often by these families to cope with spina bifida. Escape/Avoidance, confrontive coping, and distancing were the methods used the least. Even though the population belonged to a support group such as the Spina Bifida Association, planful problem solving was not the method of choice. Table 8 lists the results of the WCC.

Table 8

Ways of Coping Checklist (WCC)

Scale/subscale	No. of items	Mean	S.D.	Total Possible	Maximum	Minimum
Confrontive Coping	6	6.19	3.34	18	13.00	2.00
Distancing	6	5.42	2.95	18	13.00	1.00
Seeks Social Support	6	10.96	3.34	18	18.00	1.00
Escape/Avoidance	8	6.46	3.82	24	18.00	5.00
Accepts Responsibility	4	2.93	2.52	12	8.00	0.00
Self Controlling	7	9.11	3.59	21	16.00	1.00
Positive Reappraisal	7	12.51	3.73	21	20.00	4.00
Planful Problem Solving	6	9.14	2.42	18	14.00	6.00

Note: N = 28; Scoring range per item: 0-3

Social Support

The level of social support was indicated by a mean of 85.84 and a standard deviation of 29.16. This mean is consistent with results obtained with other groups of parents of chronically ill children (Ferrari, 1986). Even though these parents belonged to a support organization, the mean score was still compatible with past research. Thus, social support is still a need in this population. Kurtosis equaled -1.22 indicating that fewer than expected subjects scored in the mid-portion of the distribution. The skew of .46 shows a

small tendency toward scores in the higher range of the social support scale. Analysis of the subscales reveals that there was no difference among them and that all contributed to the total score. Table 9 portrays the results of the ISSB.

Table 9

Perceived Social Support (ISSB)

Scale/subscale	# of items	Mean	S.D.	Total Possible	Maximum	Minimum
Total ISSB	40	85.84	29.16	200	146.00	46.00
Tangible Support	12	20.63	6.90	60	42.00	12.00
Guidance Support	14	27.78	9.32	70	47.28	14.00
Emotional Support	11	29.86	12.40	55	50.00	15.00
Social Interaction	3	7.57	3.34	15	15.00	3.00

Note: N = 28

Family Functioning

The family functioning scale is a unidimensional test, with only a total score reported. Mean for the Family APGAR Scale was 14.00. The mean was consistent with previous reults in healthy populations (Smilkstein et al, 1982). Standard deviation of the mean was 3.97 with a range of 13.00 (min. = 7.00 and max. = 20.00). The lowest and highest possible scores range from 0 to 20.

In summary the results indicated that uncertainty was present in this population but at a level lower than those obtained in parents of hospitalized children (Mishel, 1983). Despite the low reliability, the Ways of Coping indicated that positive reappraisal was the

method used most often by these families in coping with their children's spina bifida. Social support attained a level consistent with other parents of chronically ill children (Ferrari, 1986), despite the fact that these parents belong to a support group. Finally, family functioning was at a level comparable with healthy populations(Smilkstein et al, 1982), indicating that spina bifida is not an apparent detriment to family functioning. Now that the levels of the variables in this population were discussed, the relationships between these variables need to be determined.

Realtionships between Uncertainty, Coping, Social Support and Family Functioning

The final purpose of the study was to determine the relationships between uncertainty, coping, social support, and family functioning. Correlational analysis consisted of using the Pearson's Correlation Coefficient with a two-tailed level of probability. Relationships were determined between the total test scores and the subscales of all instruments, as well as, the total score and demographic variables. Finally one-way analysis of variance was used to determine if there were differences between groups, based on age of the child with spina bifida and scores on the uncertainy, coping, social support, and family functioning instruments.

The total score for the Parents' Perception of Uncertainty Scale (PPUS) was postively related to the planful problem solving subscale of the WCC ($r = .40$; $p \leq .04$). The total score of the Inventory of Socially Supportive Behaviors (ISSB) had a positive correlation with the seeking social support subscale of the Ways of Coping Checklist (WCC) ($r = .54$; $p \leq .003$), as well as a positve relationship with the total score on the Family APGAR ($r = .67$; $p \leq .001$). No other correlations among the four instruments existed ($r = -.29$ to $.29$)($p \leq .06$ - $.98$).

Correlational analysis was also conducted between total instrument and subscale

scores and responses to demographic variables. Age of the child with spina bifida was negatively related to the total score on the ISSB (r=-.33; $p \leq .09$) however the significance is minimal. The sex of the child with spina bifida was negatively related to the seeking social support subscale of the WCC (r=-.31; $p \leq .10$) but the relationship is not statistically significant. Socioeconomic status (SES) was positively related to the total score on the Family APGAR Scale (r=.41; $p \leq .04$), and the relationship is statistically significant.

Negative relationships were indicated between the presence of paralysis and several subscales of the WCC. Confrontive coping and the presence of paralysis had a negative relationship of r= -.32; $p \leq .09$. The correlation between the presence of paralysis and distancing equaled r=-.36; $p \leq .06$. Because the p value in each of the above relationships is greater than .05, statistical significance is questionable. Self-controlling coping styles were also negativley related to paralysis with r=-.38; $p \leq .04$. Accepting responsibility was related to the presence of paralysis with r=-.44; $p \leq .02$. Learning disabilities were related to the total score on the ISSB with r=.34; $p \leq .01$. The number of surgeries related to spina bifida was negatively related to both the total score on the ISSB (r=-.52; $p \leq .005$), and the total score on the Family APGAR Scale (r=-.56; $p \leq .004$). The relationships between the number of surgeries with the ISSB and the Family APGAR Scale were both strong, as well as significant. Therefore, a high number of surgeries experienced by the child with spina bifida may result in deficiencies in family functioning and perceived social support.

Analysis of Variance Between Age and Uncertainty, Coping, Social Support and Family Functioning

One-way analysis of variance was conducted between the age categories of the child with spina bifida and the total scores of the instruments, as well as, the scores of the

subscales. Group 1 was comprised of parents with children between 2-5 years (n=16); group 2 consisted of parents with children between 6 and 11 years (n=5). Group 3 consisted of parents of children between 12 and 18 years (n=7). Group 1 was significantly different from group 2 on the seeking social support subscale of the Ways of Coping checklist (F= 3.95, p=.05). There were no other differences.

Correlational analysis indicated a relationship between family functioning and social support that has not been previously mentioned in the literature. However, there was little relationship between uncertainty and coping, social support, and family functioning. Uncertainty was not related to any of the demographic variables, although both famiy functioning and social supprt were related to several variables including socioecnomic status, number of surgeries, and age of the child. Results for the WCC must be interpreted with caution because of the poor reliability of the test. Even if certain subscales correlated with demographic variables or scores on other instruments, the relationship is difficult to interpret because of measurement problems.

Summary

In conclusion, the sample consisted of a population of primarily white, middle class, married women. This bias might affect generalizability of the results. Other results indicate good reliability for all the instruments with the exception of the WCC. This lack of reliability hampers the interpretation of the results in the next chapter. Although the reliability was low, positive reappraisal was indicated as a method used often by these parents. Responses on the PPUS, the ISSB, and the Family APGAR Scale were reflective of the group. Uncertainty was at a level lower than that of parents of hospitalized children (Mishel, 1983). Social support was at a level consistent with other parents of chronically ill children (Ferrari, 1986). Family functioning was at level comparable to healthy populations (Smilkstein, et al, 1982). Further comparisons with past research in

the next chapter will aid in describing levels of uncertainty, social support, and family functioning in this population. Correlational analysis indicated a strong positive relationship between social support and family functioning. Negative relationships resulted between the number of surgeries and both the ISSB and the Family APGAR Scale.

CHAPTER 5 DISCUSSION

Introduction

The purposes of this study were: to determine the reliability of the Parents' Perception of Uncertainty Scale in this population; to describe the degree of parental uncertainty, coping, social support, and family functioning in this population; and to describe the relationships between perceptions of uncertainty, coping, social support , and family functioning using the Behavioral Systems Model. In the conceptual framework section, relationships between uncertainty, coping, social support, and family functioning were determined based on the Behavioral Systems Model. The purposes and conceptual framework will be discussed in light of the statistical analysis, followed by sections on limitations and implications for further research.

Reliability of the Instruments

Reliability of the PPUS was assessed in this population by Cronbach's Alpha. The standardized alpha for the instrument was .94 for the total score. The subscales of lack of clarity and multi-attributed ambiguity achieved alphas of .88 and .89, respectively. This corresponded with the reliability values obtained by Mishel for these factors (multi-attributed ambiguity, a = .87 and lack of clarity, a = .81). However, the alphas for the subscales, lack of information and unpredictability, only reached .63 and .68 respectively. For Mishel (1983) these factors achieved alphas .73 (lack of information) and .72 (unpredictability). Part of the decreased subscale reliability could be due to the fact that the test was used in a population of parents of non-hospitalized children, while Mishel (1983) measured uncertainty in parents of hospitalized children. The mothers in this study had children who were chronically ill but not currently hospitalized. Reliability may have also been affected by the small sample size (N=28). However, the strong overall reliability indicates that the PPUS could be used in this population.

Reliability was not supported in this population for the Ways of Coping Checklist. Only one subscale, accepting resopnsibility, achieved an alpha = .78. Since the interview component of the test was not used in this study, reliability may have been adversely affected. The reliability coefficients in this study were lower than those obtained in the orginal study. An explaination may be found from the differences in the two samples. The original study considered coping in two healthy populations: one of college students and one of a middle aged community (Folkman and Lazarus, 1980). Possibly the instrument has difficulty measuring coping methods in a population that has to deal with a chronic illness. Also the low reliability coefficients may be due to the small sample size in this study. Because reliability is in question, the assessment of coping styles of parents of children with spina bifida should be viewed cautiously. Relationships between coping and uncertainty, social support and family functioning may be weak due to measurement error.

Both the Inventory of Socially Supportive Behaviors and the Family APGAR Scale attained Cronbach's alpha coefficients of .96 and .89, supporting reliability in this population. These findings are consistent with others (Ferrari, 1986; Smilkstein et al, 1982), and add to the base of work with these scales. Relationships between social support, family functioning, and uncertainty will be discussed next.

Uncertainty, Coping, Social Support, and Family Functioning in Parents of Children with Spina Bifida

The second purpose of the study was to determine the degree of uncertainty, coping, social support, and family functioning in this population. In this study the mean for the total PPUS score in this population was 68.09. In preceeding studies with hospitalized children, means on the PPUS ranged from 80-92 (Mishel, 1983). Although a mean of 68.09 is in the lower end of the total possible scores, the degree of uncertainty is difficult

to interpret because it has not been determined at what point on the scale does uncertainty become an issue. Only repeated administrations of the instrument will resolve this issue. Also individuals may respond differently to the same level of uncertainty. From this study it can be said that parents of non-hospitalized children experience less uncertainty than parents of hospitalized children. Hospitalization may add to already existing fears. The threat of a worsening illness that requires hospitalization may increase parental uncertainty. These threats and fears are not present in an out-patient population so uncertainty may be decreased. Additionally, the age of the child ranged from two to eighteen years, and concomittantly, the malformation had been present that long. The parents' had to deal with the condition for an extended period and uncertainty levels may be lower because they may have become accustomed to or resolved issues generating uncertainty. Perhaps too, there is more uncertainty when the child is an infant and the degree of side effects cannot be determined. Analysis of thhe individual scores for lack of information, lack of clarity, multi-attributed ambiguity, and unpredictability were consistent with the descriptive analysis for the total score. There were no unusual increases or decreases in these subscales when compared to the total score, and therefore none of the subscales was overly responsible for the level of uncertainty. Rather, the results indicated an equal presence of all of the attributes of uncertainty. For example, it could not be said that lack of information had more presence than either multi-attributed ambiguity or lack of clarity. Unpredictability might relate to number of surgeries or complications from spina bifida, but this could not be determined in this sample.

Because reliability of the WCC was low in this population, individual methods for coping need to be interpreted with caution. Measurement error in this case may cause results to be inconclusive. The relationships that failed to be substantively interesting with the WCC may be because of sample size or measurement error.

Although reliability of the instrument impedes interpretation, several interesting comments can be made about the results. First positive reappraisal appeared to be a method that parents of children with spina bifida used the most often. It attained a mean of 12.51 out of a total possible 21 points. After careful consideration, this finding seemed compatible with the side effects of spina bifida. Parents watch these children carefully for signs of improvement, and the attainment of developmental milestones. By focusing on the progress the child has made rather than the amount of delay that is present, parents may be able to cope with the illness more effectively. Escape -avoidance appeared to be the least method used. Since the sample consisted of the primary caretakers of the child, it would be hard for them to avoid the situation. The method may be used by other family members or significant others who are not assuming primary responsibilty for the care of the child. Planful problem solving attained a mean of 9.14 out of a possible 18.00 points. Interstingly, this score was attained from a sample of people that belong to a support group such as the Spina Bifida Association. Problem solving is usually a main function of a support group, and yet these parents are not using problem solving as a means of coping.

Social support was determined by descriptive analysis of the ISSB. The mean score of the ISSB, (X= 85.84,) was consistent with the use of the test with other parents of chronically ill children (Ferrari, 1986). In parents of diabetic children and autistic children the means were 83.13 and 89.13, respectively, while in parents of healthy children, the mean equaled 97.3 (Ferrari, 1986). This and the prior studies indicate that families of children with chronic conditions, including spina bifida, might experience lower levels of social support. However, the social support findings may be affected by the sample. As previously stated in Chapter 4, the sample consisted of primarily white, middle class, married women, a group that might be expected to have a larger support system or at least

more resources for developing a network. This was also a population that belonged to a support group, an indication that a broader support network was in place. In spite of these factors, the results demonstrated that a low level of social support existed, and that this result was consistent with the levels of social support in parents of chronically ill children in a different population. Possibly, this population may not view the Spina Bifida Association as a source of support, or identify it as a support network. Individual chapter differences may influence how social support is provided. The Spina Bifida Association may need to clearly identify itself as a source of support for these families, and the individual chapters may need to have a more active role in fostering social support.

Other questions revolve around those that do not belong to such an organization. Perhaps they are in even a greater need of social support. Single parent families as well as families from lower economic spheres may have a require a larger support system. Single parent families may not have the time or the energy to develop such a support system when much of their time is spent on providing income and caring for a chronically ill child. Likewise families from lower socio-economic circles may not have the resources available to them. Families from differen ethnic groups may have different levels of support depending on the culture. Belonging to a support group may be a totally foreign idea to some cultures. Finally our society itself may have an influencial role in the need for social support. Our society is highly complex with large emphases placed on the individual nuclear family, and mobility, with families moving towards areas of opportunity. Thus, individuals are removed from their extended families which could serve as a support system and are placed in communities that may offer varying levels of support depending on the economic state of the community. If it is economically feasible, communities offer these parents with support programs such as infant-child development, special education, physical therapy. These programs assume some of the responsibility for the

care of the child and relieve the parent of the sole caretaker role. However, these programs are expensive, and in communities depleted by unemployment and poverty, they are not available. Thus, individual families may be in communities that have limited resources and that are removed from their extended families. In these cases it is up to the individual family to start developing a support system, and this is a process that takes time and effort. Families of chronically ill children may not have the time or the effort to do this. Thus, social support will be even more decreased in these families.

In further analysis, social support was negatively related to the number of surgeries a child has undergone ($r = -.52$, $p \leq .005$). The increase in number of surgeries could be indicative of worsening status of the child. One would expect social support to be higher in these families with the support system revolving around the ill child, but apparently this is not the case. The social support system may be fatigued by the worsening state of the child. The need for more surgeries removes the mother from the family for extended periods of time. There is an increased demand for other family members to assume some of the mother's responsibilities as she cares for the ill child. Thus, a strain is placed on the family which is the main unit of social support. Also, the mother is removed from extended support systems. As was previously mentioned, part of social support is reciprocity. Namely, that as support is given, it is also expected to be offered, so that the network can thrive. In order to adequately care for an ill child, the mother places demands upon the support network. However, her ability to reciprocate with the network is decreased and finally it is exhausted. Therefore as the child requires more surgeries, the mother's increased involvement in the care of her child, diminishes her capacity to reciprocate with the support system. The support system will respond to the demands of the mother for a period, but once that reciprocity is not forthcoming, the support system may begin to diminsh.

Since the family is the main unit of social support in our society, it is important to consider the level of family functioning in this population. The mean of the Family APGAR Scale was 14.00 which was comparable to other uses of the test in healthy populations where the mean equaled 14.93 (Smilkstein et al, 1982). An adequate level of family functioning seems to be present in this population (Dorner, 1975; and Martin, 1975). Thus, the idea that family functioning might not be affected by spina bifida was supported. In the past studies, however, the main indicator of family functioning was the marital status of the families (Dorner, 1975; and Martin, 1975). The past literature relating family funcitoning with spina bifida, assumed that if the parents were married that the family was functioning. It was found that marital status in these families was no different that in the general population (Dorner, 1975; Martin, 1975). Although marital status is often an indicator of family functioning, it is not the sole indicator. Rather, this study measured overall family functioning and found it to be consistent with the results in healthy populations. It must be noted, however that, the sample may have biased this finding. Since the great majority of subjects are married, this could be a contributing factor for the high level of family functioning. Single parent families might have a different perception depending on how they define family functioning. Single parent families may rely on extended family members more or may have a broader interpretation of family to include close friends. Also, socioeconeomic status has an effect in family functioning. According to Smilkstein et al (1982), higher socioeconomic status allows the family to attain more resources that will enhance functioning. The families in this study were mid to upper middle class and thus had more resources economically available to them

The major descriptive findings in this study are consistent with previous research in the respective fields. By discussing the results in relation to previous research, indicators of uncertainty, social support, and family functioning may be determined. Uncertainty was

found to be present in this population but at a level lower than that of parents of hospitalized children. Although the Ways of Coping Checklist had low reliability, parents of children with spina bifida seemed to use positive reappraisal as the coping method of choice. Social support was at a level consistent with other parents of chronically ill children, even though this population would seem to have more opportunities for developing a broader support system due to their marital and socioeconomic status as well as belonging to a support group. Social support was neagtively related to the number of surgeries the child has experienced. It may be that the support system was being fatigued by the demands placed upon it and by decreased reciprocity, thus, it was no longer able to provide adequate support to the family. Finally, family functioning seemed to be consistent with a healthy population, and thus spina bifida is not an indicator of family maladjustment. After considering the levels of uncertainty, coping, social support, and family functioning in this population, the relationships between these variables will be described using the Behavioral Systems Model.

The Behavioral Systems Model and Uncertainty, Coping, Social Support, and Family Functioning

The final purpose of the study was to describe the relationships between the variables according to the Behavioral Systems Model. The model describes man as having eight interrelated subsystems of behavior: achievement, affiliative, eliminative, ingestive, dependency, reproductive, restorative, and aggressive/protective. Sustenal imperatives make up the driving forces behind each of the subsystems that protect, nurture, and stimulate. One interpretation of uncertainty is that it is an environmental stimulus that results in stimulation of the achievement subsystem in order to eliminate it . The achievement subsystem accomplishes this by encouraging the person to seek information in order to clarify ambiguous and unpredictable situations (Mishel, 1984).

Coping styles aid to protect the person from uncertainty. Another interpretation of coping styles concludes that some individuals use uncertainty as a stress buffer to protect them from adversive situations (Miller and Mangon, 1983). Social support and family functioning are sustenal imperatives of the affiliative susbsystem. Stimulation of the affiliative subsystem occurs when the support system provides the individual with information and tangible support. Protection and nurturance of the affiliative subsystem is accomplished when the social support network and/or the family provides the individual with social interaction and guidance.

The conceptual framework was partially supported in this study. Uncertainty had no statistically significant relationship to coping, social support, or family functioning. Reasons for this finding varied. First, since the coping scale was not reliable for the population, it was difficult to determine the relationship of coping with uncertainty. Coping styles are diverse and affected by numerous variables including culture, religion, education, and childhood experiences. Samples need to be randomly selected to lessen the chance of a systematic bias. The original scale consisted of a narrative and a questionnaire that is based on the narrative. Because of time and financial constraints, the narrative was not used. This might account for some of the low reliability scores. Finally, reliability values for healthy populations ranged from .61 to .79 (Folkman, 1981). Possibly the fact that the subjects in this study were parents of children with spina bifida instead of parents of healthy children may have accounted for the lack of reliability. When chronic illness is present, the test may not be appropriate as modified in this study. Because reliability was not indicated, correlational analysis of the Ways of Coping Checklist with the other instruments and demographic variable was found to be statistically insignificant.

There was no evidence of relationships that existed between uncertainty, social

support, and family functioning. Perhaps the low levels of uncertainty in this population do not require a high level of social support. Also, uncertainty may be a phenomenon that has to be coped with on an individual basis, rather than within a social network. Uncertainty may have varying effects within a given social setting. Thus, one person may not respond to the uncertainty or the stress that it causes while another may. If some do not respond to the uncertainty, the relationship between the amount of received social support and the perception of uncertainty is weakened. Length of illness may affect how the social network responds to the uncertainty. Possibly, people become accustomed to uncertainty and either adapt to it or tolerate it. Since there were no newborns in the study, it is difficult to determine what level of uncertainty is produced by a new diagnosis of spina bifida. However, family functioning did not correlate with either uncertainty or coping, though it did demonstrate a strong relationship to social support. Thus, uncertainty had little effect on the sustenal imperatives of the affiliative subsystem.

The strongest relationship was indicated between the sustenal imperatives of the affiliative subsystem: social support and family functioning. This relationship existed even though social support was at a level consistent with parents of chronically ill children and family functioning was at a level consistent with a healthy population. A postive correlation of $r = .67$ between social support and family functioning supports a strong, direct relationship in this population. It also indicates that social support and family functioning are, in fact, sustenal imperatives of this subsystem as is specified by the conceptual framework. In the literature on family functioning and children with spina bifida, differences were hypothesized to exist, but were not supported by statistical analysis (Martin, 1975; Dorner, 1975). Nevertheless, no study related family functioning with received social support. Social support could be the key indicator in determining the level of family functioning in children with spina bifida. Families that receive more

community and extended family support in the form of increased guidance, emotional support, tangible support, and social interaction will have a higher level of family functioning than those who receive little or no support.

The purposes of the study were for the most part fulfilled. The Parents' Perceptions of Uncertainty Scale was reliable for a population of parents of non-hospitalized children with spina bifida. Degrees of uncertainty, social support, and family functioning were consistent with past research findings, and served to further describe the variables. Assesment of coping styles in this situation was difficult to determine due to the lack of reliability of the Ways of Coping Checklist, however postivie reappraisal seemed to be the method used the most often in these parents. Although uncertainty was not indicated as a main stimulant of the sustenal imperatives of the achievement and affiliative subsystems, the framework could explain some of the phenomena of the affiliative subsystem. The relationship beween family functioning and social support begins to describe some of the sustenal imperatives of the affiliative subsystem. As little work has been accomplished in this area, the findings only serve as a basis for further research.

Limitations

There are several limitations to this study that require reiteration. Due to sample size and description, the findings are hardly generalizable. Limitations also exist because of the lack of reliability of the Ways of Coping Checklist.

The sample consisted of mostly white, middle class, educated, married women. Only four mothers were not white (1 black and 3 hispanic). There were no representatives of the Asian race. Only three mothers were divorced. Results on the instruments, therefore, were highly biased due to the composition of this group. Although the findings describe the attitudes of one sector of society, society as a whole cannot be described by the results. Since every parent in the two chapters of the Spina Bifida

Association of a child with myelomeningocele had a chance to respond to the survey, it is difficult to explain why this particular group of mothers replied. It should be noted, however that, although both chapters consisted of mostly white, middle class families, there was positive representation of many groups. Perhaps the original population was biased. Possibly different ethnic and socioeconomic groups are not aware of an organization such as the Spina Bifida Association, perhaps single mothers did not have time to fill out the forms. It would be expected that differences would have existed between variables of race and marital status. Marital status is often used as an index of social support as well as family functioning. Single parents may have a harder time taking care of an ill child and providing materially for the family. They may rely more on extended family members and friends to help support them during this period. Likewise certain ethnic groups depend on extended family members to aid in the care of chronically ill children. Another variable that may have biased the results was the level of education of the mothers. None of the mothers described herself as having only an elementary education. Of the sample, 19 out of 28 mothers had at least a college education. College educated mothers may have an easier time communicating with health professionals and may perceive less uncertainty. Also college educated mothers may have better employment opportunities and, thereby, be able to provide their child with more resources. Concurrent with the level of education, the socioeconomic status (SES) was also increased with 16 out of 28 subjects reporting an annual income of between $30,000 and $70,000. The high SES of the sample may indicate increased resources and increased social support. Brandt (1984) hypothesized similar findings; however, her research showed only that low SES was significantly related to low social support, though no correlation was noted between SES and the level of education. Also it should be noted that, since the sample in this study consisted only of mothers, findings are not

generalziable to fathers. Mothers were used because they are often the primary caretakers of the children (Litman, 1974), however it must be remembered that fathers may have different perceptions.

Overall sample size is also a limitation. 28 subjects serve only as a base for further exploration, but are inadequate for generalizability. Initially, over 150 subjects were contacted. Of these, only 35 responded, and from this group, 28 were eligible (23%). This is a figure not consistent with other mail surveys with no second attempt to contact. The reasons for the small response could be numerous. Possibly many of those contacted did not perceive the study to be important, or perhaps the time required to participate was too great.

Limitations also exist due to the low reliability of the WCC. Because the test is not necessarily appropriate for this population, important questions regarding the relationship of uncertainty to coping remain unanswered at this time.

Whether uncertainty is an environmental source of stress requiring active coping styles that try to eliminate it, or whether uncertainty is itself a coping style cannot be addressed from the results of this study. Also questions of the correlation between coping, social support, and family functioning are difficult to answer. Overall, the issues of measurement error affected the capacity of the conceptual framework to describe phenomena.

As was stated earlier, this study is limited by its sample size and the unreliability of the WCC. The sample was strongly biased in terms of white, well-educated, married, middle class mothers. It does not represent any other group of society. Generalizability of the results is strongly impeded by this bias and by the overall sample size. The unreliability of the WCC resulted in unanswered questions, which undermined the conceptual framework.

Implications

This study has several implications for further research. More research needs to be conducted with the PPUS in order to determine its reliability with other groups of families and ascertain degrees of uncertainty between groups. A future study could measure parental perceptions of uncertainty between parents of non-hospitalized acutely ill children and parents of chronically ill children. More research on uncertainty in parents of children with spina bifida should be conducted in order to determine if uncertainty is present during the neonatal period. The effect of uncertainty on these families and its possible resoultion over time needs to be described.

The relationship between coping and uncertainty requires further study and anlysis in order to determine its strength and direction. An instrument other than the WCC should be used. The WCC should be retested for reliability in parents of children with spina bifida by administering it in conjunction with other indices of coping. Since positive reappraisal appeared to be a method that was often used, further research should be directed at this use in this population. Because spina bifida is a lifelong illness, patterns of coping may be different for families of children with this anomaly. Possibly, duration of illness may precipate changes in the group over time. Coping, for example, might be difficult when the child is an infant, but may become easier as the child grows and accepts more responsibility for his or her care. Also the length of illness factor may allow time for parents to deveop adequate coping strategies.

This study revealed that social support had a strong positive correlation with family functioning, and that more research needs to be conducted on this relationship in this population. The family functioning literature indicates no change in family functioning between parents of children with spina bifida and parents of healthy children (Dorner, 1975; Martin, 1975). The current literature has noted that cohesive families tend to stay

together when confronted with a crisis such as having a child with spina bifida (Dorner, 1975; Martin, 1975). However, no mention was made of the actual amount of social support the family should recieve. Possibly, social support rather than marital status is the key issue in this population. The social network's response to length of illness also needs to be determined. Does the network become "used to" the child with spina bifida and begin to withdraw support, or is it active in supporting the family throughout the entire period? Family adaptation may also change as the child grows. What is the reaction of brothers and sisters to their sibling with spina bifida? Sibling response has not been studied at all. In this age of decreasing social resources for the chronically ill, more and more responsibility will be placed on the family, thus increasing the stress of the situation. Further research on social support and family functioning needs to be completed in order to fully determine the strength of this relationship.

More research needs to be done on social support in general in this population. This was a population that belonged to a support group, yet their results were no different than those from other studies on parents of chronically ill children. Questions about the effectiveness of support orgainzations upon the support networks of these families need to be answered. Possibly the parents are not identifying the support organization as a means of attaining support. Likewise questions arise regarding how the parents view the supportive role of the health care system. The the role and the responsibility society plays in providing support to these families should also be examined. Finally more research on the effect of numerous surgeries on social support needs to be conducted. Questions also arise concerning the effect of non-surgical hosptializations. Do they have the same effect on social support as do surgical admissions? If so this could be an important indicator of a stressed support system especially to the nursing staff. Nurses could then have an effect on the social support system through interventions such as

primary nursing.

Finally, more research should be completed on the Behavioral Systems Model. Although Johnson developed the model, she left it up to her colleagues and disciples to refine it in research. Thus, several areas of the model remain uncharted, especially that of the sustenal imperative component. The description and function of the sustenal imperatives in relation to the subsystems need further clarification. This particular study only addresses a few of the imperatives of the achievement and affiliative subsystems. There are more for these subsystems, and the six subsystems remaining. The sustenal imperatives need to be further categorized and documented since they provide the crucial supporting structure for the rest of the Behavioral Systems Model.

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Appendix A - Correspondence

Newsletter Advertisement

Attention Mothers !!

Ms. Marilyn Miller, R.N., a graduate student at the University of California San Francisco, School of Nursing, is conducting a research study on families of children with Spina Bifida. She is particularly interested in observing the levels of uncertainty, ways of coping, amount of social support, and the level of family functioning of these families.

Participants will be asked to fill out several questionnaires that will be mailed to them upon their consent to be in the study.

Only mothers will be used in the study.

1. Mothers must have children between the ages of 2 and 18 years, and the children must have myelomeningocele.
2. The mothers must be the primary caretakers of their children.
3. Mothers must be able to read and write English.

Strict Confidentiality will be maintained as far as is possible. No names or addresses will be released. Participation will in no way affect the care your child is receiving now or in the future. Participants may choose to refuse at any time during the study.

If you are interested in participating, please call :

Marilyn Miller (415) 588-5354

University of California, San Francisco

(Introductory Letter)

Dear Ms._____ :

My name is Marilyn Miller and I am a master's candidate in the School of Nursing at the University of California at San Francisco. I am conducting a study on parents' perceptions of uncertainty, social support, coping and family functioning in families of children with myelomeningocele. Your local chapter of the Spina Bifida Association has contacted you on my behalf and I am asking you for your participation in this study. Because of chapter policy, your name and adress has not been released to me. After you agree to participate (if you want to) , your chapter will give this information to me.

Please read the attached consent form. If you wish to participate in the study, sign and date both forms. Keep one for your records, and send the other to me in the envelope provided. All information that you submit will be kept confidential as far as is possible. Participation or refusal to participate will in no way affect the care your child is receiving now or in the future. If you agree to participate, I will send you a packet of questionnaires to be completed by you. If you have any questions please feel free to call me at (415) 588-5354 or call Dr. Sandra Ferketich, R.N., Ph.D. at (415) 476-4658. Thank you for your time.

Sincerely

Marilyn Miller, R.N.

University of California, San Francisco

(Follow-up Letter)

Dear Ms._____ :

This is a letter to remind you to fill out your questionnaires for the Parental Uncertainty, Social Support, Coping, and Family Functioning Study. I want to thank you for your participation in the project. I also want you to know that your results are important to me. However you do have the right to refuse participation at any time. This is the last letter I will send you. If you do not return the forms within 30 days of receiving this letter, I will assume that you no longer want to participate, and I will drop you from the subject list. If you have any questions call me at (415) 588-5354. Thank you again for your participation

Sincerely

Marilyn Miller, R.N.

Appendix B - Consent form

University of California, San Francisco

Consent to be a Research Subject

Purpose and Background

Marilyn Miller, a master's candidate in the School of Nursing at the University of California , San Francisco, is conducting a study to determine parents' perceptions of uncertainty, coping, social support, and family functioning, in families of children with myelomeningocele Often parents of children with long-term illnesses such as Spina Bifida have feelings of uncertainty due to the unknown aspects of the disease. Uncertainty may be related to the way parents cope with stress of illness. There may be a relation between levels of uncertainty and the amount and types of social support these parents receive. Also levels of family functioning may affect parental uncertainty. To this time, no one has studied how mothers of children with myelomeningocele experience uncertainty. Nor has anyone researched the ways these mothers cope with congential anomalies, or the social and familial support they receive. Ms. Miller would like to study and describe these areas so that health care may be improved.

Procedures

If I agree to participate in this study, I will be asked to fill out several questionnaires. The first will be a demographic data sheet, which asks questions such as name, sex, age, number of children, etc. It should take about 10 minutes to complete. The second will be the Parents' Perception of Uncertainty Scale, which will take 10 minutes to complete. Third will be the Ways of Coping Scale which will take about 20 minutes to complete. Fourth will be the Inventory of Socially Supportive Behaviors which will take about 30 minutes to complete. Finally the Smilkstein Family Apgar will be administered. It will take 1-2 minutes to complete.

If I agree to participate, I will sign and date two copies of the consent form and send one back to Ms. Miller. The other I will keep for my records. If I agree to participate, I agree to let my local chapter of the Spina Bifida Association release my name and address to Ms. Miller, for purposes of further contact in order that I may participate. After Ms. Miller receives the signed consent form, she will send me the packet of questionnaires to be completed and returned in the stamped envelope provided. I may be contacted once again, by mail if I do not return the forms within two weeks (15 days).

Risks and Discomforts

I will be asked to give up one hour - one hour and fifteen minutes to complete the questionnaires. There is a potential risk of loss of privacy. The confidentiality of the records will be maintained as far as is possible. Identifying data (names, addresses, etc.) will be kept in a locked box avialable only to Ms. Miller. When my questionnaire is received by the investigator, or if I have not returned the questionnaire within 45 days, my name and address will be deleted from the subject list. No identifying data will be released. No individual results will be reported. Some of the questions may be personal or may increase stress, however I have the right to refuse to answer any question

Benefits

There will be no direct benefits to me from this study. However findings may improve the care of future families and patients with myelomeningocele. Care may be improved by providing better patient/family education and/or by providing better supportive services.

Questions

If I have any questions, I may contact Ms. Miller at (415) 588-5354, or Dr. Sandra Ferketich at (415) 476-4658.

Consent

I have a copy of this form and a copy of the Experimental Subjects' Bill of Rights

Voluntary Participation

I have the right to decline to participate or to withdraw at any point in this study without jepordy to my child's medical care now or in the future. If I wish to participate, I should sign this form.

_____ _____

Date Subject's Signature

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

EXPERIMENTAL SUBJECT'S BILL OF RIGHTS

The rights below are the rights of every person who is asked to be in a research study. As an experimental subject I have the following rights:

1) To be told what the study is trying to find out,

2) To be told what will happen to me and whether any of the procedures, drugs, or devices is different from what would be used in standard practice,

3) To be told about the frequent and/or important risks, side effects or discomforts of the things that will happen to me for research purposes,

4) To be told if I can expect any benefit from participating, and, if so, what the benefit might be,

5) To be told the other choices I have and how they may be better or worse than being in the study,

6) To be allowed to ask any questions concerning the study both before agreeing to be involved and during the course of the study,

7) To be told what sort of medical treatment is available if any complications arise,

8) To refuse to participate at all or to change my mind about participation after the study is started. This decision will not affect my right to receive the care I would receive if I were not in the study.

9) To receive a copy of the signed and dated consent form,

10) To be free of pressure when considering whether I wish to agree to be in the study.

If I have other questions I should ask the researcher or the research assistant. In addition, I may contact the Committee on Human Research, which is concerned with protection of volunteers in research projects. I may reach the committee office by calling: (415) 476-1814 from 8:00 AM to 5:00 PM, Monday to Friday, or by writing to the Committee on Human Research, University of California, San Francisco, CA 94143.

Call X1814 for information on translations.

Appendix C - Instruments

DEMOGRAPHIC DATA

Date_____

ID. No._____

Check one for each of the following.

Race: Caucasian____ Black____ Asian_____ Hispanic_____ Other_____

Economic status: Is your annual family income between? (check one)

0- $5,000_____ $5,000- $10,000_____ $10,000- $15,000_____

$15,000- $20,000_____ $20,000- $30,000____ $30,000- $50,000____

$50,000- $70,000_____ $70,000- $100,000_____ over $100,000_____

Marital status: Married____ Single_____ Divorced_____

Education: Graduate___ College_____ HS_____ Elem.____

Sex: Male____ Female____

Age of parent filling out the form_____

Number of children_____

List children by age and sex in order of birth. Include child with Spina Bifida.

Age Sex

a.

b.

c.

d.

Information regarding child with spina bifida.

Age___ Sex____

Type of Spina Bifida myelomeningocele____ meningocele____ occulta____

Does your child have (check if applies):

Incontinence of bowel____ bladder____

Paralysis___ Hydrocephalus____ Braces____

Crutches____ Wheelchair_____ Kyphosis____

Scoliosis____ Knee problems____ Foot problems___

Learning disabilities____ Mental Retardation _____

How many surgeries has your child had related to spina bifida? (list type, year, and any repeated surgeries, may continue on the back)

a.

b.

c.

d.

e.

How many times has your child been hospitalized for things other than surgery? (list reason and year, may continue on back)

a.

b.

c.

d.

e.

What is your greatest concern regarding your child's diagnosis with Spina Bifida?

How have nurses helped you in the past, in dealing with your child's illness?

How can nurses help you more in the future?

Family Apgar

The following questions have been designed to help us better understand you and your family. You should feel free to ask questions about any item in the questionnaire.

Comment space should be used if you wish to give additional information or if you wish to discuss the way the question applies to your family. Please try to answer all questions.

"Family" is the individual(s) with whom you usually live. If you live alone, consider family as those with whom you now have the strongest emotional ties.

	Always	Almost always	Some of the time	Hardly ever	Never
1. I am satisfied that I can turn to my family for help when something is troubling me.	_____	_____	_____	_____	____
Comments:					
2. I am satisfied with the way my family talks over things with me and shares problems with me.	_____	_____	_____	_____	____
Comments:					
3. I am satisfied that my family accepts and supports my wishes to take on new activites or directions.	_____	_____	_____	_____	____
Comments:					

	Always	Almost always	Some of the time	Hardly ever	Never
4. I am satisfied with the way my family expresses affection, and responds to my emotions, such as anger, sorrow, or love.	_____	_____	_____	_____	_____

Comments:

5. I am satisfied with the way my family and I share time together.	_____	_____	_____	_____	_____

Comments:

No._____

MISHEL UNCERTAINTY IN ILLNESS SCALE--PARENT/CHILD FORM

Instructions: Please read each statement. Take your time and think about what each statement says. Then place an "X" under the column that most closely measures how you are feeling about your child TODAY. If you agree with a statement, then you would mark under either "Strongly Agree" or "Agree." If you disagree with a statement, then mark under either "Strongly Disagree" or "Disagree." If you are undecided about how you feel about your child, then mark under "Undecided" for that statement. Please respond to every statement.

1. I don't know what is wrong with my child.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

2. I have a lot of questions without answers.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

3. I am unsure if my child's illness is getting better or worse.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

4. It is unclear how bad my child's pain will be.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

5. The explanations they give about my child seem hazy to me.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

6. The purpose of each treatment for my child is clear to me.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

7. I do not know when to expect things will be done to my child.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

8. My child's symptoms continue to change unpredictably.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

9. I understand everything explained to me.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

10. The doctors say things to me that could have many meanings.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

11. I can predict how long my child's illness will last.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

12. My child's treatment is too complex to figure out.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

13. It is difficult to know if the treatments or medications my child is getting are helping.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

14. There are so many different types of staff, it's unclear who is responsible for what.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

15. Because of the unpredictability of my child's illness, I cannot plan for the future.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

16. The course of my child's illness keeps changing. He/she has good and bad days.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

17. It's vague to me how I will manage the care of my child after he/she leaves the hospital.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

18. It is not clear what is going to happen to my child.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

19. I usually know if my child is going to have a good or bad day.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

20. The results of my child's tests are inconsistent.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

21. The effectiveness of the treatment is undetermined.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

22. It is difficult to determine how long it will be before I can care for my child by myself.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

23. I can generally predict the course of my child's illness.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

24. Because of the treatment, what my child can do and cannot do keeps changing.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

25. I'm certain they will not find anything else wrong with my child.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

26. They have not given my child a specific diagnosis.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

27. My child's physical distress is predictable, I know when it is going to get better or worse.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

28. My child's diagnosis is definite and will not change.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

29. I can depend on the nurses to be there when I need them.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

30. The seriousness of my child's illness has been determined.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

31. The doctors and nurses use everyday language so I can understand what they are saying.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

Inventory of Socially Supportive Behaviors

INSTRUCTIONS: We are interested in learning about some of the ways that you feel people have helped you or tried to make life more pleasant for you over the past four weeks. Below you will find a list of activities that other people might have done for you, to you, or with you in recent weeks. Please read each item carefully and indicate how often these activities happened to you during the past four weeks.

Please read each item carefully and select the rating that you think is the most accurate.

During the past four weeks, how often did other people do these activities for you, to you, or with you:

INCLUDE MATE

	Not at All	Once or Twice	About Once a Week	Several Times a Week	About Every Day	
1. Looked after a family member while you were away.	___	___	___	___	___	(37)
2. Was right there with you (physically) in a stressful situation.	___	___	___	___	___	(38)
3. Provided you with a place where you could get away for awhile.	___	___	___	___	___	(39)
4. Watched after your possessions when you were away (pets, plants, home, apartment, etc.).	___	___	___	___	___	(40)
5. Told you what she/he did in a situation that was similar to yours.	___	___	___	___	___	(41)
6. Did some activity with you to help you get your mind off of things.	___	___	___	___	___	(42)
7. Talked with you about some interests of yours.	___	___	___	___	___	(43)
8. Let you know that you did something well.	___	___	___	___	___	(44)
9. Went with you to someone who could take action.	___	___	___	___	___	(45)
10. Told you that you are OK just the way you are.	___	___	___	___	___	(46)
11. Told you that she/he would keep the things you talk about private--just between the two of you.	___	___	___	___	___	(47)
12. Assisted you in a setting a goal for yourself.	___	___	___	___	___	(48)

	Not at All	Once or Twice	About Once a Week	Several Times a Week	About Every Day	
13. Made it clear what was expected of you.	___	___	___	___	___	(49)
14. Expressed esteem or respect for a competency or personal quality of yours.	___	___	___	___	___	(50)
15. Gave you some information on how to do something.	___	___	___	___	___	(51)
16. Suggested some action that you should take.	___	___	___	___	___	(52)
17. Gave you over $25.	___	___	___	___	___	(53)
18. Comforted you by showing you some physical affection.	___	___	___	___	___	(54)
19. Gave you some information to help you understand a situation you were in.	___	___	___	___	___	(55)
20. Provided you with some transportation.	___	___	___	___	___	(56)
21. Checked back with you to see if you followed the advice you were given.	___	___	___	___	___	(57)
22. Gave you under $25.	___	___	___	___	___	(58)
23. Helped you understand why you didn't do something well.	___	___	___	___	___	(59)
24. Listened to you talk about your private feelings.	___	___	___	___	___	(60)
25. Loaned or gave you something (a physical object other than money) that you needed.	___	___	___	___	___	(61)
26. Agreed that what you wanted to do was right.	___	___	___	___	___	(62)
27. Said things that make your situation clearer and easier to understand.	___	___	___	___	___	(63)
28. Told you how he/she felt in a situation that was similar to yours.	___	___	___	___	___	(64)
29. Let you know that he/she will always be around if you need assistance.	___	___	___	___	___	(65)

	Not at All	Once or Twice	About Once a Week	Several Times a Week	About Every Day	
30. Expressed interest and concern in your well-being.	___	___	___	___	___	(66)
31. Told you that she/he feels very close to you.	___	___	___	___	___	(67)
32. Told you who you should see for assistance.	___	___	___	___	___	(68)
33. Told you what to expect in a situation that was about to happen.	___	___	___	___	___	(69)
34. Loaned you over $25.	___	___	___	___	___	(70)
35. Taught you how to do something.	___	___	___	___	___	(71)
36. Gave you feedback on how you were doing without saying it was good or bad.	___	___	___	___	___	(72)
37. Joked and kidded to try to cheer you up.	___	___	___	___	___	(73)
38. Provided you with a place to stay.	___	___	___	___	___	(74)
39. Pitched in to help you do something that needed to get done.	___	___	___	___	___	(75)
40. Loaned you under $25.	___	___	___	___	___	(76)

WAYS OF COPING (Revised)

Please read each item below and indicate, by circling the appropriate category, to what extent you used it [illegible] with your child's Spina Bifida.

		Not used	Used somewhat	Used quite a bit	Used a great deal
1.	Just concentrated on what I had to do next -- the next step.	0	1	2	3
2.	I tried to analyze the problem in order to understand it better.	0	1	2	3
3.	Turned to work or substitute activity to take my mind off things.	0	1	2	3
4.	I felt that time would make a difference -- the only thing to do was to wait.	0	1	2	3
5.	Bargained or compromised to get something positive from the situation.	0	1	2	3
6.	I did something which I didn't think would work, but at least I was doing something.	0	1	2	3
7.	Tried to get the person responsible to change his or her mind.	0	1	2	3
8.	Talked to someone to find out more about the situation.	0	1	2	3
9.	Criticized or lectured myself.	0	1	2	3
10.	Tried not to burn my bridges, but leave things open somewhat.	0	1	2	3
11.	Hoped a miracle would happen.	0	1	2	3
12.	Went along with fate; sometimes I just have bad luck.	0	1	2	3
13.	Went on as if nothing had happened.	0	1	2	3
14.	I tried to keep my feelings to myself.	0	1	2	3
15.	Looked for the silver lining, so to speak; tried to look on the bright side of things.	0	1	2	3
16.	Slept more than usual.	0	1	2	3
17.	I expressed anger to the person(s) who caused the problem.	0	1	2	3
18.	Accepted sympathy and understanding from someone.	0	1	2	3
19.	I told myself things that helped me to feel better.	0	1	2	3
20.	I was inspired to do something creative.	0	1	2	3
21.	Tried to forget the whole thing.	0	1	2	3
22.	I got professional help.	0	1	2	3

		Not used	Used somewhat	Used quite a bit	Used a great deal
23.	Changed or grew as a person in a good way.	0	1	2	3
24.	I waited to see what would happen before doing anything.	0	1	2	3
25.	I apologized or did something to make up.	0	1	2	3
26.	I made a plan of action and followed it.	0	1	2	3
27.	I accepted the next best thing to what I wanted.	0	1	2	3
28.	I let my feelings out somehow.	0	1	2	3
29.	Realized I brought the problem on myself.	0	1	2	3
30.	I came out of the experience better than when I went in.	0	1	2	3
31.	Talked to someone who could do something concrete about the problem.	0	1	2	3
32.	Got away from it for a while; tried to rest or take a vacation.	0	1	2	3
33.	Tried to make myself feel better by eating, drinking, smoking, using drugs or medication, etc.	0	1	2	3
34.	Took a big chance or did something very risky.	0	1	2	3
35.	I tried not to act too hastily or follow my first hunch.	0	1	2	3
36.	Found new faith.	0	1	2	3
37.	Maintained my pride and kept a stiff upper lip.	0	1	2	3
38.	Rediscovered what is important in life.	0	1	2	3
39.	Changed something so things would turn out all right.	0	1	2	3
40.	Avoided being with people in general.	0	1	2	3
41.	Didn't let it get to me; refused to think too much about it.	0	1	2	3
42.	I asked a relative or friend I respected for advice.	0	1	2	3
43.	Kept others from knowing how bad things were.	0	1	2	3
44.	Made light of the situation; refused to get too serious about it.	0	1	2	3
45.	Talked to someone about how I was feeling.	0	1	2	3
46.	Stood my ground and fought for what I wanted.	0	1	2	3
47.	Took it out on other people.	0	1	2	3

		Not used	Used somewhat	Used quite a bit	Used a great deal
48.	Drew on my past experiences; I was in a similar situation before.	0	1	2	3
49.	I knew what had to be done, so I doubled my efforts to make things work.	0	1	2	3
50.	Refused to believe that it had happened.	0	1	2	3
51.	I made a promise to myself that things would be different next time.	0	1	2	3
52.	Came up with a couple of different solutions to the problem.	0	1	2	3
53.	Accepted it, since nothing could be done.	0	1	2	3
54.	I tried to keep my feelings from interfering with others things too much.	0	1	2	3
55.	Wished that I could change what had happened or how I felt.	0	1	2	3
56.	I changed something about myself.	0	1	2	3
57.	I daydreamed or imagined a better time or place than the one I was in.	0	1	2	3
58.	Wished that the situation would go away or somehow be over with.	0	1	2	3
59.	Had fantasies or wishes about how things might turn out.	0	1	2	3
60.	I prayed.	0	1	2	3
61.	I prepared myself for the worst.	0	1	2	3
62.	I went over in my mind what I would say or do.	0	1	2	3
63.	I thought about how a person I admire would handle this situation and used that as a model.	0	1	2	3
64.	I tried to see things from the other person's point of view.	0	1	2	3
65.	I reminded myself how much worse things could be.	0	1	2	3
66.	I jogged or exercised.	0	1	2	3