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Spina Bifida: How Are Pediatric Patients and Their Mothers Coping?

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LOYOLA UNIVERSITY OF CHICAGO

SPINA BIFIDA: HOW ARE PEDIATRIC PATIENTS AND THEIR MOTHERS COPING?

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BY
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TABLE OF CONTENTS

ACKNOWLEDGEMENTS iii

LIST OF FIGURES viii

LIST OF TABLES ix

Chapter

I. REVIEW OF THE RELATED LITERATURE 1
    Introduction 1
    Children Born with Myelomeningocele (MM) 3
    Behavior Across Disorders or a Disease Specific Model? 6
        Increased risks? 7
        The Noncategorical Approach 9
        Classifying Chronic Illnesses 13
            Role of CNS involvement 13
        Family Characteristics 15
        Marginality 19
    Methodological Issues 22
    Adjustment to MM 24
        Social Isolation 24
        Depression 26
        Self-Concept 28
        Behavior Problems 30
        Social Competence 33
        Effects on the Family 35
            Psychological functioning of mothers . . 37
            Marital stress 40
            Factors affecting perceived impact on the family 41
            Family conflict 42
            Social support 43
            Other aspects of family coping 45
    Coping 49
        Problem-focused Coping and Emotion-focused Coping 57
        Coping in Children and Adolescents 59
            Coping and behavior problems 59
            Modeling 62
        Coping with Chronic Illness 66
        Child Characteristics 70
    Is a Comparison Group Necessary? 71
    Goals of Study 73

Chapter Page

II. METHOD 75
Setting 75
Subjects 75
Procedure 79
Measures 81
Kidcope 81
Parentcope 83
CHIP 89
Clinician's Overall Burden Index 90
CBCL-R 92
Harter's Self-Perception Profile for Children 93
FACES III 95
Hypotheses 97

III. RESULTS 100
Preliminary Analyses 100
Internal Consistencies of the Kidcope/ Parentcope Scales 100
Psychosocial Adjustment 103
Multiple Regression Analyses 109
Hypothesis 1 115
Hypothesis 2 125
Hypothesis 3 126
Hypothesis 4 128
Hypothesis 5 128
Exploratory Analyses 131

IV. DISCUSSION 137
Overview 137
Purpose of the Study 137
Summary and Interpretation of the Findings by Hypothesis 138
Hypothesis 1 138
Hypothesis 2 144
Hypothesis 3 145
Hypothesis 4 146
Hypothesis 5 147
Exploratory Analyses 148
Summary of Results 149
Limitations 151
Implications for Future Research and Interventions 155

APPENDIX Page

A. MEASURES ADMINISTERED TO CHILDREN 161
  Informed Consent 162
  Name and Address Cover Sheet 164
  Student Demographics Questionnaire 165
  Harter's Self-Perception Profile for Children 168
  FACES III 173
  Kidcope 174

B. MEASURES ADMINISTERED TO MOTHERS 176
  Informed Consent 177
  Parent Cover Sheet 179
  Demographics Questionnaire 180
  Rating Scale of Child's Actual Behavior 184
  Child Behavior Checklist 186
  CHIP 190
  Parentcope 194

REFERENCES 196

VITA 211

LIST OF FIGURES

Figure Page

1. Order of entry of predictor variables in multiple regression analyses, and outcome variables . . . 74

LIST OF TABLES

Table Page

1. Selected Characteristics of the Sample 77
2. Internal Consistencies of Kidcope and Parentcope Scales 102
3. Mean Scores on Dependent Variables of Psychosocial Adjustment 105
4. Mean Scores on Predictor Variables 106
5. Percentage of Children who Reported Using Specific Coping Strategies on the Kidcope . . . 108
6. Problems Identified on the Kidcope/Parentcope . . 110
7. Pearson Product-Moment Correlations Among the Predictor Variables 111
8. Pearson Product-Moment Correlations Between Predictor and Dependent Variables 113
9. Pearson Product-Moment Correlations Among the Dependent Variables 114
10. Multiple Regression Analysis of Independent Variable Clusters Predicting Children's Report of Self-Worth 117
11. Multiple Regression Analysis of the Prediction of Mothers' Reports of Externalizing Behavior Problems by Independent Variable Clusters . . . 119
12. Multiple Regression Analysis of the Prediction of Children's Report of Social Competence by Independent Variable Clusters 121
13. Multiple Regression Analysis of the Prediction of Mothers' Report of Social Competence by Independent Variable Clusters 122

Table Page

14. Multiple Regression Analysis of the Prediction of Mothers' Reports of Internalizing Behavior Problems by Independent Variable Clusters . . . 127

15. One Way Analysis of Variance with Severity by Externalizing Behavior Problems 130

16. Multiple Regression Analysis of the Prediction of Children's Report of Social Competence by Multiple Coping Strategies (Complexity) 132

17. Multiple Regression Analysis of the Prediction of Mothers' Report of Social Competence by Multiple Coping Strategies (Complexity) in their Children 134

CHAPTER 1

REVIEW OF THE RELATED LITERATURE

Introduction

With improvements in medical technology, concern has shifted from survival risks to lifelong adaptation to disability for children with many chronic illnesses. A review of the medical literature pertaining to spina bifida reveals that Lorber (1971) discussed the advantages and disadvantages, in terms of quality of life, of the decision to surgically treat children born with spina bifida in Great Britain. Castree and Walker (1981) also discussed policies regarding the selection for surgery. Since more children survive the early treatments, morbidity rather then mortality must be addressed in the research. The focus must be on assessing and improving the adaptation of individuals with chronic illness and their families' adjustment (Drotar, 1981; Kazak & Clark, 1986; Tavormina, Kastner, Slater, & Watt, 1976; Varni & Wallander, 1988; Willis, Elliott, & Jay, 1982). Haggerty (1984) reported that about one million children and adolescents in the United States have severe chronic illnesses that warrant ongoing comprehensive medical care. In addition, 10 million other children have less serious chronic conditions which may necessitate regular monitoring and specialized care. Comprehensive care may be defined as the "systematic inclusion" of psychosocial issues in the child's medical care "within a family and community context" (Rothenberg, 1976, p. 1099).

Children's techniques of coping with everyday problems as well as with disability-specific issues are one important aspect of their overall psychological adjustment. The purpose of this study is to examine the coping mechanisms of children with myelomeningocele (a type of spina bifida) as well as their mothers' coping styles. The role of coping as a predictor of child adjustment (self-worth, social competence, and behavior problems) above and beyond other variables (such as demographics, severity of disease, family functioning, and child characteristics) will be investigated. An assessment of coping styles is important because it focuses on the potential strengths and competencies of the children and adolescents rather than merely identifying the existence of problems. An investigation of the various types of coping styles used by youth with spina bifida and their mothers also has important implications for clinical interventions that may be employed with those lacking effective coping strategies. Further, some coping strategies employed by chronically ill children may be necessary responses to a realistic predicament.

To understand the significance of this research, it is necessary to review some of the major findings from the chronic illness literature, in general. It is also important to review briefly some of the strengths and weaknesses of the methodologies of previous studies in this area to ascertain the value of the conclusions that can be drawn from them about children with chronic physical illnesses, and try to avoid methodological weaknesses in the present study. A review of the specific literature that exists on spina bifida will be presented to demonstrate that the focus has been on a limited number of variables, such as self-concept, behavior problems, social competence and the effects of a child with MM on the family. Coping styles have not been addressed in this literature to date. Finally, the coping literature as it pertains to healthy and ill adults will be reviewed briefly and the literature on child and adolescent coping will be presented. Before an examination of the psychosocial consequences of having spina bifida is possible, a basic understanding of the disease itself is required.

Children Born with Myelomeningocele (MM)

Approximately one infant in 1000 live births is born with spina bifida, the most frequently occurring central nervous system (CNS) malformation, second only to congenital heart defects (Varni & Wallander, 1988).

A perusal of the titles or sample description in the references to this paper illustrates the heterogeneity of the samples used to study the psychosocial ramifications of spina bifida. Included among the terms, that are not all synonymous, are spina bifida, myelodysplasia, myelomeningocele, meningomyelocele, and meningocele. Myelodysplasia is a more general term referring to spina bifida aperta or manifesta, meningomyelocele, myelomeningocele, caudal regression syndromes, meningocele, myelocystocele, and lipomeningomyelocele (Shurtleff (1980)).

There are three levels of severity of spina bifida, with myelomeningocele (MM) considered to be the most severe accounting for 90% of the lesions (Myers, 1984). In this case the child is born with a visible sac on the back consisting of spinal fluid and part of the spinal cord. Today, surgery to close the spine is done within a few days after birth in order to prevent rupture and subsequent infection of the lesion. Frequently, a shunt is surgically inserted in the child's ventricles to drain off excess spinal fluid. Children with shunts may have to have surgical revisions at several points in their lives if symptoms such as headaches or learning problems persist and tests reveal increased intracranial pressure. In addition, shunt infections (ventriculitis) may occur, contributing to further complications.

The impact of spina bifida on the child is variable. Although many children with spina bifida have average or better intelligence, learning problems especially in visual-perceptual-organizational cognitive functioning are common (Wills, Holmbeck, Dillon, & McLone, 1990). The degree of physical disability is generally determined by the location of the lesion on the spinal cord. Thus, children affected by spina bifida are a heterogeneous group with some needing no braces or crutches while others may be wheelchair-bound. Orthopedic surgeries are common for problems such as scoliosis (lateral curvature of the spine), kyphosis (increased convexity in the curvature of the thoracic spine as viewed from the side), and other anomalies (Mosby's Medical Nursing Dictionary, 1986).

Neurogenic incontinence creates the need for continual monitoring and treatment to avoid renal dysfunction which was a major cause of the increased mortality rate in these patients in the past. Today parents, and later the patients, themselves, are instructed how to use intermittent catheterization. Whereas this medical technology has improved survival rates, it has also produced certain types of psychosocial stress in some patients. The need to employ a catheter may affect the same child differently as s/he proceeds through developmental transitions, with adolescence being a particularly vulnerable stage (Hayden, 1985). An associated problem is precocious puberty, particularly in girls (i.e., menarche and pubertal changes occurring several years earlier than is usual) (Hayden, Davenport, & Campbell, 1979). Other medical problems include decubiti ulcers and obesity especially in children who use wheelchairs.

In summary, children born with spina bifida are a heterogeneous group who may have to cope with both visible (e.g., physical disabilities) and more subtle (e.g., learning disabilities) consequences of their illness. Frequent hospitalizations for surgery may contribute to unpredictability in their lives. Moreover, the need for continual re-adjustment, at each developmental transition, contributes to insecurity. For example, a child may be coping fairly well with his/her disability until puberty, when issues related to adolescence, such as social pressures, contribute to what may be viewed as regressive tendencies. While the complexity of the medical treatment of MM is clear, the effects of these multiple complications on the psychosocial adjustment of the patient and his/her family are not as well studied. Nor is there a clear understanding of the coping mechanisms that are relied upon by patients and their family members to confront stressful situations related to the medical condition.

Behavior Across Disorders or a Disease-Specific Model?

Although the current study will focus on the adjustment of children with MM, it is important to digress briefly to a discussion of the theoretical literature that has evolved from studies on chronic illness in general. This is critical because there are only a limited number of studies on the psychosocial sequelae of spina bifida (Varni & Wallander, 1988), and many investigators have challenged a disease-specific model for the psychosocial consequences of chronic illness in children (Jessop & Stein, 1985; Pless & Pinkerton, 1975; Stein & Jessop, 1982, 1989).

Increased risks?

Controversy in the literature exists as to whether children with chronic illness are at increased risk for psychological maladjustment, compared to healthy children (Breslau, 1985; Cadman, Boyle, Szatmari, & Offord, 1987; Mattsson, 1972; McAnarney, Pless, Satterwhite, & Friedman, 1974; Pless & Roghmann, 1971; Stein & Jessop, 1984; Tavormina et al., 1976). A complete review of this debate is beyond the scope of this paper, but a few highlights will be mentioned (See Drotar, Owens, & Gotthold, 1980; Lavigne & Faier-Routman, 1992; Pless & Pinkerton, 1975, for a review). For example, a frequently cited study in defense of the strengths of children with chronic physical disorders is one conducted by Tavormina and colleagues (1976) with children with multiple chronic physical disorders. They administered a battery of psychological tests to 144 pediatric patients with asthma, diabetes, cystic fibrosis (CF) or a hearing disorder. The hearing impaired children's scores most typified the concept of increased vulnerability, but the authors emphasized the strengths present in the other three patient groups. The mean scores for these patients were significantly higher than the norms on the Piers-Harris Self-Concept Inventory, reflecting more positive self-concepts when compared to norms.

Similarly, Gayton, Friedman, Tavormina, and Tucker (1977) reported no significant differences in mean scores between patients with CF and their closest aged healthy siblings on the Piers Harris Self-Concept Scale or the Missouri Children's Picture Series for a sample of 5-13 year old children. Performance on the Holtzman Inkblot Test was also within normal limits. However, measures of parents' functioning revealed strain.

No significant differences in anxiety and self-esteem between adolescents with various chronic illnesses and healthy controls were noted. However, Zeltzer, Kellerman, Ellenberg, Dash, and Rigler (1980) cautioned that the lack of psychopathology in the medical illness group, "does not preclude illness-related life disruption..." (p.132).

The majority of the studies described in the remainder of this literature review have found children with chronic physical disorders to be at risk for psychosocial adjustment problems. However, greater understanding of the risk factors is needed. There are several explanations that can be offered to attempt to understand the discrepant findings. First, earlier studies relied on clinical impressions rather than more stringent empirical investigations. More recently, better instruments have been developed and standardized to assess adjustment in children (e.g., Achenbach & Edelbrock, 1983). Depending on the rater (e.g., teacher, parent, mental health worker) different results may be obtained. Those studies that found no differences in the adjustment of the chronically ill used smaller sample sizes and tended to employ a single disorder. Whether the selection of a single disorder is important to the results probably depends on the disorder selected because the research has demonstrated that the effects of disorders involving CNS functioning are different from the effects of disorders without involvement in brain functioning (Wallander, Varni, Babani, Banis, & Wilcox, 1988).

The Noncategorical Approach

Early research on the effects of chronic illness merely described children with chronic illness, as in case studies, providing little means of comparison with other children. Later, research focused on comparing certain disease groups to others (e.g., diabetics compared to patients with spina bifida) and/or a disease group to healthy children. The heterogeneity within disease groups was ignored, unfortunately: "There is as much within disease variability as between disease variability in terms of disease status and adjustment" (Wallander et al., 1988). Pless and Pinkerton (1975) questioned the assumption in the literature that psychosocial consequences were tied to specific diseases. They hypothesized that the critical variables were prognosis, visibility, nature and time of onset, severity, disability, and the type of care that was involved rather than the medical diagnostic categories.

Following Pless and Pinkerton's (1975) challenge of the disease-specific model of psychosocial consequences of chronic illness, Stein and Jessop (1984) coined the term, the "noncategorical approach" to studying chronic illness. This hypothesis suggests that, in studying the psychosocial adaptation to chronic illness, the commonalities across disorders are more important than the differences. That is, the specific disease groups included in the investigation were not as important as the generic dimensions across disease groups that may influence adjustment. Stein and Jessop (1989) found no significant differences between four illness groups (MM/hydrocephalus, seizure disorders, hemoglobinopathy, and asthma) on 35 variables (including functional status, child's psychological adjustment, mother's psychiatric symptoms, and the judged ability to cope scale). Significant differences between the groups were noted for the Clinician's Burden of Illness score (COBI), financial impact, nonmedical sources of care, sibling ratio of symptoms, and similar variables related to the provision of medical care.

Wallander and colleagues (1988) empirically tested the noncategorical approach by examining the CBCL scores of patients with six pediatric chronic disorders (juvenile diabetes, spina bifida, hemophilia, chronic obesity, juvenile rheumatoid arthritis and cerebral palsy). There were no significant differences on the internalizing scale of the CBCL across disorders. For the externalizing scale, only the score for the juvenile rheumatoid arthritis group was significantly lower than the other groups. Similarly, for the social competence scale, only the score for the cerebral palsy group was significantly below the scores of the other patient groups. Wallander and colleagues concluded that the results support the noncategorical approach to studying psychosocial adjustment to chronic illness. Further, there was not a consistent pattern of results in those children exhibiting problems to suggest that it was determined by the physical disorder. The authors concluded that the problems were more likely to have been caused by individual or their environmental characteristics.

In summary, Stein and Jessop's (1984, 1985, 1989) work evolved from the questions raised about the relevance of the disease-specific model to studying adjustment to chronic childhood illness. Although the noncategorical approach sheds light on the need to identify critical variables (that were not typically considered in the literature), a limitation of the model is that some of the variables that are considered important overlap within an illness group (e.g., visibility and functional status in MM). Thus, a particular dimension cannot be isolated within certain disorders. Additionally, most medical disorders are characterized by multiple dimensions (e.g. visibility, unpredictable course, potentially fatal, sensory or motor component), but sufficient information is lacking about a hierarchy of importance of these dimensions or whether they interact to predict risk of adjustment problems. Further data is needed to provide a high quality test of the noncategorical approach (Lavigne & Faier-Routman, 1992). Short of conducting a large-scale test of the noncategorical approach, rigorous empirical research examining adjustment issues for a particular illness group (such as MM) can prove to be highly informative.

Employing a meta-analytic design, Lavigne and Faier-Routman (1992) have reviewed over 700 studies on chronic childhood disorders to assess the critical variables that affect the child's adjustment. Results, from the 87 studies that met the inclusion criteria, suggested that children with physical disorders are at risk for psychological adjustment problems and that internalizing problems are more common than externalizing problems, as reported by teachers, but externalizing problems were also evident from parents' ratings. Consistent with the noncategorical approach to studying the effects of chronic illness, disease/disability parameters were poorer predictors of the children's adjustment than were family/parent or child variables. The vast majority of the studies examining the adjustment of children with chronic illness look at disease variables, such as severity and exclude other important variables, such as the child's resources or family variables (Lavigne & Faier-Routman, 1993).

Classifying Chronic Illnesses

In their attempt to classify specific disease groups according to differences in adjustment of the patients, Pless and Roghmann (1971) reviewed three large epidemiological studies of children with chronic illnesses. The Isle of Wright study reported psychiatric disorders in 17% of chronically ill children compared to 7% in healthy children. Overall, there was a 1.5 to 3 times greater risk of psychosocial maladjustment in chronically ill children. Those patients with sensory disorders were at the greatest risk compared to those with motor or cosmetic disorders. The risk of psychological maladjustment was found to be roughly proportionate to the duration of the disease and to a lesser degree to its severity. This was one of the first studies to challenge the common-sense assumption that children with more severe disorders are likely to have greater adjustment problems than those with less severe disorders.

Role of CNS involvement. Further clarification regarding the role of disease variables was provided by Rutter, Graham, and Yule (1970) and Rutter, Tizard, and Whitmore (1970). They divided chronic physical disorders in two groups - those with and without brain involvement. A greater proportion of those individuals with brain involvement had psychiatric disorders than those without brain involvement. This was interpreted as an organic role for those with brain disorders and an indirect influence on psychosocial adjustment for those without brain involvement. Requiring further study, however, is the question of whether the severe disability that frequently co-exists with disorders having brain involvement could account for the increased psychological risk. Breslau's (1985) findings replicated Rutter, Graham, and Yule's (1970) work and Seidel, Chadwick, and Rutter's (1975) results, but the latter study controlled for the possible confound of the visibility of the handicaps of the two groups.

In summary, the general consensus in the literature is that there is as much within disease variability as between disease variability with respect to psychosocial problems. The major exception is for disorders involving the central nervous system (including MM) which create a greater risk of psychosocial sequelae. While many variables are being studied to determine what best predicts later problems or better adjustment, thus far there is little consensus in the literature as to the critical determinants. Even severity of disorder, which was once thought to be a common-sense approach to studying adjustment, has not always been supported in empirical studies as a predictor of later problems. The impact of severity of disorder on adjustment will be addressed at the end of the discussion on the noncategorical approach (marginality). In addition to the more apparent disease-related variables children with chronic illnesses are vulnerable to the same stresses as healthy children (e.g., effects of family conflict). These "normal" stressors may interact with disease-related variables.

Family Characteristics

More recently, elaborative schemas have been developed to aid our understanding of the multiplicity of factors that may contribute to the psychosocial adjustment in chronically ill children. A model to account for both the risk and resistance factors (such as intrapersonal factors, social-ecological factors, and stress processing strategies) of chronically ill children has been proposed (Varni & Wallander, 1988; Wallander, Varni, Babani, Banis, & Wilcox, 1989).

With a combined sample of children and adolescents with either juvenile diabetes, spina bifida, juvenile rheumatoid arthritis, cerebral palsy or chronic obesity, Wallander, Varni, Babani, Banis, and Wilcox (1989) found that family resources, both utilitarian and psychological, contribute to explaining why some, but not all, children with chronic illness are at increased risk for psychological adjustment problems. Lower levels of maternal education were significantly related to increased behavior problems and social competence in the child, as measured by the CBCL, even when other family resources were considered. This finding, of the importance of considering utilitarian variables, supports the role of family composition in relation to the child's psychological adjustment, as reported by Stein and Jessop (1984).

Family psychological resources, as measured by the Family Environment Scale (FES; Moos & Moos, 1981), also added significantly to the variance in child adjustment, beyond that accounted for by utilitarian resources. Within family psychological resources, significant regression coefficients were obtained for family organization in predicting internalizing behavior problems and for family conflict in predicting externalizing problems. Family cohesion, conflict and control, in conjunction with income and maternal education, contributed significantly and independently to the variance in child's social competence. The findings highlight the importance of examining multiple risk factors influencing the adjustment of pediatric patients. In this study the two types of family resources accounted for about 17% of the variance in the behavioral adjustment of the patients and 44% in the social adjustment of the patients. A major limitation of this study was the reliance only on mothers for ratings of both child and family functioning. Another bias was the use of the social competence scale of the CBCL as the sole measure of social adjustment since it is limited in scope and many of the items, such as hobbies and social activities, are especially dependent on financial resources. Again, it is not clear from this study if there is a direct relationship between lower maternal education and child's behavior problems or if a variable such as maternal coping style would provide a better explanation for the child's maladjustment. "Education fosters a cognitive complexity that facilitates realistic stress perception and problem-solving skills" (Menaghan, 1983). Mothers with lower levels of education may use less problem-solving coping strategies and react to stress differently than mothers with higher education. The current study will examine the contribution of child and mother's coping to child adjustment.

In a meta-analytic review Lavigne and Faier-Routman (1993) examined variables such as family/parent characteristics, stressors, SES, child characteristics (temperament, coping, I.Q., and self-concept), and disease characteristics (e.g., appearance, severity, duration, functional status) in relation to the adjustment of chronically ill children. Although the correlations are rather small, the results suggest that the most significant variables relating to the child's adjustment across disorders are family cohesion, maternal maladjustment, and child variables (e.g., coping, IQ, and self-concept). These results must be considered cautiously because only disease severity was included in a respectable number of studies ($\underline{n}$=43) that examined psychological adjustment issues. Each of the other variables were included in nine or fewer studies. Poorer coping was associated with overall maladjustment ($\underline{r}$=.43) (Lavigne & Faier-Routman, 1993). It must be underscored that only 38 studies (from a review of 700 articles) met the inclusion criteria, and of these only two examined coping in relation to adjustment in one or more chronic medical disorders. The results suggest that important noncategorical variables are likely to be psychosocial in nature rather than directly related to chronic illness. Thus, an examination of coping in MM is a valuable addition to the literature because it helps researchers to understand one of the mediating processes between chronic illness and subsequent psychosocial adjustment.

In summary, family characteristics, including, cohesion, adaptability, family structure, SES, and maternal education and psychological adjustment, have been studied across illness groups and have been shown either to interact with chronic illness variables or to affect directly the adjustment of the pediatric patient and his/her family. The literature lacks an explanation of how the family's coping with chronic illness and other daily stressors affects the pediatric patient's coping and general adjustment. Although these studies are correlational and do not provide a direction of effect, the reciprocity of these relationships is important to bear in mind (i.e., an ill child may contribute to increased financial and marital stress which in turn may contribute to poorer family functioning, which is likely to increase stress in the child and result in poorer coping). The current study will examine the direct effects of demographic (maternal education, SES) and family (cohesion and adaptability) variables as well as the effects of the child's and mother's coping on the child's behavior problems, social competence and self-worth.

Marginality

The concept of "marginality" (Barker, Wright, Myerson, & Gonick, 1953; Bruhn, Hampton, & Chandler, 1971; McAnarney et al., 1974; Pless & Pinkerton, 1975) evolved to explain how patients with less severe and frequently non-visible disorders not only have a difficult time integrating themselves with healthy peers, but also do not fit into the more visible or severe "handicapped" groups. This theory suggests that these marginal cases will experience greater psychological sequelae than patients with more severe disorders.

In a sample of children with spina bifida or CP, social competence difficulties (measured by the Child Behavior Checklist, Achenbach & Edelbrock, 1983) were associated with disability parameters (including: (a) severity, as measured by a 5 point physical handicap scale included in a 30 minute interview with parent; (b) functional status, measured by the Adaptive Behavior Scale (ABS) completed by the teacher, and; (c) an estimate of IQ) (Wallander, Varni, Babani, Banis, DeHaan, & Wilcox, 1989). In contrast, no relationship was found between differing degrees of physical problems within a sample of children with spina bifida and adjustment, measured by the internalizing, externalizing and social competence scales of the Child Behavior Checklist (Wallander, Feldman, & Varni, 1989).

In a recent study of 6-11 year old children with MM, severity of the physical handicap, based on lesion level, was not significantly associated with child adjustment variables (perceived self-competence, internalizing and externalizing behavior problems) (Barakat & Linney, 1992).

Marginality is an important concept in the current study because of the heterogeneous consequences of MM. For example, some aspects of the disease can be visible (e.g. wheel-chair-bound, use of orthopedic braces, etc.) while other aspects are less apparent (learning problems, need for catheterization). It is not clear whether the MM patient with more visible or functional effects of the illness will cope more poorly than the patient with less visible or functional effects. In the case of MM there may also be a significant degree of overlap between the variables of severity, visibility and functional status, creating an unavoidable confound in measurement. The relationship between marginality and outcome may be nonlinear with the mild cases having outcomes equivalent to the more severe cases, while the moderate cases have the best outcome. Moreover, other variables, such as family functioning, demographics, the child's characteristics, (gender, age), and/or coping may prove to be more important than, or interact with, severity (and the concept of marginality).

In summary, it is apparent that the examination of the psychological sequelae of chronic childhood illness is not as simple as once thought. Although it is estimated that less than one third of the children with chronic illness may exhibit signs of maladjustment (Nolan & Pless, 1986), it may not be the illness variables (e.g., diagnosis, severity, etc.) that are the significant risk factors. Indeed, the concept of marginality suggests that patients with less severe or less visible chronic disorders are at greater risk for adjustment problems because of their ambiguous roles. Some investigators have concluded that the personality strengths of chronically ill children outweigh their deficits (Drotar et al., 1980; Gayton et al., 1977; Tavormina et al., 1976). Children who demonstrate strengths despite their difficult circumstances may employ more effective coping mechanisms than their counterparts who are exhibiting difficulties in their adjustment. Similarly, children who exhibit strengths may come from families where their parents are better copers, provide a less stressful environment for the children, and model effective coping mechanisms. The interaction of specific medical and generic dimensions of chronic illness and/or the secondary consequences of chronic illness are complex and further study is necessary to understand how these variables enhance or diminish coping.

Methodological Issues

A related problem in understanding the risk factors that contribute to psychological adaptation is estimating the value of reported results in studies which have not employed methodologically rigorous designs. A few methodological problems in the studies reviewed will be highlighted, but a complete analysis of methodological issues is beyond the scope of this paper (See Drotar, 1981; Spaulding & Morgan, 1986; Lavigne & Faier-Routman, 1992, 1993 for a review). Some of the variations in findings result from the type of sample selected {i.e., the degree of homogeneity, e.g., diagnoses included, severity (percentage of sample representing a distribution of lesion levels), ambulation status, visible and/or functional effects of the disability, inclusion criteria for variables such as IQ, demographics, age, etc.}, whether a control group was employed, and whether it was a healthy control group or comparison chronic disorder. If a comparison group was employed the logic in selecting a comparison disease has not always been clear, and may have frequently been a matter of convenience of subject recruitment.

Different results were obtained in a large meta-analytic study examining adjustment in children with chronic medical disorders based on whether the illness group was compared to a control group (healthy controls or siblings) or normative data (Lavigne & Faier-Routman, 1992). Studies employing normative comparisons yielded the largest effect size for adjustment problems in children with chronic medical disorders, and differences between chronically ill children and population norms were significant in contrast to nonsignificant differences between ill children and a comparison control group. This difference may be explained, in part, by the fact that studies employing a control group included better matching of subjects, but it was also noted that matching did not always include important variables such as SES.

Drotar (1981) advised investigators to cautiously interpret obtained differences on measures of psychological adjustment between chronic illness groups and normative data that were derived from a healthy standardization sample.

Wide variability exists in the type of measures used (interview, self-report, clinical rater's questionnaire), whether standardized norms were available for that measure, and whether a single measure or multiple measures were employed. If clinical raters were employed, it is not always clear that they were blind to the child's condition. Thus, quality research is still needed to add to our understanding of the specific nature of, and interrelationships between, the psychosocial variables that may either aid or impair adjustment.

Adjustment to MM

A review of the MM literature reveals variations in the conclusions drawn that relate to the design of the studies. Some researchers employed an interview format with patients with spina bifida and/or their parents, and reported findings in a descriptive manner. Other researchers included empirical measures for the patient and/or his/her parent to complete. Only some of the studies included control groups. Except for some consistent reports of patients' functioning with respect to behavior problems, self-esteem and social competence, there are only scattered impressionistic reports relating to miscellaneous aspects of adjustment in the literature. The potential for social isolation and depression in MM patients has also been discussed by many researchers.

Social Isolation

Shurtleff (1977) posited that the capacity for ambulation is closely associated with social and friendship patterns. Castree and Walker (1981) noted that the individual's perception of the disability is a greater influence than the physical severity on social isolation. Adolescents with myelodysplasia had far fewer friends than healthy controls (39 vs. 96); however, the small number of friends was not associated with lesion level (low vs. high) (Hayden et al., 1979). [Lesion level is closely correlated with functional mobility; the higher the lesion, the more likely is the child to be using long-leg braces and a wheelchair.]

Since spina bifida frequently includes central nervous system (CNS) involvement, it is one of the chronic illnesses that would likely be associated with a greater risk of psychosocial sequelae (Rutter, Graham, & Yule, 1970; Rutter, Tizard, & Whitmore, 1970; Seidel et al., 1975). Employing a mixed sample of children and adolescents with cystic fibrosis, myelodysplasia, cerebral palsy and multiple physical handicaps, Breslau (1985) found that the children with conditions involving the brain, even when mental retardation was not involved, were more socially isolated and withdrawn than the children with cystic fibrosis (no brain involvement). Breslau interpreted this finding, in part, as a secondary consequence to the physical (functional) handicaps that accompany brain disorders and limit the ability to socialize after school. She concluded, "Their increased social isolation might have reflected not only the direct effect of brain abnormality upon behavior repertoire, {speech impairment, auditory and visual deficits} but also barriers to organized means for social contact" (Breslau, 1985, p. 94). Social isolation is considered a potentially important antecedent of later psychological problems.

Employing a sample of 6-11 year old children with either CP or spina bifida, Wallander, Varni, Babani, Banis, DeHaan, and Wilcox (1989) did not find social withdrawal to be problematic, according to their mothers' reports on the CBCL. It is possible that social withdrawal is a problem for adolescents more than younger children.

Depression

Feelings of depression at least once a month were reported by 65% (23) of McAndrew's (1979) sample, and 85% of the adolescents in Dorner's (1976) sample felt "miserable and unhappy" (25% of these had suicidal ideation). Dorner did not find an association between depression and mobility problems or severity of disorder. It is possible that the absence of a significant correlation was the result of a ceiling effect because the base rate of depression was so high. Wallander, Varni, Babani, Banis, DeHaan, and Wilcox (1989) noted a lack of depression, as reported by their mothers on the CBCL, in a sample of 6-11 year olds with either spina bifida or CP. The disparity between the findings of these two studies may reflect an age or cohort effect. From 1976 to 1989 there may have been advances in medical care, school access, recreational opportunities, and family education and advocacy.

Breslau (1985) provided an explanation for the lack of depression for a mixed sample of children with chronic medical disorders. She discussed the possible measurement problems because of reliance on mothers' reports on Langner's Psychiatric Screening Inventory, which may provide an underestimate of depressive symptoms. It was further suggested that mothers may have identified anger and irritability in their children and categorized it as conflict with parents, when an underlying depression was actually present. Adolescents with myelodysplasia reported similar levels of feelings of depression as healthy controls, but many of the parents in each group were not aware of these feelings in their children (Hayden et al., 1979). This finding highlights the importance of obtaining measures from both the patient's and parent's perspective. Findings are thus inconclusive regarding the presence of depressive feelings; sample selection or different measurement techniques and instruments may contribute to this variability. Increased methodological rigor in future studies is likely to produce more clear-cut results.

In summary, since MM involves CNS functioning, the consensus in the literature to date is that youth with this disorder are at greater risk for psychosocial difficulties than children with chronic disorders that do not involve the CNS. Among the problems studied, social isolation has been identified as a common problem, but whether it results from the direct effects of brain damage or indirect effects of factors associated with disability remains unclear. Depression may be common in youth with spina bifida, but more rigorous empirical studies are needed. A few areas of psychosocial adjustment (self-concept, behavior problems, social competence and the effects on the family) have been examined in greater depth in the recent literature, and reviews of these are now presented.

Self-Concept

Pless and Roghmann (1971) assumed that behavior problems are a latent effect of impaired self esteem that is an earlier, direct effect of chronic illness. Children between the ages of seven and eight years with MM had significantly lower self-concepts (as measured by the Piers-Harris) than a healthy comparison group (Kazak & Clark, 1986). Significant differences were noted for all scales except physical appearance. A significant inverse relationship was also noted between the child's self-concept and maternal parenting stress, with higher stress associated with lowered self-concept. Similarly, two thirds of the adolescents with MM whom McAndrew (1979) interviewed suffered from low self-esteem based on a sentence completion beginning with, "I am...", and the interviewee's perception of the contribution s/he could make to the community.

In a study of 6-11 year old children with MM, significantly lower self-concept scores, as measured by a total of their subscale scores, on the Pictorial Scale of Perceived Competence and Social Acceptance for Young Children (Harter & Pike, 1984), were reported compared to a comparison group of children without handicaps. Although Barakat and

Linney (1992) made efforts to match the two samples, they differed on SES, parent education, race, child PPVT-R scores and classroom placement.

In summary, a poor self-concept has been a frequent finding in studies of children and adolescents with spina bifida. Use of various measures of self-concept create difficulties in drawing direct comparisons across studies. Although Barakat and Linney (1992) employed a well-respected measure of self-concept, difficulties matching their sample with a comparison group, raise questions about their finding that the MM sample had lower self-concepts, and further research is needed to confirm these results.

However, not all studies have found poor self-concept in children with spina bifida. A sample of non-retarded children with spina bifida between the ages of 5 and 15 years actually exceeded the norms for self-concept on the Piers-Harris (Spaulding & Morgan, 1986). The contrast between this finding and the rest of the studies may relate to sample selection. The sample was small (20 subjects of originally 38 requested to participate), restricted to the Memphis area, and described as having restricted ambulation, but were not severely impaired (i.e., wheel-chair bound). They were non-retarded (IQ>70) and had two parents in the home. Further research is needed to assess self-concept in a larger heterogeneous sample of children with MM. The Self-Perception

Profile for Children (Harter, 1985) will be employed in the current study to assess the children's self-worth.

Behavior Problems

Behavior problems, as reported by patients' parents, have been a common finding in the psychological literature addressing chronic illness. In one study, compared to the community norm sample, 16% of the children with spina bifida were considered maladjusted based on internalizing behaviors and 19% based on externalizing behaviors; the expected proportion of these difficulties in the general population would be 10% (Wallander, Feldman, & Varni, 1989). Further, no significant differences in behavioral adaptation were found based on lesion level, number of surgeries for shunt, number of total surgeries, and ambulation status. When a disability composite index was created, this, too, did not correlate significantly with either of the behavior scales. Only total number of surgeries was significantly correlated with internalizing behavior problems, but the authors felt it may have been a spurious finding because of the numerous analyses computed to investigate the relationship between disease parameters and adjustment.

These results, in conjunction with other work by these authors (Wallander et al., 1988; Wallander, Varni, Babani, Banis, DeHaan, & Wilcox, 1989) suggest that, "once diagnosed with a physically handicapping condition, variation in physical status per se does not account for much of the observed differential adjustment in the children..." (Wallander, Feldman, & Varni, 1989, p.99). It should be noted that the authors reported a possible methodological problem with the choice of disability variables (e.g., a weighted index of disability parameters may have provided a better estimate).

No significant differences in the reports of either internalizing or externalizing behavior problems of 6-11 year old children with MM and a comparison group of nondisabled children were found by Barakat and Linney (1992), and both groups fell within the normal range, as defined by the normative sample of the CBCL.

In a small sample of 3-8 year old children with MM the total behavior problem score on the CBCL was twice that expected, i.e., 25% of the sample exceeded the criterion for total behavior problems and for internalizing problems (Lavigne, Nolan, & McLone, 1988). A significant difference for both sexes combined and for boys alone on the internalizing scale was noted, but the sample did not differ from the norms in externalizing behavior problems. Regression analyses revealed that the combination of temperamental difficulties, low distractibility and family cohesiveness were the best predictors of behavior problems. A measure of self-coping was also shown to contribute significantly to the variance, but these were responses from the patients' mothers.

Thus, Lavigne and colleagues did not examine coping using self-report, as will be done in the current study.

The average child in a sample of 6-11 year old children with either spina bifida or cerebral palsy exhibited more internalizing behavior problems than 84% of the normative community sample and more externalizing problems than 82% of this sample (Wallander, Varni, Babani, Banis, DeHaan, & Wilcox, 1989). However, these children displayed less behavior problems than children referred for mental health services. The disability variables (measuring severity) were generally not related to the child's adaptation except for a positive correlation between personal-social responsibility (one of three factor scores on the teacher-rated Adaptive Behavior Scale measuring chronic strain, which was operationalized in terms of the child's functional status), and internalizing behavior problems in the child. The authors critiqued their work, noting that operationalizing chronic strain in terms of functional status assessed by teachers may not have been the optimal strategy in light of Lazarus and Folkman's (1984) view that the perception of strain is more important than its objective occurrence.

In summary, children with spina bifida appear to be at increased risk for behavior problems compared to the general population. Presenting problems tend to cluster around internalizing behavior problems, but some differences across studies exist, perhaps as a result of sample selection or unexamined mediating variables. Overall, illness variables (e.g., severity, lesion level, ambulation status, etc.) were not associated with behavior problems. The current study will examine behavior problems in children and adolescents with MM in relation to predictor variables such as coping, family dynamics, demographics, disability parameters, and child characteristics.

Social Competence

Adolescents and young adults with spina bifida lagged behind normal expectations for social skills, based on their mothers' ratings of their behavior on the social interaction category, measuring how free time is used, of the Functional Activities Scale (Sousa, Gordon, & Shurtleff, 1976). Functional independence was associated with severity of disability in a sample of 10-18 year old individuals with myelodysplasia (Campbell et al., 1977). Only 50% of the youth with spina bifida that Hayden and colleagues (1979) interviewed had specific chores at home compared to almost all healthy subjects.

Twenty-three percent of the children with spina bifida in Wallander, Feldman, and Varni's (1989) sample were also found to evidence problems in social competence, as measured by the Child Behavior Checklist (Revised). A combined sample of children with either spina bifida or cerebral palsy were also reported to score significantly lower on social competence than the normative sample of children referred for mental health services and lower than 96% of children in the normative community sample. Additionally, social competence was one of the only measures that correlated with the disability variables and measures of chronic strain (Wallander, Varni, Babani, Banis, DeHaan, & Wilcox, 1989). Chronically ill children and adolescents with disability were reported to demonstrate lower competence in recreational activities compared to the chronically ill sample without disability. Disability status also differentiated the two samples with regard to school functioning (Cadman et al., 1987).

In contrast to findings regarding behavior problems, results are more consistent across studies measuring social competence difficulties in children with spina bifida. Further, social competence difficulties are more directly related to disability parameters than are other measures of psychological adjustment (behavior problems, self-esteem). As with behavior problems, the current investigation will examine the contribution of coping, family dynamics, illness severity, and demographic variables to the social competence of MM patients, as measured by The Self-Perception Profile for Children (Harter, 1985).

Effects on the Family

Family systems theory posits that an influence on one member of the family has ramifications for the whole system and vice versa. This nonlinear approach thus implies that a chronically ill child influences the family and the family members, in turn, influence the adjustment of the chronically ill member.

There are numerous family variables that can be examined in relation to the child's adjustment, such as, parental psychological adjustment (Dorner, 1975; Tew & Laurence, 1973; Wallander, Varni, Babani, Banis, Dehaan, & Wilcox, 1989); financial strains (Drotar, 1981; McCormick, Charney, & Stemmler, 1986; Wallander, Varni, Babani, Banis, & Wilcox, 1989); structure of the family (Litman, 1974; McCormick et al., 1986); flexibility of family roles (Drotar, 1981; Kazak & Meadows, 1989; Murch & Cohen, 1989); sibling relationships (Gayton et al., 1977; Tew & Laurence, 1973); other stresses on the family (Kalnins, Churchill, & Terry, 1980); communication styles (Nevin & McCubbin, 1979); stage in the family life cycle (Nielsen, 1980); marital strain (Kazak & Clark, 1986; Kolin, Scherzer, New, & Garfield, 1971; Martin, 1975; Tew, Payne, & Laurence, 1974); extended family relationships (Kazak, Reber, & Carter, 1988); coping styles of parents (Chaney & Peterson, 1989; McCubbin, Nevin, Cauble, Larsen, Comeau, & Peterson, 1982); and resources for social support (Kazak & Marvin, 1984; Kazak et al., 1988; Nevin & McCubbin, 1979). Some of these variables have been examined empirically in the literature and a review of them as they relate to spina bifida is presented. Since many of the studies are correlational, it is not always clear whether the child (or disease) variable is influencing family functioning or if the family variable is having an impact on the child's adjustment. As noted above, family systems theory posits a reciprocal relationship in any event.

The impact on the family occurs immediately after the birth of the child with MM. In the midst of their shock and grief, parents must make critical decisions about surgery and treatment with the health care providers. Sometimes the baby has to be transferred to another special care facility, leaving the burden of decision-making on the father while the mother remains in the hospital where the delivery took place (Myers, 1984). These unpredictable, emergency procedures may contribute to poor communication in decision-making between the spouses (as well as between one spouse and the medical professionals), the mother's feelings of being cut-off from the decision-making process and from her infant, or blame and counter-blame for the decisions that were made. Thus, communication skills, cohesiveness (emotional bonding; see p. 47 for more in-depth definitions), and flexibility affect the couple's coping style (which also includes cognitive efforts to manage stress, and resources for social support) from the moment the child with MM is born.

The behavioral and emotional patterns a family adopts in response to illness are frequently transferred from old relationships to new relationships and continued from one generation to the next one. These patterns shed light on the couple's values and expectations (Penn, 1983). Illnesses are frequently assigned meaning by the family members (e.g., punishment). Their style of dealing with the illness may quickly need to be adapted to state of the art medical advances as they are confronted with the demands of caring for a chronically ill member. Thus, while some changes in the family may occur more or less spontaneously in response to their new needs, other changes may require intervention on the part of the medical staff, a support group, or a mental health professional. Family functioning prior to the onset of the chronic illness is generally considered to be a good predictor of how the family will respond to the new crisis.

Psychological functioning of mothers. Several investigators have examined mothers' functioning in relation to chronic illness in a child. Dorner (1975) reported that 31.9% of the mothers of a child with spina bifida responded in a manner indicative of malaise compared to 10.7% of mothers in a large epidemiological study on the Isle of Wright (Rutter, Tizard, & Whitmore, 1970). Additionally, 31.6% of the mothers responded in a manner reflecting marked depression in contrast to 15.1% of Rutter's normative sample. However, the mothers in Dorner's sample did not attribute their depression to the problems in raising a child with a disability, but cited other stresses in their lives.

Reports of mothers' malaise become more significant when its relationship to other family members' functioning is examined. A significant relationship between mothers' malaise scores and the siblings elevated behavior problem scores on a school report was noted by Tew and Laurence (1973). The mothers of children with MM in this sample had higher stress scores on the Malaise Inventory than mothers of children with psychiatric problems, brain disorders and physical handicaps in the Isle of Wright study (Rutter, Tizard, & Whitmore, 1970).

Similarly, Wallander, Varni, Babani, Banis, DeHaan, and Wilcox (1989) found that mothers of children with either spina bifida or CP reported significantly more mental and physical health complaints than a general sample of mothers and a number similar to that reported by mothers of psychiatrically disturbed children on the Isle of Wright (Rutter, Tizard, & Whitmore, 1970). These results are compatible with those reported by other investigators (Dorner, 1975; Tew & Laurence, 1973, Walker, Thomas, & Russell, 1971). A relationship between severity of the child's MM and parenting stress among mothers was noted by Kazak and Clark (1986).

Mothers of children with spina bifida had elevated scores relative to the norms on the SCL-90 scales of somatization, depression, anxiety, and the global severity index (GSI). Forty four percent of the sample met the criteria for poor psychological adjustment (Kronenberger & Thompson, 1992).

A significant relationship was not found between maternal adjustment, as measured by the Brief Symptom Inventory (Derogatis & Melisaratos, 1983), and child adjustment (self-concept, behavior problems) in a sample of 6-11 year old children with MM (Barakat & Linney, 1992).

In summary, reports of mothers' functioning tend to converge on increased depression and somatic complaints in mothers of youth with spina bifida. The effects on fathers have rarely been studied, and it is not clear if mothers, who generally have the primary caretaking responsibilities, suffer greater consequences to their mental health than do fathers.

Only one study included significant findings related to fathers' perceptions; most disturbing to both mothers and fathers of the more severely impaired children with MM was their children's distractibility and activity level. However, the investigators noted that the scores of both the severely and less severely affected groups of parents were in the range that has reflected the need for psychological consultation (Kazak & Clark, 1986), which suggests that even mild cases of MM may adversely affect parental adaptation to a significant extent.

Marital stress. The earlier literature tended to use marital stress, and especially divorce rates, as a marker of family adaptation to chronic illness in a child (Kolin et al., 1971; Martin, 1975; Tew et al., 1974). Similarly, severity of disorder was examined in relation to marital strain with mixed results. A relationship between severity of child's disorder and marital stress was not found by Tew and colleagues (1974), although parents of children with spina bifida did differ from parents of nondisabled children with respect to marital difficulties. Kolin and colleagues (1971) also concluded that parental adaptation was not related to the severity of the child's disability. Instead the stability of the marriage at the time of the birth of the affected child (e.g., greater than 5 years in length) was considered to be critical to both the parents' and child's adjustment to the disability.

Marital quality/support, as measured by the Dyadic Adjustment Scale (DAS), was positively related to better adjustment in mothers of children with spina bifida (Kronenberger & Thompson, 1992). A less controlling family environment, as measured by the FES, was also associated with better adjustment in these mothers.

One study reported the counterintuitive finding that parents of more severely affected children reported greater levels of marital satisfaction compared to parents of less severely disabled youngsters (Kazak & Clark, 1986). Further, no significant differences in parenting attitudes, marital adjustment, and overall family functioning between a sample of children with MM and healthy controls were reported by Spaulding & Morgan (1986). As noted above, cohort effects may account for these differences; the recent studies tend to be more optimistic, in general. It seems that assessing the parents' adjustment must go beyond the rough estimate of whether the birth of the affected child may have contributed to divorce. There are several other variables associated with parental adjustment (e.g., depression, stress, coping, etc.) that can be analyzed empirically. Nevin and McCubbin (1979) noted that the earlier research focused on family structure (e.g., number of divorces, separations, etc.) in contrast to measures of family cohesiveness. The current study will examine family functioning, as measured by the Family Adaptability and Cohesion Scale (FACES III), and mothers' coping as measured by the Coping Health Inventory for Parents (CHIP) and the Parentcope.

Factors affecting perceived impact on the family.

A study by McCormick and colleagues (1986) of the perceived impact on the family of the health problems of a child with spina bifida highlights the importance of considering multiple variables and their interaction effects. Multivariate analyses identified eight important variables that accounted for most of the variance in impact score. Primary among them were the number of activities limited by the child's health, and the parent's perception of fair or poor health of the child. When all factors were assessed, variables such as lesion level, number of related problems, and other health care use became less important. Thus, mother's educational attainment, number of adults in the home, insurance status, family income, number of visits to the doctor in the month prior to the interview, and paternal employment were better predictors of the stressful effects on the family than the disease variables.

Family conflict. As might be expected, perceived family conflict was associated with depression in adolescents with spina bifida (Murch & Cohen, 1989). There was also an inverse relationship between family conflict and self-esteem. The three scales on the Family Environment Scale (FES) that were positively related to self-esteem were Independence, Cohesion and Expressiveness. The scale measuring the family's Cohesion was inversely related to the adolescent's reported depression. These authors suggest a "stress-buffering effect" of lower levels of family conflict and control. However, the interaction of multiple variables is important since they found that with low levels of life stress, perceived independence is somewhat protective, or serves as a resistance factor, with respect to anxiety and depression. However, with higher levels of life stress a greater sense of independence is less adaptive.

This study not only underscores the important interrelationships between family functioning and the individual's adjustment, but it also identifies specific situational variables (type of stress) that may interact with family functioning and influence the child's adjustment. The importance of whether the stress was controllable or not was highlighted, but the investigation was limited to the adolescent's adjustment (depression, self-esteem, and anxiety) and did not examine the importance of coping mechanisms with respect to stress or family functioning. The current investigation will attempt to bridge some of these gaps by examining coping mechanisms in relation to family, child, and disease variables.

Social support. Social isolation affects both the social development of the child or adolescent with MM (as noted above), and the family members' adaptation. Nevin and McCubbin (1979) differentiated families of children with MM who made a good adaptation from those who were less successful based on their development of family and community resources. They posited that both the "internal resources" and the "range of family's coping strategies" (including social support systems) are important components of the parents' ability to cope with the physical handicap in a child. Their theory posits that the family's ability to develop interpersonal relationships is critical to strengthening the family's internal organization and functioning. Social support has been viewed as a protective factor that promotes recovery from stress (McCubbin, Joy, Cauble, Comeau, Patterson, & Needle, 1980).

Nevin and McCubbin (1979) tested their hypothesis about the family's coping, and found that families with low stress scored higher on the FES cohesion, recreation and organization scales, and lower on conflict than high stress families. Contrary to their prediction, low stress families did not differ from high stress families in intra-family relationships or in maintaining personal and psychological stability, but they were significantly different from each other in family/community relationships, with low stress families reporting greater involvement in religious-community activities and developing support networks with families in similar stressful circumstances. Severe physical problems in the child were more prevalent in the high stress group compared to the low stress group. They also found that the severity of the child's mobility problems, in particular, distinguished low from high stress families, but the severity of other factors related to spina bifida (urinary or bowel function, weight, ulcers below the waist) did not differentiate the two groups.

The investigation of whether the use of social resources by mothers of children with spina bifida helped them to regulate negative emotions revealed that family and marital coping (measured by a self-report questionnaire designed for their study), was not significantly related to mothers' adjustment. Moreover, the counterintuitive finding that coping using friends was significantly related to adjustment difficulties was reported by Kronenberger & Thompson (1992).

In a sample of 6-11 year old children with MM, Barakat and Linney (1992) reported that the greater the social support of the mothers, as measured by the Arizona Social Support Interview Schedule (Barrera, Sandler, & Ramsay, 1981) the fewer externalizing behavior problems reported for the child on the CBCL. The authors hypothesized that adaptive responses to stress for the mothers of children with MM could lead to better adjustment outcomes for both the mothers and children. However, they only examined social support; one of several coping mechanisms available to mothers. Although social support (including support groups) for patients and families has been popularized by the media and integrated into many health programs, it is actually only one of the coping resources available to the patient and family. The current study will investigate an array of coping strategies employed by mothers as well as their children, in relation to the children's adjustment. Other coping mechanisms will be discussed in the next section.

Other aspects of family coping. Just as the individual's coping is likely to be influenced by multiple factors, including the family's functioning, so too, the family's coping is influenced by multiple variables.

> Since the family functions as a system, coping behavior involves the management of various dimensions of family life simultaneously: (1) maintaining satisfactory internal conditions for communication and family organization, (2) promoting member independence and self-esteem, (3) maintenance of family bonds of coherence and unity, (4) maintenance and development of social supports in transactions with the community, and (5) maintenance of some efforts to control the impact of the stressor and the amount of change in the family unit. (McCubbin et al., 1980, p. 865)

Further, coping is modified over time and new hurdles are presented at each developmental transition (Kazak, 1989). This has an effect on both the family and the child (Maddaux, Roberts, Sledden, & Wright (1986). Nielsen (1980) noted that parents of children born with MM appeared to be going though a "crisis period" at the 18 month exam, perhaps because the child's condition became more real for them by that point and they were projecting the possible burden of care for a disabled child in the future. However, by the pre-school age many of the parents in the study appeared calmer, perhaps because of their increased knowledge and experience that aided their adaptation. In family systems terms, they may have reached a new phase of equilibrium. Although Nielsen only studied children through age six, a parent's comment to this researcher (JFR) underscores the need for readjustment at each developmental stage. Referring to precocious puberty, a mother of an adolescent female commented, "Just as things were settling down and we thought we were over the worst, this crops up".

Advocating for a systems approach, Drotar (1981) underscored the multiple effects of a chronic illness on the family.

> Since the chronically ill children's relationships with other family members are a critical source of emotional support (Anthony, 1970; Caplan & Killea, 1976; Litman, 1974; Sourkes, 1977) the quality of family coping with the financial, organizational and relationship stresses incurred by a chronic illness should be a primary focus of assessment. Unfortunately, the emphasis on the child's physical condition tends to deflect total family participation from comprehensive care. (Drotar, 1981, p.214)

While some investigators have explored the relationship of family variables to child coping with a chronic illness (Chaney & Peterson, 1989; Greenberg, Kazak, & Meadows, 1989; Kazak & Meadows, 1989, Wertlieb, Hauser, & Jacobsen, 1986) still fewer have employed instruments with documented validity and reliability, such as the Family Environment Scale (FES) (Moos, 1981) or the Family Adaptability and Cohesion Scale (FACES) when studying families with a child with spina bifida (Murch & Cohen, 1989; Nevin & McCubbin, 1979). Thus, the current investigation of family dynamics can enhance our understanding of how family variables, (such as cohesiveness and adaptability) affect the child's adjustment and whether these variables are associated with other factors such as disease characteristics (e.g., severity) or child characteristics (e.g., self-esteem, behavior problems, or coping style). Family cohesion is defined as, "the emotional bonding members have with one another". Family adaptability is defined as, "the ability of a ...family system to change its power structure, role relationships, and relationship rules in response to situational and developmental stresses" (Olson, Russell, & Sprenkle, 1983, p. 70). It thus seems that the family's adaptability may be especially important as they confront the demands of a chronic illness in one of their members and adjusts to the necessary changes with each developmental transition.

In summary, the family's functioning is a critical influence on the adaptation of the pediatric patient, perhaps even more critical than disease variables, such as severity. Further, family functioning also influences the parents' ability to cope with raising a chronically ill child. Aspects of family functioning most frequently studied empirically are adaptability, cohesion, conflict, and communication. Additionally, the social support system developed by the family may serve as a protective factor in relation to stress. Also noteworthy is the potential need for the family to renegotiate its tasks and roles at each developmental transition in order to enhance their coping strategies.

One purpose of the present study is to examine the effects of family cohesion and adaptability on the adjustment of children and adolescents with spina bifida, and to assess whether the children's and mothers' coping styles predict child outcome above and beyond that of family functioning, alone. Before the specific goals of the study are described, a brief discussion of the coping literature, in general, and as it relates to healthy children, will be presented. There are several promising directions in the study of children's coping, but some of them are beyond the scope of this study; they will be discussed briefly in order to provide a context for the study of coping in children with MM.

Coping

The majority of coping studies in the psychology literature examine adult populations (Billings & Moos, 1981; Felton & Revenson, 1984; Myerowitz, Heinrich, & Schag, 1983; Pearlin & Schooler, 1978; Stone & Neal, 1984; Viney & Westbrook, 1982, 1984; and Vitaliano, Maiuro, Russo, Katon, DeWolfe, & Hall, 1990). The limited number of studies investigating child or adolescent coping (Causey & Dubow, 1992; Compas, 1987; Compas, Malcarne, & Fondacarao, 1988) tend to use more contrived designs and utilize simple school or social situations, providing no basis for comparisons to the potentially stressful predicaments in the medical arena confronted by chronic illness populations at various stages in their development. Despite the unique set of variables relevant to pediatric patients, it is helpful to briefly review some of the general coping literature to gain perspective on the current state of the field.

In their study of normative coping responses of healthy adults, Pearlin and Schooler (1978) noted:

> The limited attention social science has given to coping stands in striking contrast to its long and abundant interest in circumstances that are potentially deleterious to the well-being of people...(p. 2)

They suggested that the lack of empirical studies addressing coping has left it to clinicians, resulting in a possibly erroneous tendency to consider coping a highly individualized process.

Coping may be defined as the, "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p.141). Even in studies with healthy adults, little consensus exists in the literature about the nature and efficacy of coping and how it is measured. For example, controversy exists among researchers examining coping as to whether coping and defense mechanisms are distinct from each other. For example, Haan (1977) differentiated three concepts: coping, defensiveness, and fragmentation:

> Coping involves purpose, choice, and flexible shift, adheres to intersubjective reality and logic, and allows and enhances proportionate affective expression; defensiveness is compelled, negating, rigid, distorting of intersubjective reality and logic, allows covert impulse expression and embodies the expectancy that anxiety can be relieved without directly addressing the problem; fragmentation is automated, ritualistic, privatistically formulated, affectively directed, and irrationally expressed in the sense that intersubjective reality is clearly violated. (p. 34)

Speaking from a psychoanalytic perspective Haan notes, "The person will cope if he can, defend if he must, and fragment if forced, but whichever mode he uses, it is still in the service of his attempt to maintain organization" (p.42). Moreover, according to Haan, people tend to move up (or down) a hierarchy of preferred or situationally indicated processes and they frequently employ both coping and defensive strategies.

A frequently discussed defense mechanism in the literature examining coping in chronic illness populations is denial. Controversy exists as to whether denial is adaptive. The answer seems to depend on multiple factors, including whether it is employed on a short or long-term basis and the perceived controllability of the stress. Also noted was the tendency to mislabel certain behaviors as examples of "denial" (e.g., avoiding talking to a social worker or psychologist about one's illness while in the hospital) (Dansak & Cordes, 1979; Lazarus & Folkman, 1984; Meyerowitz et al., 1983).

In contrast to Haan, Lazarus and Folkman (1984) are opposed to a hierarchy in which some defenses are assumed to be less efficacious than coping mechanisms. They feel both coping or defenses can work well or poorly in particular situations. Stressing the need for further empirical studies of coping processes, they also caution against confounding the process of coping with the outcome by such efficacy judgments.

Lazarus and Folkman (1984) prefer to view coping in terms of (a) complexity (the range of strategies used by an individual at any given time and across times in dealing with a situation), and (b) flexibility (assessing whether the individual employs the same strategy or group of strategies in different situations or whether there is variation). Further, all efforts at adaptation are not considered to be coping. For example, they note that cognitive styles are adaptational, but are more automatic than coping. They also stress that the knowledge of an individual's resources (e.g., health, energy, positive beliefs, problem-solving skills, social skills, social support, material resources, etc.) is not sufficient to predict coping. The relationship between resources and coping is mediated by personal and environmental constraints as well as level of threat.

Researchers have categorized the same coping strategies according to different models. For example, some have divided attempts to cope into (a) passive versus active strategies (Carver, Scheier, & Weintraub (1989); Kliewer, 1991; Lamontagne, 1984, 1987; Moos, Cronkite, Billings, & Finney, 1987); (b) strategies reflecting fatalism vs. optimism (Viney & Westbrook, 1982, 1984); or (c) problem-focused versus emotion-focused strategies (Compas et al., 1988). Other researchers have examined the role of perceived control over the individual or their situation. Still other investigators have highlighted the role of social supports and interpersonal coping (Viney & Westbrook, 1984). When investigators employ different measurement techniques, categorize coping strategies according to different schemas, and employ different types of populations, it is difficult to draw any conclusions about coping.

Pearlin and Schooler (1978) tested the relationship between psychological resources [e.g., self-esteem, self-denigration and mastery (degree of perceived control over situation)] and coping responses (defined as, "any response to external life strains that serves to prevent, avoid, or control emotional distress"). In marriage, coping responses were more helpful in blocking stress than were psychological resources. In parenting, there was no significant difference between psychological resources and coping responses in terms of efficacy. For financial problems, psychological resources were somewhat more helpful than coping responses. In occupational problems, stress was more closely associated with psychological resources, though, unlike the other categories, neither was particularly successful in buffering job stress. The authors suggest that there is not a simple answer to the question of whether personal resources or coping response is more efficacious in buffering strain and stress, but each is dependent on the type of problem. They concluded that psychological resources are more helpful to people confronting strains in situations over which they have little control (e.g., finances, occupation) whereas in close interpersonal situations it is the coping responses that make the most difference. Since their study addressed normal issues faced by adults, they caution against generalizing their findings to problems that deal with unexpected or unusual crises or transitions which may evoke different types of coping responses.

> ...having a particular weapon in one's arsenal is less important than having a variety of weapons. The single coping response, regardless of its efficacy, may be less effective than...a range of responses...Perhaps effective coping depends not only on what we do, but also on how much we do. (Pearlin & Schooler, 1978, pp. 13-14)

This research highlights several important points that may affect the current study. First, the situation in which the problem is embedded may influence the type of coping employed by an individual. Pearlin and Schooler found different results across different situational contexts within a sample of healthy adults. It seems that there may be at least as much, if not more, variation in coping styles, within a sample of chronic illness patients because they are dealing with everyday problems at school, with family and friends, etc., in addition to disease-related problems (e.g., at hospital, with family members, etc.). The coping strategies that are adaptive in one situation may not be as effective in another situation. Additionally, whether patients and their mothers tend to employ multiple coping strategies will be examined in the current study to determine if this coping style is more adaptive than one in which only one or two strategies tend to be employed.

An examination of the degree of controllability of several medical illnesses in relation to adult patients' coping strategies revealed that the consequences of coping were not affected by differences in controllability (as dichotomized by the Health Locus of Control Scale). Felton and Revenson (1984) explained these findings by suggesting, "the uncontrollability inherent in **any** serious chronic illness is powerful enough to override the effects on coping of relatively smaller illness-to-illness variations in opportunities for control" (p.352). This conclusion seems to support the noncategorical approach to studying adjustment to chronic illness. In summary, these studies highlight the difficulties of measuring some types of coping, especially those typically considered defense mechanisms, and the importance of perceived control over oneself or one's situation.

In a study of coping in adult cancer patients, Myerowitz and colleagues (1983) noted that the patient does not cope with the disease, but rather the multiple daily problems it causes. They recommended a competency-based model of coping in which (1) daily stressors are identified; (2) a large number of patients are interviewed to determine the range of responses that are typical for each situation; and (3) the relative efficacy of each response is measured. Similarly, Kessler, Price, and Wortman (1985) highlighted the lack of agreement among researchers as to the focus of questions about coping with a crisis. For example, in studying bereavement, should questions relate to the experience of loss, in general, or should they probe the impact of the life crisis with questions about how the individual is coping with problems that accompany the loss, such as financial strains, household tasks, etc.? This focus complements the non-categorical approach to studying chronic illness because it is not the disease, per se, that is the stressor, but the commonalities across diseases that lead to stress.

In the current study, MM patients will have the opportunity to identify perceived stressors and rate how they attempted to cope with them. For example, if a child cites being teased by peers as a stressor, this problem is potentially stressful for any child with a disorder that makes them appear or act differently from the mainstream group. Thus, it is not having MM, per se that is the stressor, but having an appearance that makes them stand out as different. Examples of potentially stressful situations that children with different chronic illnesses share include complex and long-term treatment regimens, multiple clinic appointments, periodic hospitalizations, aversive medical procedures, acute exacerbation of the chronic condition, handicapping potential, social stigma and child's sense of being different (Wallander, Feldman, & Varni, 1989; Wallander et al., 1988). Thus, the indirect effects of the child's disability/disease status may contribute to significant stress, but one's coping ability can potentially moderate such strain (Wallander, Varni, Babani, Banis, DeHaan, & Wilcox, 1989).

Problem-focused Coping and Emotion-focused Coping

As noted above, one of the more popular ways of categorizing coping has been problem-focused solutions and emotional-focused solutions, with the former defined as "efforts to act on the source of the stress to change it" (e.g., studying more) and the latter relating to emotional regulation associated with or resulting from stressful events (e.g., calming oneself down, ignoring the situation, or maladaptive solutions such as hitting the other person) (Compas et al., 1988, p. 405). Stress management can include a wide array of behaviors including accepting, tolerance, avoidance, in addition to the techniques that attempt to gain mastery over the environment. Coping is not limited to only successful attempts to manage stress, but to all purposeful attempts (Lazarus & Folkman, 1984).

This synopsis of the general coping literature with adults leaves many questions about the process of coping unanswered. Most recently Stone (Adler, 1991) critiqued the Ways of Coping (WOC) questionnaire (Lazarus & Folkman), which is one of the most popular instruments in the literature. For example, he noted that it was revised based on college students' responses to the stress of coping with an exam and cautioned that these types of responses could not be generalized to other populations dealing with personal stressors. Stone also noted that the WOC does not distinguish between individuals coping with familiar problems versus novel or less frequently occurring problems. He suggested that individuals may employ fewer coping mechanisms with familiar problems. Carver and colleagues (1989) also critiqued the WOC, noting that investigators construct an empirical scale by examining how people cope and then, "let statistical tools such as factor analysis tell them what the important underlying dimensions might be" (p. 268). Carver and colleagues corrected this weakness by including theoretically derived coping scales in their questionnaire, COPE. They also viewed the distinction between problem-focused and emotion-focused coping as too simplistic, and suggested that behaviors categorized as emotion-focused may be very different from each other and have different implications for the individual's ability to cope. A limitation of Carver's et al. questionnaire is that it was also standardized with a population of college students.

Despite weaknesses in the measurement of coping and a lack of consensus in the literature about what coping entails, if one is careful to provide a replicable operational definition of "coping", it is nevertheless informative to explore coping in illness populations, such as MM, because coping has not been examined in MM patients, and it can enhance our understanding of the adjustment process.

The last section of this review will address the literature that examines coping in children and adolescents in general. A brief description of the goals of this study will follow.

Coping in Children and Adolescents

A developmental trend was noted in the use of problem-focused versus emotion-focused strategies, with eighth graders reporting more of the latter compared to sixth and seventh graders (Compas et al., 1988). The interaction of development and coping style appears to be a critical factor in the study of children's coping. Gender and type of stressor (academic versus interpersonal) were also moderating variables. For example, girls reported using more coping strategies with social stressors than did boys in the sixth grade. Sixth grade boys used fewer strategies than did seventh and eighth grade boys, but girls' scores did not change with age. Girls also reported employing more emotion-focused strategies with academic stressors than did boys.

Coping and behavior problems. The interaction of coping and behavior problems was empirically tested by Compas et al., (1988). Healthy adolescents were asked to generate a list of possible ways they could have handled their stressful situation (alternatives), and then to indicate the coping mechanisms they actually used in the situation. The number of problem-focused alternatives generated by healthy adolescents was inversely related to their parents' reports of behavior problems on the CBCL. In contrast, the number of emotion-focused coping alternatives generated and strategies used were positively correlated with behavior problems reported on the CBCL.

Since emotion-focused strategies include behaviors such as calming oneself down, as well as hitting and yelling, quantifying the number of emotion-focused strategies reported by eighth graders is not sufficient to assess a maturational trend. Although eighth graders used more emotion-focused strategies than sixth and seventh graders, an additional qualitative shift, with less reports of hitting and yelling, would reflect more adaptive efforts at emotion-focused coping. Such a shift may develop with continued maturation and/or intervention.

Employing an approach/avoidance conceptualization of coping, Causey and Dubow (1992) developed a 30 item questionnaire with 5 factors: seeking social support, self-reliance/problem-solving, distancing, internalizing, and externalizing. Healthy fourth through sixth graders who reported seeking support and/or using problem-solving strategies were more satisfied with their behavior (as reported on the Self-Perception Profile for Children; Harter, 1985). Children who approached the academic stressor with problem-solving strategies were more likely to be happy with themselves. Children who distanced themselves and/or externalized their feelings were more likely to view their behaviors as generally unacceptable. Children who reported using distancing as a coping strategy were less likely to feel good about themselves. Several of the predicted relationships between coping and self-concept did not emerge: seeking social support was unrelated to Global Self-worth; Internalizing was unrelated to Global Self-worth or Behavioral Conduct.

It may thus be anticipated that the MM patients will vary in their coping strategies according to developmental maturation and gender. If different results can be obtained with a healthy sample of adolescents across situations, it is anticipated that there may be even greater variability in the coping strategies of MM patients because the diversity of their stressors is greater (e.g., an array of medical events that may be predictable or unpredictable in addition to the more typical stressors of healthy children and adolescents). A coping strategy, such as distraction, may be adaptive for aversive medical procedures, but maladaptive in dealing with interpersonal stressors (Compas, 1987).

Healthy adolescents perceived more control over academic stressors than interpersonal stressors (Compas et al., 1988). Several hypotheses regarding the differences in coping styles between pediatric patients and their healthy counterparts are plausible. It may be argued that MM patients gradually accumulate a repertoire of coping strategies to handle their medical problems, and they may minimize the significance of other stressors which may seem minor in comparison to surgeries or survival issues. Alternatively, since they have more experience handling medical stressors, they may feel less adept in handling social stressors because of tendencies toward social isolation. It is thus difficult to anticipate how the coping of MM patients will differ from reports of coping in healthy children and adolescents. In summary, important variables to examine when studying the coping strategies employed by children and adolescents include: gender, developmental level, type of stressor, and the degree of perceived control over stressor.

Modeling. Research on children's coping is in its infancy, but preliminary findings suggest that modeling of parental coping may be important, even if specific parental behaviors have not yet been identified as critical to adolescent coping (Kendall & Fischler, 1984; Kennedy, Felner, Cauce, & Primavera, 1988). FES scales and adolescent coping were significantly correlated, with higher total FES scores associated with dialogue as a problem-solving strategy (Kennedy et al., 1988). Healthy adolescents who rated their families as characterized by personal development dimensions were more likely to use dialogue to solve social problems.

Since the child is more dependent on his/her family than the adult, his/her coping style may be influenced by family variables.

Krohne (1979) posited that the child's coping patterns depend on his/her learning history, especially with regard to family socialization. Preliminary results suggested that parental inconsistency, restrictiveness and use of punishment were related to repression-sensitization in children. Krohne assigned different coping models to a unidimensional, bipolar personality dimension called repression-sensitization. The middle of the continuum is normal coping (flexible and situation adequate) and each pole is considered "abnormal" (defensive). Sensitizers use strategies similar to "monitoring" (being alert and sensitized to the negative, or potentially negative, aspects of an experience). Repressors use strategies similar to "blunting" (distraction, and cognitively protecting oneself from danger).

To account for the significant correlations found between high school students coping and their mothers' levels of ego development, Hauser and colleagues (1991) suggested that one possible explanation is that the adolescents observe their parents' coping and thus learn strategies for dealing with stressful situations. Their assumption is that the parents' ego development is the underlying factor of their coping behaviors.

In a study of 7-17 year old children and adolescents with sickle cell disease (SCD), there was a significant positive correlation between parent and child coping, as measured by the Coping Strategies Questionnaire (CSQ) for SCD (Rosenstiel & Keefe, 1983), on "Passive Adherence" (relied on concrete coping strategies, such as increasing their fluid intake, resting, praying). Parents who coped actively, using a variety of cognitive and behavioral coping strategies ("Coping Attempts"), had children who employed less negative thinking (Gil, Williams, Thompson, & Kinney, 1991). Parents who utilized multiple coping strategies had children with lower percentages of reduction in household and social activities and fewer visits/calls to physicians. Parents high on Passive Adherence had children with higher percentages of household, school and social activity reduction. Parents high on Negative Thinking had children with more internalizing and externalizing behavior problems, as reported on the Missouri Children's Behavior Checklist (MCBC; Sines, Pauker, Sines, & Owen, 1969).

In a recent study examining the coping of mothers of disabled children (4.3% were children with spina bifida), a significant positive relationship was reported between mothers' emotion-focused coping [particularly escape-avoidance, taking-responsibility, and self-controlling, as measured by the Ways of Coping Questionnaire (Folkman & Lazarus, 1988)] and their overall psychological distress index, as measured by the General Severity Index of the Brief Symptom Inventory (Derogatis & Spencer, 1982). A significant negative relationship was also found between mothers' problem-focused coping and psychological distress. Planful problem-solving, in contrast to social support or confrontive strategies was associated with decreased psychological distress (Miller, Gordon, Daniele, & Diller, 1992). The authors remind the reader of Lazarus & Folkman's (1984) caution against, "artificially dichotomizing affective and problem-solving coping" since "emotion-focused coping can facilitate problem-focused coping if it is used to manage emotions that would otherwise impede problem-focused activity (Miller et al., p. 602).

In summary, the literature with healthy children and adolescents suggests that coping is associated with behavior problems and family variables. An analysis of coping in a sample with another chronic illness suggests that there are similarities between parents and children's coping which may be explained by modeling. Further, some coping strategies in mothers seem to contribute to better management of their children's illness which suggests that certain types of interventions may be successful with chronic illness groups. Emotion-focused and problem-solving strategies used by mothers of disabled children were also shown to contribute to their own psychological distress.

It is expected that coping will be associated with behavior problems, and that family dynamics will also explain some of the variance in child adjustment. Mothers' coping may influence the children's coping; thus, an examination of mothers' coping is a useful addition to the literature.

Coping with Chronic Illness

While increased knowledge about pediatric patients' and their families' adaptation is gradually accumulating as a result of more refined research, major gaps still exist. Part of the problem is that there are still only a limited number of empirical measures that are appropriate for studying some of the unique problems of chronically ill children (Spirito, Stark, Cobiella, Drigan, Androkites, & Hewett, (1990). While studies in the field of behavioral medicine address coping with specific medical procedures, research that describes pediatric patients' general coping (with both the medical and non-medical aspects of their lives) is lacking.

Employing a sample of children undergoing orthopedic surgery, Robins (1987) found that those children who used a greater number of coping responses, as assessed prior to surgery, exhibited less anxiety and withdrawal after surgery. Although this finding may be intuitively sound, a standardized coping questionnaire was not employed. To measure coping, the author used the adaptive scales of Roberts Apperception Test for Children (RATC). This instrument is more of a projective measure, and the situations to which the children responded were hypothetical rather than actually experienced.

In a review of studies examining active coping in pediatric patients undergoing stressful medical procedures (e.g., venipuncture, anesthesia induction, postoperative discomfort) Peterson (1989) noted that the coping process was frequently indirectly inferred from children's choice of toys, Rorschach responses, etc., and the need for the inclusion of self-report measures in addition to behavioral measures was stressed in order to differentiate ambiguous coping behaviors.

In a sample of 7-17 year old children in remission from cancer Bull and Drotar (1991) found that emotion-management strategies and problem-solving strategies were used about equally in dealing with non-cancer related stressors, as reported on The Children's Stress Inventory (CSI; Wertlieb, Weigel, & Feldstein, 1987). In contrast, emotion-management was used significantly more frequently than problem-solving when addressing a cancer related stress, as reported on the cancer-related stress and coping measure (McCabe & Weisz, 1988). The children typically did not use similar coping strategies across cancer-related and general stressors. The exception was that children who used more intrapsychic coping modes in cancer-related situations also used this strategy in general stressful life situations. In this sample females used significantly more emotion-management than males, and males used significantly more problem-solving strategies than females.

In a sample of 7-17 year old children with sickle cell disease (SCD), coping style, as measured by the CSQ for SCD (Rosenstiel & Keefe, 1983), accounted for a significant proportion of the variance in ER visits even after controlling for the effects of age and frequency of painful episodes. That is, children who coped actively, using a variety of cognitive and behavioral coping strategies ("Coping Attempts"), had fewer ER visits. Children who relied on concrete coping strategies, such as increasing their fluid intake, or resting ("Passive Adherence"), had more frequent ER visits. Children high on Passive Adherence also had significantly higher percentages of reduction in household, school and social activities, as reported by their parents (Gil et al., 1991). In this study child coping did not contribute significantly to the prediction of pain intensity or duration, hospitalizations or visits/calls to physicians. Thus, the examination of coping in pediatric patients may help to generate recommendations about useful interventions in the medical setting.

In the present study the MM patients will be asked to identify a problem that they experienced related to having MM, and rate the coping mechanisms they employed. This design may overcome the methodological problem in the literature of hypothetical generation of problem-solving strategies compared to actual coping with a problem. It is anticipated that a similar association, as reported by Compas and colleagues (1988), between coping styles and behavior problems will be found in the sample of MM patients, with increased behavior problems related to reliance on only a limited repertoire of coping strategies. Additionally, emotion-focused and problem-focused strategies will be examined in relation to behavior problems, social competence, and self-worth. Instruments that tap adult coping styles are more prevalent (Viney & Westbrook, 1984) than instruments assessing pediatric patients' coping. Since coping with chronic illness may be very different from general coping, Spirito, Stark, and Williams (1988) developed the Kidcope, and this measure has been selected for application in the present study. The coping styles included are: problem-solving, social support, social withdrawal, distraction, self-criticism, blaming others, resignation, wishful thinking, cognitive restructuring, and emotional regulation. Their rationale is:

> Flexible use of a variety of coping strategies is likely to be an important mediator of the emotional sequelae of a chronic illness and lead to more adaptive functioning. Closely studying protective factors, such as coping, will be needed before conclusions about adaptive functioning in chronic illness can be reached. (p. 573)

Since children and adolescents have unique developmental characteristics, adult versions of coping scales cannot simply be applied to children. Further, the process of coping, apart from its measurement, may actually be different for children and adolescents because of these developmental considerations. It is thus important to keep in mind certain child characteristics that may affect or interact with coping.

Child Characteristics

Child characteristics are important variables that may predict adjustment or interact with other variables such as family or disease characteristics. These variables may not only help us to identify those children at risk, but may contribute to our understanding of the "protective factors" or "resiliency" (Garmezy, 1987) in some children who demonstrate strengths despite their difficult predicament. For example, self-esteem has been identified as one of the critical factors contributing to resiliency (Compas, 1987). Indeed, it is important to keep in mind that despite the findings that children with chronic illness are at increased risk for psychological adjustment problems (Breslau, 1985, Cadman et al., 1987; Pless & Roghmann, 1971; Rutter, Tizard, & Whitmore, 1970; Wallander et al., 1988), the majority of those with chronic illness are functioning without reported psychological maladjustment (Cadman et al., 1987; Tavormina et al., 1976; Wallander et al., 1988). Thus, it is important for intervention purposes to discriminate which coping strategies and other variables contribute to the success of well adjusted children so that patients (and their families) with adjustment problems may be assisted in learning better coping strategies.

Much of the research described earlier has focused on parent reports of the child's behavior, employing instruments such as the CBCL (Achenbach & Edelbrock, 1983) Even when children's view were tapped, they were more likely to be describing their self-concept or depression than the active strategies they may or may not use to cope with the problems in daily living that they confront. It seems that the examination of the individual's ability to cope with real problems is more critical than findings that merely report the presence or absence of problems. One's coping style may also interact with behavior problems. Coping may thus help to explain the variability in adjustment of children faced with a life stress, such as a chronic illness, whether the outcome be measured in terms of self-concept, behavior problems, or social competence.

Is a Comparison Group Necessary?

A control group will not be used for the purposes of this study. In light of the noncategorical approach to chronic illness (which emphasizes commonalities rather than differences across groups), a cogent argument cannot be made for the comparison between disease groups on coping measures. Even if one were to compare coping in children with MM to another illness group, the findings could not be generalized any further. Since spina bifida is one of the most common congenital disorders, the current research is designed to learn more about coping with this chronic illness, and it is anticipated that the findings will be informative. This study is in the tradition of the ethological/descriptive research.

Kazak (1989) pointed out that although inclusion of a comparison group is **methodologically** desirable, there are risks involved in either anticipating a poorer outcome for the illness group, or in prematurely concluding families of ill children are similar to "normal" families if group differences are not confirmed. Kazak suggested that the comparison group design may not serve the important function of designing studies to explore the processes that are of importance to families with chronically-ill children, particularly the predictors of adaptation. As noted earlier, there is much controversy in the literature as to whether children with chronic illness are at risk for adjustment problems. There is evidence to suggest that the psychosocial variables are more important than the illness variables (Lavigne & Faier-Routman, 1993) which suggests that children with chronic illness may be no worse off than children with other stressors such as low SES, family dysfunction, etc. The purpose of the study is thus to assess the contribution of coping above and beyond other predictors of adjustment (e.g., demographics, illness severity, child characteristics, and family dynamics) to develop a better understanding of some of the risk and resistance factors that influence the psychosocial adjustment of children and adolescents with MM.

Goals of Study

The goals of this study are to examine the problems related to MM that children and adolescents report, and the frequency and efficacy of the coping strategies they employ to deal with the problem described. The role of coping (for children and their mothers) as an independent and significant contributor to the prediction of child adjustment (self-worth, behavior problems, social competence) above and beyond that of the other predictor variables (demographics, illness severity, child characteristics, and family functioning) will be examined. Items on the Kidcope will be clustered (e.g., emotional-regulation and problem-solving, and/or active and passive strategies). The complexity (number) of coping strategies used by the subjects will also be assessed, and treated as a continuous variable. Multivariate regression analyses will be employed to analyze the relationship between the predictor variables: (a) demographics (family income, mother's education, and family structure); (b) disease severity (lesion level, shunt status, and COBI score); (c) child characteristics (age, gender); (d) family characteristics (Cohesiveness, Adaptability as measured by FACES III); (e) child coping (Kidcope); and (f) mothers' coping (Parentcope and CHIP) and child outcome. Figure 1 presents the order of entry of the predictor variables in the multiple regression analyses, and the outcome variables.

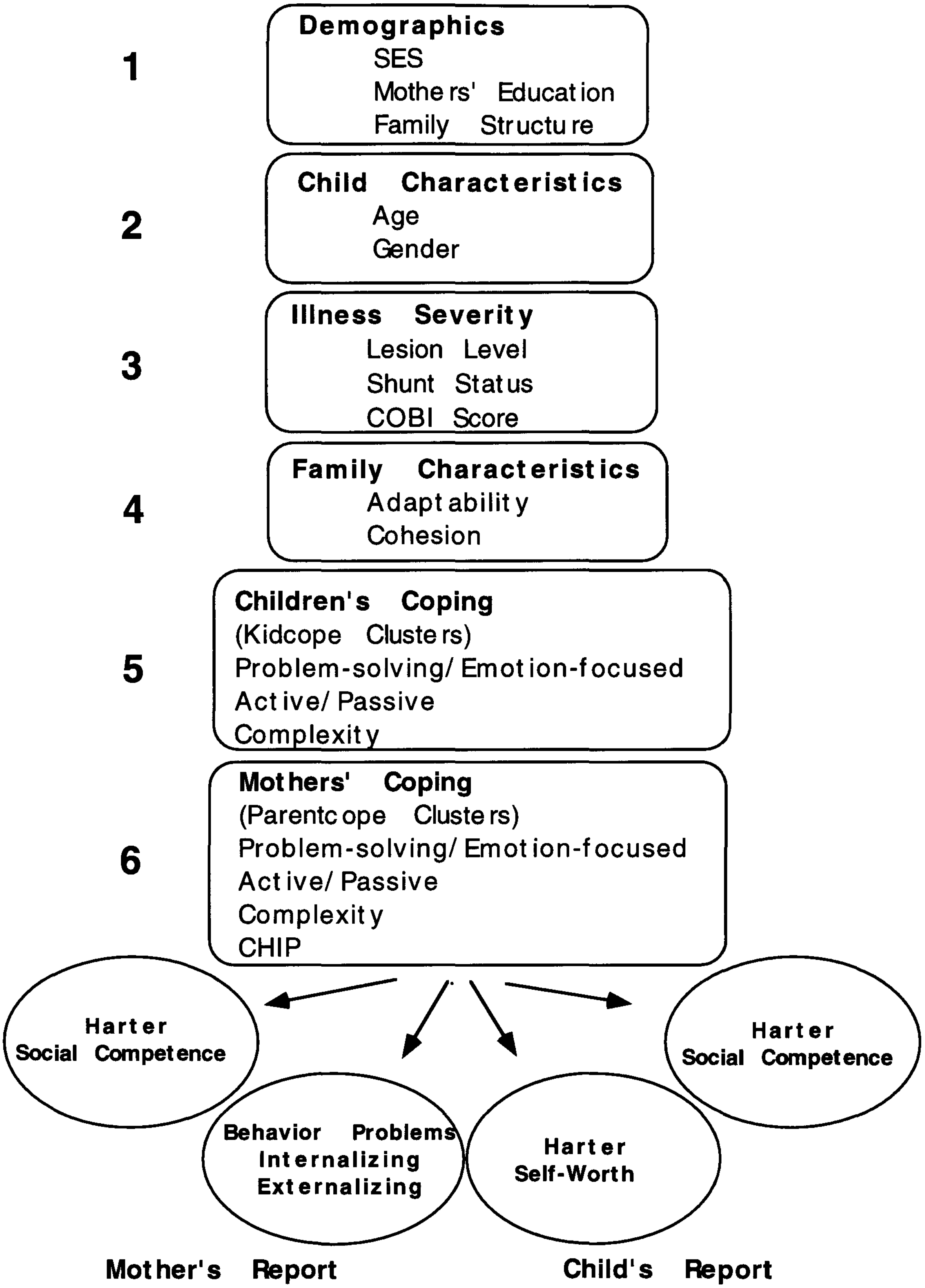

Figure 1. Order of entry of predictor variables in multiple regression analyses, and outcome variables.

CHAPTER II

METHOD

Setting

This study was conducted at a leading urban medical center in the Midwest. The medical center had a weekly interdisciplinary MM clinic which attracted ethnically diverse patients of various socioeconomic groups. Some patients commuted from other cities in neighboring states to receive their care in this clinic, but the majority were from the greater metropolitan area.

Subjects

Children and adolescents between the ages of 9 and 16 years with a diagnosis of MM and a verbal IQ of at least 80 were consecutively selected from the appointment book of the MM clinic. Excluded were those patients whose verbal IQ's were less than 80 (n = 28), non-English speaking families (n = 18), and those patients with a diagnosis of lipomeningomyelocele (n = 15) since it is associated with a milder condition than MM, or other non-MM patients (n = 3). If a family had more than one child with MM, only one child was asked to participate, and the parent was asked to complete the questionnaires with only the designated child in mind.

Since the mothers were required to complete questionnaires, families with the mother absent from the home (or deceased) were excluded (n = 2), but other single parent families were included. Two patients were excluded because they attended residential schools and lived in a nursing home, and their mothers were not available to participate. Patients with a co-diagnosis (e.g., deafness) were also excluded (n = 1). Three subjects decided not to complete the questionnaires after meeting the investigator in the clinic and briefly glancing over the packet of questionnaires. Five refusals were received in the clinic before the mother or patient even looked at the questionnaires. Despite telephone and written reminders 14 subjects did not return the questionnaires after taking them home to complete. Six subjects were excluded after they completed the questionnaires because it was determined that their IQs were below 80. Also excluded was a patient whose IQ was missing and who did not return to clinic during the period of this investigation to have a PPVT administered. (He was also living in a foster home so his family environment was not equivalent to the other subjects in the study.) One patient was excluded at the data analyses stage because of a missing lesion level and inability to obtain the information because treatment was being received at another medical center. The data analyses were performed on 61 patients and their mothers.

Table 1 summarizes the demographic data, mothers' and

Table 1

Selected Characteristics of the Sample

Characteristic	n	%
Gender		
Male	31	51
Female	30	49
Ethnicity		
Caucasian	51	83.6
Hispanic	1	1.6
Black	6	9.8
Other	3	4.9
Family Structure		
Single Parent	9	15
Two-Parent	52	85
Mothers' Education		
Less than 8th grade	1	1.6
8th grade	1	1.6
Less than 12th grade	3	4.9
Completed high school	20	32.8
Some college	17	27.9
College degree	11	18.0
Graduate School	5	8.2
Professional Degree	3	4.9
Shunt Status		
No	10	16
Yes	51	84
Lesion Level		
Sacral	26	43
Low Lumbar	27	44
Thoracic	7	12
Missing	1	1.6
Ambulatory Status		
No supports	10	16
Braces	16	26
Crutches	23	38
Wheelchair	12	20

Table 1 (continued)

Selected Characteristics of the Sample

Characteristic	Mean	Standard Deviation	Range
Child's Age	11.68	2.05	8 - 16
Mother's Age	38.43	4.39	29 - 48
SEI	47.54	25.46	83- 923
Lesion Level[a]	8.38	5.07	1 - 17

Note.

[a] Lesion level was coded as a continuous variable (1=S3, 17=thoracic).

patients' characteristics, including their ambulatory status and the distribution of lesion levels. The average child in the sample was 11.68 years old. There were 31 males and 30 females. His/her mother was 38.43 years of age. Fifty-one patients had shunts. Fifty-one children (83.6%) were Caucasian. Only one participant was Hispanic which may be a misrepresentation of the clinic's patient population since many Hispanic families were excluded because of difficulty understanding English. Fifty-two patients were from a two parent family. Only five mothers in the sample did not complete high school. The sample was predominantly middle class, although the full range of social class was represented.

The Duncan Socio-Economic Index (SEI; Duncan, 1977) yields continuous information based on parental occupation. The variable measuring socioeconomic status was created by converting SEI and income ratings to $\underline{z}$ scores and then summing them. An illness severity variable was created by converting lesion level, the COBI score, and whether the child has a shunt to $\underline{z}$ scores, and then summing them.

Procedure

Several days prior to a clinic appointment, the investigator telephoned the patient's mother to inform her about the opportunity to participate in a research project on coping with MM. The study was described to her as was the essence of the informed consent contract. They were told that both the child and the parent would be reimbursed $5.00 each for their participation in the project. If she was interested, the researcher arranged to meet her and the patient in the clinic's waiting room prior to their appointment(s).

In the clinic a written consent was obtained from both the patient and the mother. The conditions for consent were explained to the child verbally. The questionnaires were then given to the mother and child so that they could begin working on them while they waited for their appointment. The researcher remained in the clinic waiting room to respond to questions if they arose, and she collected the packets when they were completed. If the patient had difficulty with reading or reading comprehension, the researcher read the questions to him/her. For those patients who did not have a standardized measure of IQ, either in their medical charts or in the Medical Psychology department, the Peabody Picture Vocabulary Test (PPVT) was administered to roughly estimate their verbal IQs. Except for the cover sheet which listed identifying information, all questionnaires were coded by number to insure confidentiality.

If the child and/or parent did not have sufficient time to complete the questionnaires prior to the appointment, a stamped envelope was provided so they could complete them at home and return them. The parent received a follow-up call from the investigator within several weeks after their appointment date if the questionnaires had not yet been returned. A reminder memo was also mailed to those subjects who were very tardy in returning the questionnaires.

Medical information regarding orthotic devices, lesion level, shunt infections, surgeries, catheterization, etc. was recorded verbatim from the medical charts, without secondary ratings.

Measures

Kidcope

The Kidcope (Spirito, Stark & Williams, 1988) is a self-report measure that assesses the frequency and efficacy of coping strategies that are used to address a particular problem identified by the child. The 15 item version of the Kidcope (designed for ages 7-12) was used by all the patients in this study. The child was asked to think of a personal problem s/he experienced in relation to having spina bifida, that occurred in the last six months, and to describe it in one or two sentences on the form. The patient was then asked to report whether they used a particular strategy, and if so, how much it helped.

The following coping strategies are measured by two items each: distraction, social withdrawal, problem-solving, emotional regulation, wishful thinking. For example, social withdrawal is measured by responses such as: I stayed by myself; and, I kept quiet about the problem. The remainder of the coping strategies are measured by one item each (cognitive restructuring, self-criticism, blaming others, social support, and resignation). First, the child uses a two point scale to indicate if the strategy was used (yes, no). If a coping strategy was used, the subject uses a Likert-type scale to indicate how much it helped (e.g., a lot, a little or not at all). In summary, the Kidcope yields two scores, one reflecting how many coping strategies were reportedly employed (frequency), the second indicating the perceived helpfulness of the strategies (efficacy).

The majority of the reliability and validity studies for the Kidcope have been conducted on the older version of the scale (see Parentcope, below, for a description of these).

A recent study examining the reliability and validity of the younger version of the Kidcope was conducted by Spirito, Stark, Grace, Stamoulis (1991) with 39 nine year olds, 95 ten year olds, 136 11 year olds, 163 12 year olds, 162 13 year olds, and 81 14 year olds. The sample consisted of suburban, white, healthy children from middle to upper-middle class socioeconomic backgrounds. The children were asked to describe a problem that occurred in the past month, rate if it made them anxious or depressed, and rate the coping strategies they used. The types of problems reported by these 9-14 year olds were similar to those reported by older adolescents, i.e. school, siblings, parents and friends (Stark, Spirito, Williams, & Guevremont, 1989). A coping x distress interaction effect was reported; subjects who reported being distressed by a problem with friends or their parents were more likely to employ emotional regulation than subjects who were reportedly not distressed by the problem. Also noted was the wide array of coping mechanisms reported by younger children whether they responded to a personal stressor or a standard stressor (being grounded). The younger children (9-11 years) in this study tended to use cognitive restructuring, problem-solving, emotional regulation and wishful thinking more than the older subjects (14 years). Thus, coping strategies used differed by age, but not gender in this sample.

Thirty-eight percent of the fourth graders and 45% of the graders were retested on the coping strategies they employed for their self-generated problem at one and two weeks, respectively, after their initial test. Test-retest reliability of this process measure revealed mean phi coefficients at one and two week intervals of .52 and .39, respectively.

Parentcope

For the purposes of this study, the older version of the Kidcope was presented to the mothers to compare their problem selection, and their coping style to their child's problem selection, and coping ratings. There are no validity or reliability studies that employed the older version of the Kidcope as a parent report measure. This version is similar to the younger version of the Kidcope, described above, except that it is composed of 10 items, each measuring one coping strategy. Efficacy is rated by a four point Likert-type format (not at all, a little, sometimes, pretty much, very much). The administration is the same as for the younger version. Most of the reliability and validity studies on the measure have employed the older version of the scale.

Two studies have been conducted with healthy adolescents and suicide attempters, respectively. In the first study by Stark et al. (1989) the sample consisted of 131 male and 106 female 16-17 year olds, 124 male and 115 female 14 year olds and 122 male and 106 female 15 year olds. Since these were healthy adolescents, the most common problems identified by them dealt with school, parents, friends and/or boy/girlfriends. Males reported employing wishful thinking significantly more frequently than females, while females reported reliance on social support more than males. An interaction was reported for emotional regulation, with males reportedly using this strategy more with girlfriend problems while females used it more with problems encountered with friends. In terms of the reported efficacy of coping strategies, the only significant difference was found for resignation, with males more likely than females to perceive it as efficacious. When confronting a problem with a boy/girlfriend, the subjects reported using twice the number of coping strategies as when dealing with problems related to school or parents. Thus, the measure was able to discriminate between the genders: (a) for choice of strategy (frequency), alone; (b) choice of strategy interacting with problem type; and (c) one difference in terms of perceived efficacy (resignation). This study confirms that adolescents understand that different types of problems demand a different array of coping strategies.

In another study by Spirito, Overholser and Stark (1989) the Kidcope was administered to 59 female and 17 male adolescents (12-17 years) following a suicide attempt. Controls consisted of 186 adolescents who completed the Kidcope in response to a personal problem they experienced in the past month. This control group was then divided into distressed and nondistressed groups, based on their ratings on a 5-point Likert scale indicating whether the problem made them anxious and depressed. The distressed group consisted of adolescents who scored 4 or 5 on both depression and anxiety (in contrast to the nondistressed group who scored 1 or 2). While the majority of the problems reported by all three groups related to school, parents, friends or boyfriend/girlfriend, the suicide attempters reported problems with parents more often than the two control groups, and the nondistressed controls reported school problems more often than did the suicide attempters or the distressed controls.

Significant differences between the reported coping strategies employed by the suicide attempters and controls occurred for social withdrawal and wishful thinking. Suicide attempters reportedly used social withdrawal more frequently than both the distressed and nondistressed adolescents, and they used wishful thinking more than nondistressed youth, but less than distressed adolescents. Distressed youth also reported using problem-solving and resignation more than nondistressed adolescents. Given such differences between the sample, the results of this study and the previous study attest to the concurrent validity of the Kidcope measure based on adolescent self-report.

Since coping is viewed as a process measure, the reliability has been demonstrated with only brief test-retest correlations (e.g., less than 1 week apart). Highest correlations for both frequency and efficacy were obtained when healthy adolescents rated the same personal stressor three days apart (frequency: mean = .65, range = .56-.75; efficacy: mean = .54, range = .25 - .74). Somewhat lower correlations were obtained for ratings one week apart [frequency: mean = .55, range = .41-.83, (except for "blaming others", r = .07)] (efficacy: mean = .24, range = .01-.50). Since the Kidcope is a brief checklist, other means of examining reliability, such as internal consistency and factor analytic techniques were precluded (Spirito et al., 1988).

Validity was assessed with previously standardized coping measures (Coping Strategies Inventory (CSI) and the Adolescent-Coping Orientation for Problem Experiences Inventory (ACOPE) with a sample 49 healthy adolescents for each comparison measure. Correlations between the primary coping strategies of the CSI and the eight of the ten items of the Kidcope were moderate to high (mean = .58, range = .33-.77).

Correlations between the items on the ACOPE and the Kidcope that were hypothesized to be conceptually similar were somewhat lower (mean = .30, range = .08 to .62). The highest correlations were obtained for the following scales on the ACOPE and Kidcope, respectively: on the "seeking diversions" scale of the ACOPE and the "distraction" item on the Kidcope (.62); the Ventilating feelings subscale and the "emotional regulation" item ($\underline{r}$ = .50); Seeking spiritual support and seeking social support ($\underline{r}$ = .51); Developing social support and seeking social support ($\underline{r}$ = .48). Differences in the administration of the measures may also explain the lower correlations in comparison to the CSI and the Kidcope.

Thus far Spirito et al. (1988) have employed a mixed sample of 38 pediatric patients referred for psychological evaluations and a diabetic sample (n = 34) at summer camp to validate this measure. Individuals in each group were asked to complete the Kidcope in response to a specific stressor associated with their disease. In the mixed group of 10-18 year old patients with chronic illnesses (e.g. cancer, heart disease, inflammatory bowel diseases, hemophilia, etc.) girls tended to endorse emotional regulation more frequently than boys. Pediatric patients endorsed distraction and social withdrawal more often than diabetic campers or young adolescent controls referred for school problems. However, the nonreferred patients (diabetics) were not found to employ distraction more than controls.

The pediatric patients also reported using self-criticism less frequently than controls. Diabetic campers also endorsed self-criticism less often than controls. Noteworthy was the infrequent use of cognitive restructuring which may have been a developmental influence or may relate to a need for an intervention program to enhance coping.

In summary, the Kidcope has been employed with several samples of youth (healthy, psychiatric, and pediatric) to examine the reliability and validity of the measure. The instrument discriminated between boys and girls in terms of coping strategies preferred for particular types of problems. Further, it differentiated type of coping strategies preferred by healthy adolescents in comparison to suicide attempters. A different pattern of preferred coping strategies was also noted for pediatric patients, diabetic campers and healthy controls. The reliability of the Kidcope was found to be best when the same stressor was rated only three days apart. Validity was also established with correlations between the

Kidcope items and conceptually similar subscales on both the CSI and the ACOPE.

CHIP

The Coping Health Inventory for Parents (CHIP; McCubbin, McCubbin, Nevin, & Cauble, 1987) is a 45 item self-report checklist designed to assess the parent's perception of his/her general coping style in relation to his/her chronically ill child. Three coping patterns derived from factor analysis represented 71% of the variance of the original correlation matrix: (1) Maintaining family integration, cooperation, and an optimistic definition of the situation (coping pattern I: 19 items); (2) Maintaining social support, self-esteem and psychological stability (coping pattern II: 18 items); and (3) Understanding the medical situation through communication with other parents and consultation with medical staff (coping pattern III: 8 items). Cronbach alphas computed for the items of each coping pattern indicate respectable reliabilities of .79, .79 and .71, respectively. Three coping scale scores can be computed for each of the coping patterns by summing the parents' ratings of the helpfulness of each item (0 = not helpful, 1 = minimally helpful, 2 = moderately helpful; and 3 = extremely helpful). Among the validity assessments conducted, the results of the parents' reports on the CHIP were compared to an independent measure of family environment, the Family Environment Scale (FES; Moos, 1981) in a sample of 308 parents who had a child with cystic fibrosis (McCubbin, McCubbin, Patterson, Cauble, Wilson & Warwick, 1983). Mother's use of all three coping patterns was associated with the family relationship dimensions of family life (i.e., cohesiveness, expressiveness, and conflict). Coping Pattern I and II were positively associated with family cohesiveness (*r* = .21, *p*<.01; *r* = .19, *p*<.05). Coping pattern II was positively associated with family expressiveness (*r* = .19, *p*<.05). When used by the father, Coping Pattern I was also positively associated with family cohesiveness (*r* = .36, *p*<.01) and inversely related to family conflict (*r* = .21, *p*<.05). Use of Coping Pattern I by the father was also positively correlated with family organization (*r* = .32, *p*<.01) and Coping Pattern III was positively associated with both family organization (*r* = .22, *p*<.05) and family control (*r* = .19, *p*<.05).

Clinician's Overall Burden Index

The Clinician's Overall Burden Index (COBI; Stein & Riessman, 1978) was adapted for the present study to include those items that are most relevant to the needs of MM patients. The questionnaire consisted of 14 items, nine of which were from the Stein & Riessman index, two items were modified to be more specific, and the remaining three items were added to address compliance issues. The primary nurse in the MM clinic was asked to complete this questionnaire to assess the clinician's impressions of the burden of the illness on the family. To assess the inter-rater reliability of the adapted measure, another nurse in the clinic completed the same questionnaire on a subsample ($n = 17$) of the patients. Every third subject was selected for the second nurse to rate. Of those, she rated those with whom she was familiar. The Pearson product-moment correlation between the two raters was $r = .38$; $p = .13$. They were paid two dollars per questionnaire. To assess the internal consistency of the adapted measure Cronbach alphas were computed. Computation of the Cronbach alpha for the 14 item questionnaire resulted in inadequate internal consistency. Attempts were made to elevate the alpha by experimenting with various combinations of the majority of the items, but these attempts were unsuccessful in elevating the Cronbach alpha. In order to obtain acceptable internal consistency, it was thus necessary to reduce the scale to four items (10 a-d), each rated on a Likert scale of one to five (alpha = .96).

The COBI was used in the current study as an independent and objective measure of the burden of the illness on the family. The score was derived by summing the items, without the use of weights, as used in the original measure; the greater the score the greater the burden of the illness on the family.

CBCL-R

The Revised Child Behavior Checklist (CBCL-R; Achenbach & Edelbrock, 1983) is a 112 item parental report of the child's behavior. It consists of three scales: internalizing and externalizing behavior problems, and social competence. It has been widely used and standardized with both a large community sample (*n* = 1300) and a sample referred for community mental health services (*n* = 2300) of children. Analyses have yielded principal component solutions for the 118 behavior problem items that are different for the two sexes and three age groups (4-5, 6-11, and 12-16 years). Externalizing and internalizing behavior problems exist for all children, as does the social competence scale. Test-retest reliability was demonstrated for a sample of 72 children rated one week apart, with an intraclass correlation coefficient of .95 for behavior problems and .996 for social competence. Interparent agreement on item scores for mothers and fathers of 168 children in mental health settings produced an ICC of .985 for behavior problems and .978 for social competence. The median correlation of scale scores across all sex and age groups for all scales was .89 for test-retest reliabilities one week apart.

Validity of the total behavior problem score was demonstrated by correlations that ranged from .71 and .92 with the total scores on the Conners Parent Questionnaire and the Quay Petersen Revised Behavior Problem Checklist.

In the current study the data from the CBCL-R was treated continuously using T-scores.

Harter's Self-Perception Profile for Children

The Self-Perception Profile for Children (Harter, 1982, 1985) is a 36 item self-report questionnaire, measuring six dimensions - scholastic competence, social acceptance, athletic competence, physical appearance, behavioral conduct, and global self-worth. Each subscale is measured by six items. For example, one of the six items measuring scholastic competence is, "Some kids feel that they are very good at their school work, BUT Other kids worry about whether they can do the school work assigned to them". The child chooses the alternative that is most like him/her and then rates whether the item is "sort of true for me" or "really true for me". Each item is scored from one to four, with a score of one indicating the "least adequate self-judgement" (i.e., lower perceived competence), and a score of four reflecting the "most adequate self-judgement" (i.e., greater perceived competence).

Social acceptance is defined as, "the degree to which the child is accepted by peers and feels popular" (Harter, 1985, p.6). The items do not tap social skills directly. An example of one of the six social acceptance items is, "Some kids wish that more people their age liked them, BUT Others feel that most people their age do like them". Athletic competence is exemplified by, "In games and sports some kids usually watch instead of play, BUT Other kids usually play rather than just watch". Physical appearance taps the degree to which the child is happy with the way s/he looks. For example, an item in this domain reads, "Some kids wish their body was different BUT Other kids like their body the way it is". Behavioral conduct includes items measuring how the children feel about the way they behave. For example, "Some kids often do not like the way they behave, BUT Other kids usually like the way they behave. Global self-worth measures how the child likes him/her self as a person. The author designed the subscale to "encourage children to think about the global perception of their worth as a person", rather than "infer from the sum or average of their responses to specific questions about their abilities" (Harter, 1985; p. 6). An item typical of the global self-worth scale is, "Some kids are very happy being the way they are, BUT Other kids wish they were different".

The measure has been widely used in developmental and clinical research and it has good psychometric properties including a clear factor structure, reliabilities based on a sample of 3rd-8th graders all above .71, and the subscales were not highly correlated with each other (correlations are generally .50 or below, accounting for less than 25% of the variance.) Test-retest reliability was obtained from a sample of 208 children in Colorado and 810 pupils in New York, retested after 9 months. These correlations, corrected for attenuation, ranged from .69 to .87 for the four original subscales.

Harter suggests that parents can complete the teacher rating scale which parallels the children's version. The teacher or parent rates the child's actual behavior (not how s/he thinks the child would respond). For the purposes of this study, parents completed the Teacher Rating Scale. The teacher rating scale contains 15 items, three items per subscale; global self-worth is excluded since these items, "do not translate into attributes which an objective observer can rate" (Harter, 1985; p. 12).

FACES III

The Family Adaptability and Cohesion Scale (FACES III; Olson, Portner & Lavee, 1985) is another widely used instrument in the clinical literature. This 20 item, self-report measure of family dynamics yields two orthogonal dimensions, cohesion and adaptability (r=.03). It was originally posited that family adaptability ranged from very low (rigid) to extremely high (chaotic) with optimum levels near the mid-range (structured and flexible). Similarly, it was posited that the cohesion dimension ranged from very low levels (disengaged) to very high levels (enmeshed). The normative sample consisted of 2453 adults and 412 adolescents, including several types of problem families. Internal consistency for cohesion scale ($\underline{r}$ = .77) and adaptability ($\underline{r}$ = .68) as well as the Total ($\underline{r}$ =.68) has been demonstrated by Olson (1986). Test-retest reliability with FACES II (4-5 weeks apart) was adequate for cohesion ($\underline{r}$ = .83 and adaptability ($\underline{r}$ = .80). (Test-retest reliability with FACES III was not published at the time of this writing). Correlations between family members reports based on 370 husbands, wives, and adolescents were cohesion ($\underline{r}$ = .41) and adaptability ($\underline{r}$ = .25). There is good evidence for face validity and content validity according to the authors. Correlations with social desirability are low for both adaptability ($\underline{r}$ = .00) and cohesion ($\underline{r}$ = .39).

Although a curvilinear relationship was originally posited for adaptability and cohesion, respectively, more recently a linear relationship was reported for each of these scales when "normal" families were studied as part of a national survey of 1000 families across various stages of the life cycle (Olson, McCubbin, Barnes, Larsen, Muxen, Wilson, 1983). In the current study the FACES scores were thus treated linearly, i.e. higher scores on each scale reflect optimum levels of adaptability and cohesion, respectively. The children and mothers completed the FACES III separately, with each individual receiving a score for adaptability and for cohesion. The mean of the mothers' and children's scores on each scale was entered into the multiple regression analyses.

Hypotheses

1. The six sets of predictors that were hypothesized to influence child outcome (behavior problems, social competence, and self-worth) were: (1) demographics (SES, mother's education, and family structure); (2) severity (lesion level, shunt status, and COBI score); (3) child characteristics (gender, age); (4) family functioning (adaptability, cohesion); (5) child coping strategies (Kidcope clusters: active vs. passive and/or problem-solving vs. emotion-focused, complex vs. simple); and (6) mother's coping (as measured by the Parentcope clusters (as above) and the CHIP). It was predicted that coping (in both children and mothers) will account for independent and significant increments in the variance in child adjustment over and above that accounted for by demographics, severity, child characteristics, and family functioning.

Consistent with the value of relying on active coping and/or problem-solving, or multiple coping strategies, as described in the literature review (see pp. 52, 54, 64, 68), it was predicted that the use of these strategies by the pediatric patients would be positively associated with self-worth and social competence, and inversely related to behavior problems. Similarly, it was predicted that mothers reported use of multiple coping strategies, and problem-solving and/or active strategies would be positively associated with the children's self-worth and social competence, and negatively associated with behavior problems in their children.

Children's coping is more likely than mothers' coping to have a direct effect on the children's adjustment, and the relationship between mother's coping and child adjustment is currently not well understood (see pp. 45, 62-64). It was thus predicted that children's coping would be a better predictor of child adjustment than mothers' coping .

2. In light of the discussion in the literature about the role of emotional regulation in situations that are out of the patient's control, such as illness (see pp. 51, 67), it was predicted that reliance on emotional regulation as a coping strategy would be positively associated with self-worth and inversely related to behavior problems in children with more severe cases of MM. In light of the findings that girls employed more emotional-regulation than boys (see pp. 59, 67) it was also predicted that there would be a positive association between boys reliance on emotional regulation and their self-worth and social competence, and a negative association between boys use of this coping style and reported behavior problems.

3. It was expected that higher levels of SES and mother's level of education (see pp. 15-16), and a two parent family would be positively associated with a better adjustment in

children (i.e., fewer reported behavior problems, better social competence and self-worth).

4. Consistent with the importance of family dynamics in the adjustment of the child with a chronic illness (see pp. 35-37, 41-42, 46-47), it was predicted that cohesion and adaptability (FACES III scores) would be positively related to self-worth and social competence, and inversely related to behavior problems.

5. In light of the concept of marginality (which suggests that less severe/visible cases can suffer from equal or greater maladaptive effects of the illness than more severe cases; see pp. 19-20), it was predicted that milder cases will experience adjustment problems comparable to the severe cases.

CHAPTER III

RESULTS

Preliminary Analyses

There were two difficulties that arose in the preliminary stage of analyses that necessitated a modification in the plan of analyses, as described in the hypotheses section. These difficulties concern the development of the active/passive scales, and the use of the number of coping strategies employed as a variable in the multiple regression analyses.

Internal Consistencies of the Kidcope/Parentcope Scales

Initially, items on the Kidcope (and Parentcope) were clustered rationally (e.g., emotional regulation, problem solving, and/or active-passive strategies; Compas et al., 1988; Lazarus & Folkman, 1984). For example, on the active-passive dimension, items 1, 2, 5, 8-11, and 14 on the younger version of the Kidcope were categorized as active (e.g., tried to forget it, watched t.v., tried to calm myself down). Items 1, 3, 6, 7a and b, and 9 on the Parentcope correspond to these items. The remainder of the items on each of the questionnaires were categorized as passive (e.g., wished a problem never happened, didn't do anything, stayed by myself). Cronbach's alpha was computed to test the internal consistency of each scale on the Kidcope and Parentcope, respectively. If the alphas were in the unacceptable range, individual items were considered for exclusion in order to improve the alpha level. Despite numerous exploratory permutations of the scales, it was determined that the active/passive scales for the Parentcope were not usable because: (1) of low alphas (i.e., not higher than .55 for the mothers' passive scale, and; (2) items on the mothers' problem-solving scale overlapped with the mothers' active scale, elevating the correlations between the two scales (e.g., $\underline{r} = .82$, $\underline{p} < .001$). Similarly, items on the children's active scale and problem-solving scale, and their passive scale and the emotional-regulation scale overlapped ($\underline{r}$'s = 0.89, 0.92, respectively, $\underline{p}$'s<.001). The active/passive clusters were thus eliminated from further analyses. Table 2 presents the internal consistencies of the final scales derived from the Kidcope and Parentcope, respectively. Although these alphas are not ideal, the final scales were retained because of their theoretical and practical importance in examining coping in pediatric patients.

The second difficulty that developed at the preliminary stage of analyses related to the prediction in hypothesis 1 that the use of multiple coping strategies would be associated with better adjustment in children. The number of coping strategies that patients and mothers reported using were

Table 2

Internal Consistencies of Kidcope and Parentcope Scales

Kidcope

Scale	Items	Alpha (used)	Alpha (efficacy)
Emotional Regulation	1-6, 10-13, 15	.63	.56
Problem Solving	8, 9, 14	.68	.68

Parentcope

Scale	Items	Alpha (used)	Alpha (efficacy)
Emotional Regulation	1, 7B, 10	.60	.60
Problem Solving	3, 6, 9	.57	.70

treated as continuous data. However, the number of coping strategies correlated highly with the items in the emotional regulation and problem-focused scales ($\underline{r}$'s = .69 and .93 for Kidcope, and .72 and .73, for Parentcope, $\underline{p}$'s<.001). Therefore, this variable was excluded from further analyses, except for exploratory purposes (see p. 131). All of the other analyses proceeded as described in the hypotheses section.

Scoring for the Kidcope and Parentcope was slightly modified for the purposes of this study. As noted above, the original Kidcope has a Likert scale of one to three (1 = not at all) for efficacy ratings while the Parentcope has a 0-4 Likert scale (0 = "not at all"). The Parentcope was recoded from one to five in order to use "0" for missing values, and to make it more comparable to the children's version. None of the hypotheses were related to the efficacy ratings on the Kidcope/Parentcope, and these ratings were not used in subsequent analyses.

In order to preserve the sample size, missing items were included. If a subject excluded a particular item on the Kidcope/Parentcope, it was interpreted that the child did not use a particular coping strategy.

Psychosocial Adjustment

The scores on the measures employed were normally distributed. Prior to summarizing the sample's mean values on the measures administered, the reader is reminded to exercise caution in interpreting these scores since the measures were standardized on a healthy normative sample (Drotar, 1981, Perrin, Stein, & Drotar, 1991). The mean T scores obtained by the children in this sample on the CBCL were 58.92 (SD=10.04) on the internalizing behavior problems scale, and 55.26 (SD=9.55) on the externalizing behavior problems scale. Eight percent of the children with MM in this sample obtained T scores greater than 70 on the internalizing behavior problems scale, and 4.9% of the children obtained T scores greater than 70 on the externalizing behavior problems scale. Achenbach et al. (1983) suggested using T scores greater than 70, the 90th percentile cut-off in the normative sample, as an indicator of problems that were significantly greater than the mean of the community norm sample. It was expected that a chronic illness population might have elevated internalizing scores because items related to somatic complaints are included in this scale. Tables 3 and 4 present the mean scores on the dependent and independent variables, respectively.

Harter (1985) reported mean scores for boys and girls in the third through eighth grades in the normative sample. When these scores and standard deviations were averaged they equalled 2.90 for social competence (SD = 0.68), and 3.03 for self-worth (SD = 0.64).

Table 3

Mean Scores on Dependent Variables of Psychosocial Adjustment

Measure	Mean	Standard Deviation	Range
CBCL			
Internalizing	58.92	10.04	36-87
Externalizing	55.26	9.55	34-77
Harter (Children's report[a])			
Scholastic	2.42	0.66	1- 4
Social	2.74	0.74	1- 4
Athletic	2.19	0.66	1- 4
Appearance	2.51	0.80	1- 4
Conduct	3.13	0.57	1- 4
Self-worth	2.86	0.68	1- 4
Harter (Mothers' report[a])			
Social	2.87	0.81	1- 4

Note.

[a] item means

Table 4

Mean Scores on Predictor Variables

Measure	Mean	Standard Deviation	Range
Children's			
FACES			
Cohesion	34.62	7.63	14 - 48
Adaptability	23.95	6.50	14 - 46
Kidcope			
Emotional Regulation	5.21	2.37	0 - 11
Problem-Solving	1.48	1.18	0 - 3
Complexity	6.84	3.13	0 - 15
Mothers'			
FACES			
Cohesion	38.88	5.78	22 - 49
Adaptability	22.91	5.02	11 - 33
Parentcope			
Emotional Regulation	1.31	.99	0 - 3
Problem-Solving	2.16	.95	0 - 3
Complexity	4.72	1.99	0 - 8
CHIP			
Family Integration (I)	43.89	7.57	25 - 56
Support, Esteem (II)	32.59	7.95	13 - 48
Medical Communication	18.38	3.50	9 - 24

The patients in the current sample were thus within the range of scores reported by Harter. Landry et al. (1993) reported that children with spina bifida between the ages of six and twelve had a mean score of 2.95 (SD = 0.61) for social competence, which was not significantly different from the healthy control group (mean = 3.26, SD = 0.38). The parents in Landry et al.'s sample also had a mean of 3.40 (SD = 0.79) for the social competence scale, which was not significantly different from the parents' ratings in the control group (mean = 3.62, SD = 0.34).

The mean values obtained on the CHIP are within the range cited by McCubbin, McCubbin, Nevin and Cauble (1987) from a sample of 308 mothers with a chronically ill child.

The children reported using, on average, five strategies on the emotional regulation scale and one strategy on the problem-solving scale of the Kidcope. The mothers endorsed, on average, one strategy on the emotional-regulation scale and two strategies on the problem-solving scale of the Parentcope.

Table 5 specifies the number of patients who reported using particular coping strategies on the Kidcope. Although item 7 was deleted from the emotional regulation and problem-solving scales because it lowered the alpha levels, it is presented here to inform the reader of the patients' use of this strategy in relation to other strategies on the

Table 5

Percentage of Children who Reported Using Specific Coping Strategies on the Kidcope

		%	
Item	*Coping Strategy*[a]	*Yes*	*No*
1	distraction	57	43
2	distraction	39	61
3	social withdrawal	26	74
4	social withdrawal	43	57
5	cognitive restructuring	67	33
6	self-criticism	23	77
7	blaming others	15	85
8	problem-solving	43	57
9	problem-solving	51	49
10	emotional expression	28	72
11	emotional expression	56	44
12	wishful thinking	79	21
13	wishful thinking	70	30
14	social support	54	46
15	resignation	33	67

[a] Please refer to the Kidcope in the Appendix for exact wording of items.

Kidcope. Table 6 presents a description of the problems identified by the children and their mothers on the Kidcope and Parentcope, respectively. Problems categorized as medical included, shunt malfunction, catheterization, questions from peers about crutches or braces, mother's concern about whether to enroll patient in bladder stimulation program, figuring out how much patient should walk and how much s/he would use wheelchair at new larger high school, etc. Examples of socially-related problems included, complaints about inaccessible facilities, teasing about a diaper, worries about fitting in when mainstreamed, financial strain. Problems coded as other were miscellaneous issues that did not seem to relate directly to spina bifida, such as other family stress, can't do what I want, ran away from home because punished for using filthy language.

Multiple Regression Analyses

First, Pearson product-moment correlations were computed between all relevant variables. Table 7 presents the Pearson product-moment correlations of all the predictor variables. These correlations provide a context for interpreting the results of the multiple regression analyses. The correlations range from .01 to .64; with one exception, all correlations are .40 or below, reflecting low to moderate correlations. The table indicates moderately

Table 6

Problems Identified on the Kidcope

Problem Type	Frequency	Percent
Medical	44	72.1
Social	12	19.7
Other	5	8.2

Problems Identified on Parentcope

Problem Type	Frequency	Percent
Medical	41	67.2
Social	11	18.0
Other	8	13.3
Missing	1	1.6

Table 7

Pearson Product-Moment Correlations Among the Predictor Variables

Variable	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Demographics														
1. Mothers' Education	.05	.37**	-.08	.01	-.22*	.18	-.02	-.09	-.36**	.09	-.09	.13	.09	.07
2. Family Structure		.17	-.20	.13	.35**	.20	.09	.09	-.18	.22	.13	-.01	.11	-.21
3. SES/Income			-.09	.17	.10	.10	.09	-.07	-.21	.39**	.13	-.15	.16	-.02
4. Children's Age				.12	.09	-.32*	-.20	.05	.16	-.18	-.03	.03	-.18	-.04
5. Gender					.11	-.02	.01	.08	.09	-.03	-.18	-.02	.01	-.03
6. Severity						.18	-.01	.16	-.08	.09	.33*	-.13	-.14	-.11
Family Dynamics														
7. FACES Cohesion							.14	.31*	.02	.16	.00	.30*	.13	.09
8. FACES Adaptability								.01	-.06	.19	.10	-.02	.06	.02
Kidcope														
9. Problem-Solving									.39**	.00	-.07	-.07	.06	-.12
10. Emotional-Regulation										-.19	-.07	-.05	-.08	-.22
Parentcope														
11. Problem-Solving											.40**	.15	.27*	.23
12. Emotional Regulation												.04	.06	-.10
CHIP														
13. Coping Pattern I													.34**	.64**
14. Coping Pattern II														.49**
15. Coping Pattern III														

Note.

*p<.05 **p<.01

high, significant correlations among the coping scales on the CHIP (Coping Patterns I and III, r = .64; Coping Patterns II and III, r = .49). The moderately shared variance between the two coping scales suggests that they are tapping related, but separate coping strategies. Table 8 presents the Pearson product-moment correlations of the predictor and dependent variables. Correlations ranged from .00 to .28. These univariate correlations reflect low levels of shared variance. The multiple regression analyses will clarify the relative and independent contributions of the predictor and outcome variables.

Table 9 presents the Pearson product-moment correlations of the outcome variables. These correlations range from .02 to .72. The significant correlation between internalizing and externalizing behavior problems on the CBCL (r = .72, p < .001) is expected, and the common practice is to look at each scale separately (Achenbach & Edelbrock, 1983). It is thus necessary to remember that half of the variance is in common when examining the predictors of these outcome variables in the multiple regression analyses. Despite the significant correlation between children's social competence and self-worth, 75% of the variance is still not accounted for (r = .50, p < .001). Although there is significant correlation between mothers' and children's ratings of social competence (r = .63, p

Table 8

Pearson Product-Moment Correlations Between Predictor and Dependent Variables

Variable	CBCL		Mothers' Harter	Children's Harter	
	Internalizing	Externalizing	Social Competence	Self-Concept	Social Competence
Demographics					
1. Mother's Education	.26*	.02	-.27*	-.24	-.14
2. Family Structure	-.08	-.16	.09	-.08	.24
3. SES/Income	.05	-.27*	-.11	.03	-.06
4. Children's Age	.00	-.12	-.21	.02	-.19
5. Gender	-.19	-.05	-.17	-.24	-.27*
6. Severity	-.17	-.25	.17	.23	.14
Family Dynamics					
7. FACES Cohesion	.02	.14	.10	.13	.24
8. FACES Adaptability	.12	.17	.01	-.01	.16
Kidcope					
9. Problem-Solving	.16	.26*	-.04	-.18	-.05
10. Emotional-Regulation	-.08	.16	-.22	-.03	-.24
Parentcope					
11. Problem-Solving	.03	.03	.04	.12	.24
12. Emotional Regulation	-.08	-.02	.05	.15	.09
CHIP					
13. Coping Pattern I	.03	.21	.22	-.03	.11
14. Coping Pattern II	.12	.11	-.05	-.01	-.07
15. Coping Pattern III	.19	.22	.06	-.08	.03

Note.

*$p < .05$

Table 9

Pearson Product-Moment Correlations Among the Dependent Variables

Variable	1	2	3	4	5
Child:					
1. Self-worth		.50**	-.09	-.18	.27*
2. Social competence			-.02	-.05	.63**
Mother:					
3. Internalizing				.72**	-.17
4. Externalizing					-.09
5. Social competence					

Note.

*$p<.05$
**$p<.01$

<.001), it is important to look at ratings from both mothers and children.

Hypothesis 1

It was predicted that coping in both the children and their mothers will account for independent and significant increments in the variance in child adjustment over and above that accounted for by demographics, severity, child characteristics and family functioning. Multiple regression analyses were undertaken to test this hypothesis. Each variable cluster was entered hierarchically (stepwise within each set). Order of entry between sets of variables was determined a priori based on the principle of parsimony, i.e., "theoretically simpler structural variables are entered before more complex psychological variables" (Wallander, Varni, Babani, Banis, & Wilcox, 1989, p.168). Lenient criteria were used to force in the variables (i.e., PIN = .9999, POUT = 1.00, Tolerance = .001); the results must thus be considered cautiously because of the use of lenient criteria. The variables within sets were entered on the basis of a forward stepwise procedure. (That is, the computer program controls the order of entry of the variables within a step based on the largest percentage of variance accounted for by that variable. The variable that is allowed to enter second accounts for the highest percentage of residual variance.)

In step one the following variables were forced in stepwise: demographics, (SES, mother's education and family structure), the severity composite (lesion level, shunt status, and COBI score), and child characteristics (age, gender). In step two, adaptability and cohesion were entered stepwise. (The mean of the children's and mothers' ratings on the FACES was calculated and entered for each scale.) Children's coping (clusters) were the third set of variables to enter stepwise, followed by mothers' coping (clusters from the Parentcope), the fourth set of variables to enter stepwise. Finally, mothers' coping, as measured by the CHIP scales, were entered stepwise within the last step.

Since the focus of the study is coping in children with MM, the results will be presented in terms of the coping scales that predicted outcome variables, beginning with children's problem-solving. Contrary to prediction, there was an inverse relationship between the scale measuring children's problem-solving strategies from the Kidcope and children's self-worth on the Harter ($\underline{R}^2$ change = .07, $\underline{F}(9,51) = 5.22$, $\underline{p}<.03$). Table 10 presents the results of this multiple regression analysis. As presented in Table 10, severity was also a significant positive predictor of

Table 10

Multiple Regression Analysis of Independent Variable Clusters Predicting Children's Report of Self-Worth

Step	R	Beta	R^2	Change	F	Variable
1	.24	-.24	.06	.06	3.66	Children's Gender
2	.35	.26	.12	.06	4.26*	Severity
3	.40	-.19	.16	.04	2.38	Mothers' Education
4	.42	.15	.18	.02	1.22	SES/Income
5	.44	-.15	.19	.02	1.23	Family Structure
6	.44	-.00	.19	.00	0.00	Children's Age
7	.47	.17	.22	.02	1.53	FACES Cohesion
8	.47	-.02	.22	.00	0.03	FACES Adaptability
9	.54	-.29	.29	.07	5.22*	Child Problem-Solving
10	.54	-.00	.29	.00	0.00	Child Emot. Reg.
11	.55	.10	.30	.01	0.48	Mo.s' Problem Solving
12	.55	-.05	.30	.00	0.14	Mo.s' Emot. Reg.
13	.58	-.21	.33	.03	2.34	CHIP III
14	.60	.20	.36	.02	1.72	CHIP II
15	.60	.09	.36	.00	0.23	CHIP I

Note.

Emot. Reg. = Emotional Regulation

Mo.s' = Mothers'

$^*p < .05$

children's self-worth, accounting for six percent of the variance in children's self-worth, even though it was entered as a control variable in this analysis ($\underline{R}^2$ change = .06, $\underline{F}(2,58) = 4.26$, $\underline{p}<.05$).

It was also specified in the first hypothesis that reliance on problem-solving strategies would be inversely related to behavior problems. Table 11 presents the regression analysis of the prediction of externalizing behavior problems on the CBCL by problem-solving coping on the Kidcope ($\underline{R}^2$ change = .06, $\underline{F}(9,51) = 4.37$, $\underline{p}<.04$). The findings do not support the first hypothesis because the regression coefficient, though significant, was not in the expected direction. As can be see in Table 11, socioeconomic status accounted for seven percent of the variance in the prediction of externalizing behavior problems ($\underline{R}^2$ change = .07, $\underline{F}(1,59) = 4.68$, $\underline{p}<.04$); this significant finding is discussed under hypothesis three (p. 126). Children's problem-solving did not add significantly to the variance in the prediction of social competence or internalizing behavior problems. The active coping scale and multiple coping strategies were not entered in the regression equation for reasons described in the Method section; thus, this part of hypothesis one could not be

Table 11

Multiple Regression Analysis of the Prediction of Mothers' Reports of Externalizing Behavior Problems by Independent Variable Clusters

Step	R	Beta	R^2	Change	F	Variable
1	.27	-.27	.07	.07	4.68*	SES/Income
2	.35	-.22	.12	.05	3.21	Severity
3	.37	-.12	.14	.01	0.97	Children's Age
4	.38	-.09	.14	.01	0.42	Family Structure
5	.39	.08	.15	.01	0.34	Mothers' Education
6	.39	.05	.15	.00	0.15	Children's Gender
7	.43	.18	.18	.03	2.00	FACES Adaptability
8	.45	.17	.20	.02	1.50	FACES Cohesion
9	.52	.27	.27	.06	4.37*	Child Problem-Solving
10	.52	.01	.27	.00	0.01	Child Emot. Reg.
11	.53	.15	.29	.02	1.19	Mo.s' Problem-Solving
12	.54	.10	.29	.01	0.48	Mo.s' Emot. Reg.
13	.57	.22	.33	.04	2.47	CHIP III
14	.58	-.07	.33	.00	0.23	CHIP II
15	.58	-.02	.33	.00	0.01	CHIP I

Note.

Emot. Reg. = Emotional Regulation   Mo.s' = Mothers'

* $p<.05$

tested. Multiple coping strategies were tested in a set of exploratory analyses (see p. 131).

There was a significant inverse relationship in the prediction of social competence (reported by children and mothers on the Harter, respectively) by emotional regulation on the Kidcope (Children's report: R^2 change = .07, $F(9,51) = 5.05$, $p<.03$; Mothers' perspective: R^2 change = .09, $F(9,51) = 6.26$, $p<.02$) (see Tables 12 and 13, respectively). As can be seen in Table 12, gender was a significant negative predictor of children's report of social competence, accounting for seven percent of the variance in the prediction of social competence, even though it was entered as a control variable in this analysis (R^2 change = .07, $F(1,59) = 4.71$, $p<.05$). That is, females had lower perceived social competence than males. Family structure was another significant positive predictor, accounting for an additional eight percent of the variance in the prediction of children's social competence (R^2 change =.08, $F(2,58) = 5.45$, $p<.05$). This finding will be discussed under the third hypothesis.

Table 13 also indicates that mothers' coping is a significant predictor of mothers' perception of their children's social competence as measured by the Harter.

Table 12

Multiple Regression Analysis of the Prediction of Children's Report of Social Competence by Independent Variable Clusters

Step	R	Beta	R^2	Change	F	Variable
1	.27	-.27	.07	.07	4.71*	Children's Gender
2	.39	.28	.15	.08	5.45*	Family Structure
3	.42	-.16	.18	.02	1.68	Mothers' Education
4	.43	-.11	.19	.01	0.78	Children's Age
5	.44	.07	.19	.00	0.26	Severity
6	.44	-.02	.19	.00	0.02	SES/Income
7	.47	.20	.22	.03	2.15	FACES Cohesion
8	.49	.11	.24	.01	0.83	FACES Adaptability
9	.55	-.30	.31	.07	5.05*	Child Emot.-Reg.
10	.55	-.04	.31	.00	0.10	Child Problem-Solving
11	.57	.16	.33	.02	1.44	Mo.s' Problem-Solving
12	.58	-.11	.33	.01	0.57	Mo.s' Emot. Reg.
13	.60	-.17	.36	.02	1.71	CHIP II
14	.60	.10	.37	.01	0.50	CHIP I
15	.61	-.12	.37	.00	0.35	CHIP III

Note.

Emot. Reg. = Emotional Regulation

Mo.s' = Mothers'

* $p<.05$

Table 13

Multiple Regression Analysis of the Prediction of Mothers' Report of Social Competence by Independent Variable Clusters

Step	R	Beta	R^2	Change	F	Variable
1	.27	-.27	.07	.07	4.64*	Mothers' Education
2	.36	-.23	.13	.05	3.57	Children's Age
3	.38	-.14	.15	.02	1.24	Children's Gender
4	.41	.15	.17	.02	1.49	Severity
5	.41	-.04	.17	.00	0.07	SES/Income
6	.41	.03	.17	.00	0.04	Family Structure
7	.41	.05	.17	.00	0.13	FACES Cohesion
8	.42	-.04	.17	.00	0.11	FACES Adaptability
9	.51	-.34	.26	.09	6.26*	Child Emot. Reg.
10	.51	.03	.26	.00	0.04	Child Problem-Solving
11	.52	-.05	.27	.00	0.16	Mo.s' Emot. Reg.
12	.52	.01	.27	.00	0.00	Mo.s' Problem-Solving
13	.58	.31	.33	.07	4.89*	CHIP I
14	.63	-.41	.40	.07	5.06*	CHIP III
15	.64	-.09	.41	.00	0.34	CHIP II

Note.

Emot. Reg. = Emotional Regulation

Mo.s' = Mothers'

* $p < .05$

Specifically, Coping Pattern I on the CHIP, measuring family integration, cooperation and optimism, was a significant predictor of mothers' perceptions of their children's social competence as measured by the Harter (R^2 change = .07, $F(13,47) = 4.89$, $p<.04$). However, as depicted in Table 13, there was a significant inverse relationship between understanding the health care situation through communication with other parents and consultation with the health care team (Coping Pattern III on the CHIP) and mothers' perception of their children's social competence as measured by the Harter (R^2 change =.07, $F(14,46) = 5.06$, $p<.03$).

Mothers' education was also significant in this analysis, accounting for seven percent of the variance in mothers' reports of their children's social competence (R^2 change = .07, $F(1,59) = 4.64$, $p<.05$). That is, the higher the mothers' education, the lower their ratings of their children's social competence. This finding will be discussed under the third hypothesis.

Contrary to prediction, the scales measuring mothers' problem-solving and emotional regulation on the Parentcope were not significant predictors of any of the dependent variables beyond that accounted for by demographics, severity, gender or family dynamics.

It was also predicted in hypothesis one that children's coping would be a better predictor than mothers' coping of child adjustment. Limiting the assessment to the Kidcope/Parentcope, a simple quantitative summary of the significant results reveals that there were more significant findings related to children's coping, but these findings were not always in the predicted direction. Including the CHIP, there are two significant findings, but only one was in the predicted direction. Given the above results, this prediction was not confirmed.

Summarizing, problem-solving on the Kidcope was negatively associated with self-worth and positively associated with externalizing behavior problems. Although not predicted, severity was also a significant, positive predictor of children's self-worth. Emotional regulation on the Kidcope was inversely related to social competence, as rated by both children and mothers. Gender and family structure, together accounted for 15 percent of the variance in children's reports of their social competence. Mothers' education also explained seven percent of the variance in the prediction of social competence, as reported by mothers. Problem-solving on the Parentcope did not add significantly to the variance in the prediction of any of the dependent variables. Mothers' coping (as measured by coping pattern I on the CHIP) added significantly and positively to the variance in the prediction of children's social competence. That is, mothers' perception of their children's social competence was partially associated with their own ratings of family integration, cooperation and optimism, and inversely with their ratings of understanding the medical situation (Coping Pattern III on the CHIP).

Hypothesis 2

It was predicted that reliance on emotional regulation would be positively associated with self-worth and inversely related to behavior problems in the children with more severe cases of MM. Additionally, it was specified that boys' reliance on emotional regulation would be positively associated with self-worth and social competence, and inversely related to behavior problems. To test this hypothesis demographics were entered in the first step, severity (or gender) and emotional-regulation were entered in the second step, and the interaction term, severity x emotional-regulation (or gender x emotional-regulation) were entered in the final step. Contrary to prediction, there were no significant findings when the interactions between emotional-regulation and severity, and emotional regulation and gender, were entered into separate regression analyses.

Hypothesis 3

It was predicted that higher levels of SES and mother's level of education, and a two parent family would be positively associated with better adjustment in children. As predicted, family structure was a significant predictor of children's reports of social competence, with children from a two-parent home reporting better social competence (R^2 change = .08, $F(2,58) = 5.45$, $p<.05$) (see Table 12). However, family structure was not a significant predictor of any of the other outcome variables. As noted above (hypothesis 1), mothers' level of education was also a negative predictor of mothers' reports of their children's social competence (see Table 13). That is, the higher the mothers' level of education, the lower their ratings of their children's social competence. Although mothers' level of education significantly added to the variance in internalizing behavior problems (R^2 change = .07, $F(1,59) = 4.27$, $p<.05$), it was not in the predicted direction. That is, the higher the education obtained by mothers in this sample the more likely it was for them to report internalizing behavior problems in their children (see Table 14). Contrary to prediction, mothers' level of education was not a significant predictor of externalizing behavior problems, or children's reports of their self-worth or

Table 14

Multiple Regression Analysis of the Prediction of Mothers' Reports of Internalizing Behavior Problems by Independent Variable Clusters

Step	R	Beta	R^2	Change	F	Variable
1	.26	.26	.07	.07	4.27*	Mothers' Education
2	.32	-.19	.10	.04	2.42	Children's Gender
3	.34	-.10	.11	.01	0.60	Severity
4	.34	.05	.12	.00	0.17	Children's Age
5	.34	-.02	.12	.00	0.03	Family Structure
6	.34	.01	.12	.00	0.01	SES/Income
7	.37	.15	.14	.02	1.26	FACES Adaptability
8	.37	-.00	.14	.00	0.00	FACES Cohesion
9	.43	.24	.19	.05	3.14	Child Problem-Solving
10	.44	-.09	.19	.01	0.35	Child Emot. Reg.
11	.44	-.06	.20	.00	0.15	Mo.s' Emot. Reg.
12	.44	.02	.20	.00	0.02	Mo.s' Problem-Solving
13	.48	.21	.23	.03	1.99	CHIP III
14	.50	-.21	.25	.02	1.01	CHIP I
15	.50	-.02	.25	.00	0.01	CHIP II

Note.

Emot. Reg. = Emotional Regulation

Mo.s' = Mothers'

*$p < .05$

social competence. As predicted, socioeconomic status was a significant negative predictor of externalizing behavior problems (R^2 change = .07, $F(1,59) = 4.68$, $p<.04$) (see Table 11). That is, the children from more economically disadvantaged homes were reported by their mothers to experience a greater number of externalizing behavior problems, than were children from more economically advantaged homes.

Hypothesis 4

It was predicted that cohesion and adaptability would be positively related to self-worth and social competence, and inversely related to behavior problems. Contrary to prediction, cohesion and adaptability were not significant predictors of Harter self-worth, social competence or CBCL behavior problems.

Hypothesis 5

In light of the concept of marginality, it was predicted that the children with milder cases of MM were likely to experience a similar level of adjustment as the more severe cases. To test this hypothesis, the distribution of severity scores were examined, and a tripartite split was made to create three groups (high, medium, low). Separate one way analyses of variance were computed with severity as the independent variable, and each of the dependent variables of adjustment, (child Harter: self-worth and social competence; CBCL scales: internalizing and externalizing; Mothers' Harter: social competence). The only significant difference between the groups was on externalizing behavior problems ($F(2,58) = 4.81$, $p = .01$). A Scheffe test was computed and the findings indicated that the most severe group had fewer externalizing behavior problems than either of the other two groups, who did not differ significantly from each other. Since five ANOVA's were computed a conservative approach of dividing the significance level ($p = .05$) by five was taken, yielding a more stringent significance level of $p = .01$. Since the F test was $p = .01$, it was just barely significant. Table 15 presents the results of this analysis of variance and the Scheffe test.

In summary, there were no significant findings in the analyses testing the interaction between children's reliance on emotional regulation and severity. Nor were there any significant results in the analyses testing the interaction between emotional regulation and gender (hypothesis 2). Hypothesis 3 was partially confirmed as socioeconomic status was a significant predictor of externalizing behavior problems, and family structure was a significant predictor

Table 15

One Way Analysis of Variance with Severity by Externalizing Behavior Problems

Source	Sum of Squares	D.F.	Mean Squares	F	Probability
Between	779.10	2	389.55	4.81	.01
Within	4696.68	58	80.98		

Scheffe Test

Mean	Group	3	1	2
50.33	3 (most severe)			
57.71	1 (least severe)	*		
58.00	2 (mid-range)	*		

*p=.05

of children's reports of their social competence. Contrary to prediction, mothers' educational level was negatively associated with their reports of their children's social competence and positively associated with their reports of internalizing behavior problems. Contrary to the prediction in hypothesis 4, family cohesion and adaptability were not significant predictors of any of the outcome variables. Hypothesis 5 was partially confirmed in that the mild and moderate groups differed significantly from the most severe group in terms of externalizing (but not internalizing) behavior problems, with the most severe group experiencing fewer reported problems. No significant differences were noted in terms of self-worth or social competence.

Exploratory Analyses

To explore the role of multiple coping strategies (complexity) as predictors of child adjustment, this variable was entered instead of the emotional-regulation and problem-solving subscales. Use of multiple coping strategies (complexity) in children was inversely related to social competence on the children's Harter (R^2 change = .08, $F(9,51) = 5.91$, $p<.02$ (See Table 16). As noted in Table 16, although entered as control variables, gender was a

Table 16

Multiple Regression Analysis of the Prediction of Children's Report of Social-Competence by Multiple Coping Strategies (Complexity)

Step	R	Beta	R^2	Change	F	Variable
1	.27	-.27	.08	.08	4.71*	Children's Gender
2	.39	.28	.15	.08	5.45*	Family Structure
3	.42	-.15	.18	.02	1.68	Mothers' Education
4	.43	-.11	.19	.01	0.78	Children's Age
5	.44	.07	.19	.00	0.26	Severity
6	.44	-.02	.19	.00	0.02	SES/Income
7	.47	.20	.22	.03	2.15	FACES Cohesion
8	.49	.11	.23	.01	0.83	FACES Adaptability
9	.56	-.32	.32	.08	5.91*	Children's Complexity
10	.56	.02	.32	.00	0.02	Mother's Complexity
11	.58	-.13	.33	.01	1.06	CHIP II
12	.58	.10	.34	.01	0.51	CHIP I
13	.58	.01	.34	.00	0.00	CHIP III

Note.

* $p<.05$

Emot. Reg. = Emotional Regulation

Mo.s' = Mothers'

significant negative predictor, and family structure was a significant positive predictor, of children's perceived social competence, each accounting for eight percent of the variance in this analysis (Gender: $\underline{R}^2$ change = .08, $\underline{F}(1,59) = 4.71$; Family Structure: $\underline{R}^2$ change = .08, $\underline{F}(2,58) = 5.45$, $\underline{p}$'s<.05. That is, girls had lower social competence than boys, and children from two-parent homes had higher reported social competence than children from single-parent homes. Children's use of multiple coping strategies was not a significant predictor of behavior problems or Harter self-worth. Children's use of multiple coping strategies was inversely related to their mothers' ratings on the Harter of children's social competence ($\underline{R}^2$ change = .10, $\underline{F}(9,51) = 6.88$, $\underline{p} = .01$ (See Table 17). As can be seen in Table 17, mothers' education, although entered as a control variable, was a significant negative predictor of mothers' reports of their children's social competence, accounting for seven percent of the variance in this analysis ($\underline{R}^2$ change = .07, $\underline{F}(1,59) = 4.64$, $\underline{p}<.05$). That is, the higher the education, the lower the reported social competence (which is similar to the results in Table 13). Mothers' reports of employing multiple coping strategies was not a significant predictor of any of the outcome variables.

Table 17

Multiple Regression Analysis of the Prediction of Mothers' Report of Social Competence by Multiple Coping Strategies (Complexity) in their Children

Step	R	Beta	R^2	Change	F	Variable
1	.27	-.27	.07	.07	4.64*	Mothers' Education
2	.36	-.23	.13	.05	3.57	Children's Age
3	.38	-.14	.15	.02	1.24	Children's Gender
4	.41	.15	.17	.02	1.49	Severity
5	.41	-.04	.17	.00	0.07	SES/Income
6	.41	.03	.17	.00	0.04	Family Structure
7	.41	.05	.17	.00	0.13	FACES Cohesion
8	.42	-.04	.17	.00	0.11	FACES Adaptability
9	.52	-.35	.27	.10	6.88**	Children's Complexity
10	.53	-.09	.28	.01	0.44	Mothers' Complexity
11	.58	.27	.33	.06	4.22*	CHIP I
12	.61	-.28	.37	.04	2.91	CHIP III
13	.61	-.05	.37	.00	0.10	CHIP II

Note.

**$p<.01$ * $p<.05$

As noted in the Method section, the Kidcope was not designed with subscales describing coping styles. Since the subscales were designed for this particular investigation, and methodological limitations are evident (see Discussion), *t*-tests were computed to compare scores on the dependent variables (children's completion of the Harter self-worth and social competence scales, and their mothers' completion of the CBCL internalizing and externalizing scales, and the Harter social competence scale) of those children who reported using a particular coping strategy (individual items on the Kidcope) with those who reported they did not employ that strategy. Since this was an exploratory analysis of the individual Kidcope items, item 7 was not excluded, as was necessary for the development of the emotional-regulation and problem-solving scales (see Table 2). The Bonferroni adjustment was performed to generate a more stringent alpha level since there are 15 Kidcope items and five dependent variables, the alpha level of .05 was divided by 75, yielding a more conservative significance level of .0007. At this significance level none of the individual Kidcope items differentiated the two groups.

In summary, the exploratory analyses did not result in the predicted contribution of the use of multiple coping strategies, by either children or mothers, to any of the dependent variables. None of the individual items on the

Kidcope discriminated those children who were better adjusted (as measured by the dependent variables) when the Bonferroni correction was computed to achieve a more stringent significance level to correct for multiple *t*-tests.

CHAPTER IV

DISCUSSION

Overview

This chapter includes a review of the general purposes of the study, the results, and an interpretation of the findings. Finally, limitations of the study will be discussed along with implications for future research.

Purpose of the Study

The goal of the study was to examine the coping strategies of children with MM, as well as their mothers' coping styles. It was predicted that coping would influence child adjustment, even after other variables, such as demographics, disease severity, child characteristics, and family dynamics were considered. By addressing children's coping, the researcher's lens is focused on their strengths and competencies, rather than on their deficiencies or psychopathology. Exploring the role of coping in a chronic illness population, with acute illness related difficulties, in relation to child adjustment is a novel contribution to the literature. Typically, coping has been examined in healthy children in relation to hypothetical problems.

Summary and Interpretation of the Findings by Hypothesis

The current study suggests that there is merit in continuing to explore the role of coping in children with chronic illnesses.

Hypothesis 1

It was predicted that coping (in both children and their mothers) would account for independent and significant increments in the variance in child adjustment over and above that accounted for by demographics, severity, child characteristics, and family functioning. Since the focus of this study is on coping the results will be discussed in relation to the coping scales that predicted adjustment in children beginning with children's problem-solving.

Contrary to prediction, reported reliance on problem-solving was a positive predictor of externalizing behavior problems, according to their mothers' report on the CBCL. That is, the more children endorsed problem-solving as a coping strategy they employed, the greater the reported externalizing behavior problems. A possible explanation for this counterintuitive finding relates to the fact that there were only three items in the problem-solving scale, which may not be sufficient to measure it adequately. Additionally, children endorsed, on average, one item from the problem-solving scale. Kliewer (1991) suggested that problem-focused strategies may not be as adaptive for children as for adults because many situations are out of their control, and their cognitive skills are still developing.

In contrast to the current findings, Compas et al.'s (1988) results with healthy adolescents indicated that the number of problem-focused alternatives generated was inversely related to behavior problems on both the Youth Self Report (YSR) and parents' CBCL. However, it is difficult to make direct comparisons when different measures of coping are utilized and when the question about coping is varied (i.e., situation is different for healthy and physically challenged individuals).

Cognitive level of development may partially explain the findings that problem-solving was negatively associated with Harter self-worth. That is, the more the children endorsed problem-solving as a coping strategy, the lower their reported self-worth. It is possible that those children who attempted to, "fix the problem by thinking of answers" (item 8), or "doing something or talking to someone" (item 9), for example, were frustrated by their efforts, and they may not have considered alternative strategies for dealing with their problem, and thus felt worse as a result (lowered self-worth).

There may be a conceptual link between the findings that problem-solving was positively related to externalizing problems and negatively related to self-worth. That is, the findings may reflect a response bias on the part of impulsive children.

Harter (1990) recommended following-up her questionnaire with open-ended questions about the social comparison group employed by the child to be better able to interpret the scores and understand the processes involved in self-evaluative judgments. Such an interview might also have helped to identify whether those children who endorsed few problem-solving skills had inflated self-worth scores because they denied problems related to self-worth.

Bull and Drotar (1991) found that pediatric cancer patients employed emotion-management strategies significantly more frequently than problem-solving strategies when dealing with a cancer related stressor. Since coping is viewed as a process measure (i.e., in contrast to a trait, coping changes with the demands of the situation), the results of the current study cannot be generalized to explain how this sample might cope with problems that are not directly related to MM.

Although not predicted, severity also explained a significant portion of the variance in the prediction of children's self-worth, with the more severe cases reporting better self-worth. As noted in the literature review, numerous studies did not find an association between severity of chronic illness and adjustment problems (e.g., Breslau, 1985; Rutter et al., 1970; Wallander, Feldman & Varni, 1989). Barakat & Linney (1992) also did not find a significant relationship between severity and perceived self-competence in a study of 6-11 year old children with MM. The current finding may support the notion that one's appraisal of one's circumstances is an important factor to consider in studies of adjustment. That is, despite a severe case of MM, one's perception of the problem may influence one's self-worth. Since appraisal of the problem was not examined in the current study, this explanation would have to be followed-up with future research that examines this association. Another possible explanation for the current findings relates to Harter's (1981) point that children perceive themselves as more competent than their teachers do because they view themselves as they wish to be, in contrast to how they really are (Landry et al., 1993). Wish-fulfillment may be employed more frequently by the more severely disabled children.

Children's reported use of emotional regulation was a negative predictor of their own and their mothers' ratings of their social competence. That is, the less the children relied on emotional regulation as a coping strategy the greater their perceived social competence. Reviewing some of the individual items included in the emotional regulation scale sheds some light on why this association occurred. The following statements tend to reflect social isolation and lack of effective communication which are the antitheses of social competence: Item 1, "I just tried to forget it,"; item 2, "I did something like watch t.v. or played a game to forget it"; item 3, "I stayed by myself"; item 4, "I kept quiet about the problem"; item 6, "I blamed myself for causing the problem";

item 10, "I yelled, screamed or got mad". A child who tends to withdraw, for example, may not feel s/he is accepted or liked by peers; the essence of the social competence scale.

Compas, Worsham, and Ey (1992) suggested that refinement of subtypes of emotion-focused coping may be useful in discriminating which coping strategies are maladaptive under essentially all conditions, and which strategies may be beneficial under particular circumstances. Although not predicted, gender also predicted children's report of their social competence, with girls reporting lower social competence. This finding may be associated with precocious puberty experienced by them which may make them feel set-apart from their peers in social settings.

Contrary to prediction, mothers' coping efforts directed at medical consultation (self-reported on the CHIP) were a negative predictor of their ratings of their children's social competence. It is possible that parents who are more knowledgeable about the medical system also have higher expectations for their children and may be more critical of their social competence. In a study of children with diabetes, the mothers' total CHIP score was negatively related to the child's global self-worth. Kager and Holden's (1992) interpretation of this finding may apply to the current finding. They suggested that poorer self-worth may represent a chronic stressor and a cue to mothers to use and evaluate more coping strategies. Poor social competence may, similarly, serve as a stressor, and a cue to mothers to become more aware of the ramifications of their children's disorder by consulting with the medical staff, and communicating with parents in a similar situation.

Mothers' educational level was also a significant negative predictor of children's social competence, as reported by mothers; this finding will be discussed under hypothesis 3.

Mothers' coping efforts related to "family integration, cooperation, and having an optimistic definition of the situation" (CHIP I) was a significant predictor of children's social competence, as reported by their mothers. This finding supports the argument that the family can be protective of the child with a chronic illness and foster their development (Murch & Cohen, 1989). Considering the importance of social support in the literature (Kazak & Marvin, 1984; Kazak et al., 1988; Nevin & McCubbin, 1979), it is surprising that the CHIP II scale (i.e., maintaining social support) was not a significant predictor of child adjustment. Problem-solving and emotional-regulation on the Parentcope did not predict any of the child adjustment outcome variables.

It was predicted that children's coping would be a better predictor of child adjustment than mothers' coping. Limiting the assessment to the Kidcope/Parentcope, a simple quantitative summary of the significant results, reveals that there were more significant findings related to children's coping, but these findings were not always in the predicted direction. Including the CHIP, there are two significant findings, but only one was in the predicted direction. Given the above results, this prediction was not confirmed.

Hypothesis 2

It was predicted that boys' reliance on emotional regulation would be positively associated with self-esteem and social competence and inversely related to behavior problems. It was also specified that reliance on emotional regulation would be positively associated with self-esteem and inversely related to behavior problems in the more severe cases. Contrary to prediction, there were no significant findings in the analyses testing the interaction between children's reliance on emotional regulation and severity. Nor were there any significant results in the analyses testing the interaction between emotional regulation and gender.

In Spirito et al.'s (1988) study employing the Kidcope with pediatric patients with chronic illnesses, girls used more emotional regulation (individual Kidcope item) than boys, although it was not examined in relation to outcome variables. Lavigne and Faier-Routman (1993) concluded that disease severity may not be as important a predictor of child adjustment as psychosocial variables, which may help to explain the lack of an interaction between severity and emotional-regulation. Alternatively, the problems reported by the more severely disabled children were not necessarily similar in degree to problems reported by hospitalized patients with a terminal illness, for example.

Hypothesis 3

It was predicted that higher levels of SES and mother's level of education, and a two parent family would be positively associated with better adjustment in children. Children from two-parent families reported better social competence than children from single-parent homes, but family structure did not predict behavior problems or self-worth.

Mother's educational level was a positive predictor of internalizing behavior problems, and a negative predictor of mothers' reports of their children's social competence. Mothers with higher education may have greater expectations for their children or may be more critical of their children's progress. They may also be more sensitive to the subtle, frequently overlooked, problems included in the internalizing scale. In contrast to the current study, Wallander, Varni, Babani, Banis, and Wilcox (1989) found that maternal education was inversely related to internalizing and externalizing behavior problems in a mixed sample of children with five physical disorders. This difference in findings may be explained by their suggestion that maternal education may be, "a marker for a host of underlying factors, such as maternal intelligence, family size, child-rearing knowledge, and maternal adjustment, which may have causal relations with child adjustment (cf. Anthony & Cohler, 1987; Farran & McKinney, 1986)"(p. 170).

There may also be a conceptual link between the findings that mothers' education and CHIP III scores (understanding the health care situation) were negatively associated with the children's social competence, and mothers' education was positively associated with internalizing problems. That is, these mothers may be more willing to "take off the rose-colored glasses", or may have more accurate perceptions of their children's behavioral and social development.

Socioeconomic status was a negative predictor of externalizing behavior problems. The additional financial strain on a family with a chronic illness may contribute to stress and limited resources, including time and energy, to devote to the child with MM, which, in turn, may contribute to the report of externalizing behavior problems in the child.

Hypothesis 4

It was predicted that cohesion and adaptability would be positively related to self-worth and social competence, and inversely related to behavior problems. Contrary to prediction, cohesion and adaptability were not significant predictors of any of the outcome variables. Murch and Cohen (1989) found that families serve a greater stress-buffering role for their disabled children than do families of ablebodied children, and increased cohesion was protective and welcomed by the children. In contrast to the current findings, cohesion (measured by the FES) was also significantly correlated with self-esteem (as measured by the Coopersmith Self-Esteem Inventory, Form B) in Murch & Cohen's study. Measurement issues related to the psychometric properties of the FACES III may have contributed to the lack of significant findings in the current study.

Hypothesis 5

In light of the concept of marginality, it was predicted that, the children with milder cases of MM were not likely to experience better adjustment than the more severe cases.
To examine the concept of marginality, the sample was divided into thirds based on severity. Hypothesis 5 was partially supported in that the only significant difference between the groups on any of the outcome variables was that the most severe group differed from both the mildest and the middle group on externalizing behavior problems. That is, the most severe group had the fewest reports of externalizing behavior problems compared with each of the other two groups, respectively.

In their meta-analytic review of psychological adjustment in pediatric physical disorders Lavigne & Faier-Routman (1992) discussed possible explanations why teachers tended to report more internalizing, and less externalizing, behavior problems in children with physical disorders. Among them, is that children with some physical disorders may be limited in their acting-out potentials or that teachers may feel sorry for them and overlook their acting-out behavior (resulting in an underestimate of externalizing behavior problems in their ratings). The latter explanation may also explain why parents of the more severely disabled children in the current sample reported fewer externalizing problems. Overall, the findings buttress the argument that the heterogeneity within MM is critical to recognize, especially for the purposes of psychosocial interventions. Perrin, MacLean, & Perrin (1989) integrated the discrepant findings in the literature examining marginality across different disorders by noting that difficulties in coping occur at all levels of severity, and resources to assist children should not be restricted to those with severe disease.

Exploratory Analyses

The prediction that multiple coping strategies would be associated with better adjustment in children was not supported. The fact that multiple coping strategies were inversely related to Harter social competence, as rated by both mothers and children, may suggest that additional work is needed in understanding the repertoire of coping strategies in children, and the measurement of it. Surprisingly, the predicted associations between the use of multiple coping strategies and the outcome variables did not emerge. It is possible that endorsement of multiple coping strategies may reflect confusion on the part of the respondent or random endorsements. Halstead, Johnson, & Cunningham (1993) reported findings with healthy adolescents consistent with research with adults in that the 9-12th graders employed multiple coping strategies when encountering a stressful situation. However, the goal of that study was confirmatory factor analysis of a modification of the Ways of Coping Checklist (WCCL), and multiple coping strategies were not assessed in relation to outcome variables.

Mothers' reports of employing multiple coping strategies did not predict any of the outcome variables.

Summary of Results

Coping does influence different domains of adjustment, although not as many domains as predicted, or in the direction predicted. The less emotional regulation the children reported the better their social competence. Emotional-regulation also did not interact with severity to support its usefulness in certain situations encountered by children with chronic illness. Among the demographic variables, mothers' education and SES were predictive of behavior problems in children, and family structure predicted children's perceived self-worth. Mothers' understanding of the medical situation was not predictive of better outcomes in their children.

Family environment, specifically integration, cooperation, and optimism were protective of the children's social competence. A closer look at how severity affects adjustment suggested that the most severe group differed from the mild and moderate groups in terms of less externalizing behavior problems.

One interesting implication from the current findings is that outcomes of particular coping efforts are not always positive. For example, reported use of problem-solving was directly associated with increased externalizing problems, and was not necessarily protective of the children's self-worth. Haan (1977) noted, "coping does not entail socially successful final states, such as competence...the deleterious aspects of his situation may still bring...failure" (p.43). Similarly, Myerowitz and colleagues (1983) noted that coping responses may be successful (e.g., in reducing symptoms), but not necessarily adaptive in terms of the bigger picture. Alternatively, they contend that coping responses can be adaptive, but not successful. For example, a child with MM who is fearful of self-catheterization may successfully employ avoidance or wishful thinking to cope with the fears, although this response is not adaptive in terms of the potential for renal complications. The more adaptive response might be learning self-catheterization after addressing the fears in psychotherapy utilizing relaxation techniques. Alternatively, a compliant child who stoically proceeds with surgeries and procedures to improve his/her condition, without expressing fears or frustrations may be responding adaptively, but not successfully because symptoms reflecting his unexpressed fears or frustrations will most likely interfere with his/her functioning eventually.

Limitations

The results of the current study need to be interpreted cautiously because of the following limitations. The lack of a relationship between coping and adjustment may be a result of the measurement of coping rather than the construct of coping, itself. The Kidcope/Parentcope only included one or two items per coping strategy, and it is thus difficult to develop scales from it. A related problem was the notable difficulties obtaining adequate reliabilities (alphas) for the scales developed from the Kidcope/Parentcope items for the current study. The lack of predicted findings may also relate to the low test-retest reliability of the Kidcope. Future research needs to expand the Kidcope or adapt another valid coping measure for use with chronically ill children. More generally, there needs to be a greater consensus about the measurement of coping in children with chronic illness in order to promote a cross-fertilization of ideas and research findings.

A problem related to the measurement of coping was the inclusion of multiple independent variables in the regression analyses. Caution must thus be exercised when reviewing the results of this design. In future studies a more select group of predictors should be entered into the analyses for a similar sample size in order to achieve greater power.

The current study might have been improved by including an interview to probe the children's and parents' responses to the Kidcope/Parentcope to better assess the meaning of their responses, and whether the children seemed to understand the questions and rating system. It may also be advantageous to ask the children about problems that occurred in the past three months (rather than six months) to assure that the experiences are rather fresh in their memories.

Myerowitz and colleagues (1983) suggested that when inquiring about a problem that was experienced, the way the question is phrased may elicit overestimates or underestimates of its significance. For example, when asked to identify a problematic situation, the patient who coped effectively with a difficult problem may be unlikely to report it. Alternatively, if problems are defined and patients are asked about their experiences with them, they may overestimate their significance. Thus, the importance of including ratings about the patient's view of the severity of the problem is underscored.

The current study was part of a larger research project, and the children and mothers were asked to complete a large packet of questionnaires. It is conceivable that by the time they reached the Kidcope, which was the last questionnaire in the packet, they were fatigued and did not respond in a conscientious manner. This may explain why the mean number of strategies mothers endorsed in the emotional-regulation and problem-solving scales was only one and two, respectively.

The purpose of examining mothers' coping in relation to child adjustment was to explore the role of either modeling, or more generally, systemic influences in the family, i.e., coping styles of children may affect or be affected by coping styles of their mothers (Compas et al., 1992). Since none of the predicted associations between multiple coping strategies in mothers and any of the outcome variables emerged, it is difficult to evaluate the association between mothers' coping and children's outcome. This finding suggests that either mothers' coping is not a predictor of children's adjustment, or the measurement of multiple coping strategies needs to be re-examined. In light of the fact that the predicted associations between mothers' use of problem-solving or emotional-regulation and child adjustment also did not emerge, it suggests that their may have been a measurement problem in using the older version of the Kidcope for the parents. Future work can also include a measure of parental distress, e.g., the Brief-Symptom Inventory (Derogatis et al., 1982), and/or a clinical interview to first assess whether there is an association between multiple coping styles in parents and their own adjustment.

The results from the CHIP and the FACES III were disappointing, and may also relate to their psychometric properties. For example there may be insufficient validity checks conducted on the CHIP. An alternative measure of family dynamics for future research is the FES because it includes multiple scales tapping aspects of family functioning such as communication and conflict that are not specifically addressed by the FACES III.

It is important to stress that the findings from the current sample cannot be generalized to all spina bifida patients. Variations in IQ, for example, can affect the coping and adjustment of children. Since the current study included children with IQs over 80 it is possible that they may utilize a different array of coping mechanisms than children with IQs below 80. Additionally, the current sample was recruited from a leading urban medical center providing state of the art care for children with MM; this population may differ from rural samples. Cultural influences may also affect the coping and adjustment of children with MM. It was necessary to exclude many of the Hispanic families in the clinic because of language barriers. Future research can find ways to reach this part of the population to better understand the similarities and differences in the stressors they encounter and their coping strategies and adjustment.

Finally, the results of the current study are cross-sectional and evidence for the causal contribution of coping to adjustment needs to be determined through longitudinal studies. It is not possible to assert whether coping causes particular outcomes or whether coping is a reaction to behavior problems and decreased self-competence.

Implications for Future Research and Interventions

In spite of the above limitations, the current study paves the way for future research. There are advantages and disadvantages of employing self-report measures of coping. The limitations of relying on self-report measures of coping was pointed out by Wertlieb and colleagues (1987) who noted that the product of self-report coping questionnaires, "is a view of 'meta-coping', i.e., what individuals represent and express **about** their coping..." (p.550), which is not necessarily equivalent to their actual coping. Inclusion of observational measures of how children cope (most applicable in a hospital setting) in addition to their own self-report of how they handled the situation is one promising direction. Of course, not all stressors in this sample were related to hospital procedures; thus, observational data would be difficult to obtain for social stressors, for example.

Since the predicted associations were based on both child and parent reports, it is also necessary to consider influences on mothers' ratings that affect outcome variables. Wallander and colleagues (1988) noted that maternal perceptions of child behavior are a combination of maternal and child characteristics. They cited a study by Brody and Forehand (1986) where a significant interaction was found indicating that high maternal depression (as measured by the BDI) and high child noncompliance was associated with greater perceived child maladjustment by their mothers. Similarly, Barakat and Linney (1992) found that greater social support of the mother, was associated with fewer reported externalizing behavior problems. The current study did not include a measure of parental distress, which may be a helpful addition to future research.

Inclusion of additional outcome measures, such as a clinical interview or a child self-report measure of symptomatology, might assess aspects of psychological distress, and enhance the ability to detect the contribution of coping to adjustment. Similarly, health-related outcomes of coping, such as those examined in a study of children with sickle cell disease (Gil et al., 1991) may be a promising direction.

Appraisal of the problem is an important aspect of coping. Lazarus and Folkman (1984) noted that the perception of strain is more critical than its objective occurrence. Spirito et al. (1990) reported that 9-13 year olds were more likely to employ emotional regulation (measured by two individual items on the Kidcope) when distressed about a problem with their friends or parents than those who were not distressed. The measurement of severity used in the current study did not tap the children's or mothers' perceptions of strain. A valuable addition to future studies would be a question about the child's view of how much control s/he had over the problem, e.g., "Do you think you could have done something to change the situation?". Similarly, it is important to obtain ratings about the predictability of the stressor. However, it is important to note that younger children may not have the cognitive skills to differentiate aspects of their illness that are beyond their own, and their physician's, control, which from an adult's perspective is frequently referred to as requiring "acceptance".

The fact that some of the predicted associations did not emerge underscores the complexity of paradigms examining risks and resistance factors. Future research can expand on the current work by exploring the role of coping as a moderator of other predictor variables. To achieve this goal it is necessary to include a measure of negative life events. Several risk and resistance models seem promising. Thompson, Gustafson, Hamlett, and Spock (1992) included self-esteem as a psychosocial/mediational process (in contrast to an outcome variable). Lavigne and Faier-Routman (1993) decided to incorporate self-concept as an intervening variable, as did Pless and Pinkerton (1975). The debate as to whether self-concept influences child adjustment or is an aspect of adjustment needs to be settled through empirical research. In light of the modest effects of coping on adjustment found here, the role of individual resources (such as temperament, self-esteem) may be another avenue of exploration. Similarly, systemic influences on adjustment, such as the relationship with the health care team, can be explored (Kazak, 1989).

Additional empirical verification of the concept of marginality is needed. Another promising direction would be more rigorous assessment of visibility and functional status to discriminate differences within MM more than the measure of severity, alone. The need for such an assessment may explain why there were not other differences between the groups on the dependent variables.

Caution about directly applying theories/findings about coping in adults to children needs to be emphasized. A particular coping strategy categorized as emotion-focused in adult studies may not be readily incorporated in a child's repertoire of coping strategies because of cognitive limitations. Developmental differences affect how children of different ages cope. Compas and colleagues (1992) described how problem-solving strategies develop early in life, but emotion-focused strategies are still developing in adolescence, and tend to be immature (e.g., blaming, inappropriate ventilation of feelings).

Future designs need to encourage the participation of fathers. Mothers' reports were solicited as a practical consideration because children are usually brought to the clinic by mothers. Just as family therapists try to provide evening and weekend hours to accommodate working parents, investigators can be creative in their attempts to reach fathers or siblings. This study is an improvement over some of the past research because both children's and mothers' reports were included. Future work can include multiple informants such as teachers' reports on the CBCL and Harter's Perceived Self-Competence Scale, as well as multiple methods (e.g., observational measures of coping).

Based on the results of the current study it is difficult to recommend intervention programs for children with MM that reinforce particular coping strategies. Overall, it appears that the more problem-solving one engages in, the lower one's self-worth and the greater the reported externalizing behavior problems. It seems that less emotional-regulation is protective of one's social competence. In the current study, emotional-regulation was not protective for the more severe cases. Family environment served as a resistance factor to children with MM; mothers' who endorsed the usefulness of family integration, cooperation, and optimism were more likely to have children with better social competence. However, mother's understanding of the medical situation was not protective of their children's social competence. Unlike Pearlin & Schooler's conclusion that, "effective coping depends not only on what we do, but also on how much we do", the current study did not find that endorsement of multiple coping strategies was associated with better outcomes.

Perhaps the best way to summarize the current findings is that no particular generalizations about coping can be made at this stage in the research. The most critical question that might be asked by medical staff, parents, or other researchers might be a paraphrase of Paul's (1967) famous summary of the psychotherapy research: what coping strategy is most effective for an individual of what age, for which type of stressor, in what context?

APPENDIX A

MEASURES ADMINISTERED TO CHILDREN

ID # ____________________

Informed Consent (Parental Permission for Child Participation)

I, ______________________________, the parent or guardian of my child,
(name of parent or legal guardian)
______________________________, hereby request the admission of my
(child's name)
child in this study entitled: "Developmental Factors, Family Functioning, and Psychosocial Adjustment in Adolescents with Myelomeningocele (MM)." I understand that this study is being carried out under the supervision of Dr. Grayson N. Holmbeck from the Department of Psychology at Loyola University of Chicago and Dr. Karen E. Wills from Medical Psychology at Children's. The purpose of this study is to determine why some adolescents with MM have difficulties with their behavior and why others do not. Adolescence is a stage of life that brings with it certain challenges and the researchers involved in this project would like to understand better how adolescents with MM and their families deal with these challenges. My child's participation will help researchers learn more about adolescents with MM so that they may provide the proper services for those in need.

I understand that my child will complete about 45 minutes of questionnaires about him/herself and his/her family. That is, children will be asked about their feelings toward their parents and will be asked to describe their own behavior over the past 6 months. I also understand that my child will complete the same questionnaire on two occasions, separated by 6 months. He/she can complete the questionnaire at home and return it in the pre-stamped envelope provided. I understand that I can read the questionnaire to my child if necessary, but that the answers MUST be his/her own. My child will receive $5.00 as compensation for his/her participation. I recognize that there are no risks anticipated in this study except that my child may become fatigued while completing the questionnaire. Finally, I understand that the experimenter will obtain the following information (and only this information) from my child's medical chart: data on level of intelligence, shunt status, nature of MM lesion, whether my child uses a catheter, and whether my child walks normally, with braces, or uses a wheelchair.

By signing this consent form, I understand that my child's participation in this study is voluntary. I acknowledge that I have not waived any of my legal rights or released this hospital from liability for negligence.

I may revoke my consent and withdraw my child from this study at any time without penalty or loss of benefits. My child's relations with the physician(s) and staff at The Children's Memorial Hospital, now and in the future, will not be affected in any way if I refuse to participate, or if I enter my child into the program and withdraw later.

I understand that records of this study will be kept confidential with respect to any written or verbal reports making it impossible to identify my child individually.

Informed Consent (continued)

If I have any questions about the research procedures, I will contact the principal investigator, Dr. Grayson N. Holmbeck, by calling 312-508-2967 during a workday or 312-871-4718 at night or on weekends.

If I have any questions about my child's rights as a research subject, I may take them to Mr. Steven B. Pulik, Research Administrator, Children's Memorial Institute for Education and Research, 2300 Children's Plaza, Chicago, Illinois 60614, telephone number (312) 880-4987.

I have read this informed consent document. I understand its contents and I freely consent, without force, reward, or promise of reward, to have my child participate in this study under the conditions described in this document.

______________________ ______________________________________
Date Signature of Child

______________________ ______________________________________
Date Signature of Parent or Guardian

______________________ ______________________________________
Date Signature of Parent or Guardian

I certify that I have explained the above to ____________________________ and ______________________________ and believe that they fully understand its contents and that their signature(s) were affixed freely, without duress, reward, or promise of reward. I also agree to answer any questions which may arise.

______________________ ______________________________________
Date Signature of Research Assistant

Ms. Joan Faier-Routman
Typed Name of Research Assistant

ID # ______________

NAME AND ADDRESS COVER SHEET

Your Name: ____

Home Address: ____
____
____

City: ____

State: ____

Zip Code: ____

Home Phone Number: (   ) ________________________

Grade: ________________

School: ____

Teacher's Name: ____

Are you the oldest child in your family? ____ yes ____ no

Please list the FIRST AND LAST name of your mother or step-mother (whoever lives with you): ____________________________

Leave BLANK if a mother or step-mother does NOT live with you.

Please list the FIRST AND LAST name of your father or step-father (whoever lives with you): ____________________________

Leave BLANK if a father or step-father does NOT live with you.

ID # ____________

Student Demographics Questionnaire

1. Today's Date: ______________________
Month Day Year

2. Birthdate: ______________________ 3. Age: __________
Month Day Year

4. Grade: __________________

5. School: ____

6. Teacher's Name: ______________________________________

7. Sex: ____ (male or female)? 8. Race: ________

9. What is one TV program that you like to watch?

____

1. Are your parents married? _____ yes _______ no

2. Are your parents divorced? _____ yes _______ no

3. Are your parents separated? _____ yes _______ no

4. Were you adopted? _____ yes _______ no

5. Is your natural mother living? _____ yes _______ no

6. Is your mother or a step-mother living with you? ____ yes ____ no

IF YES, is she your step-mother <u>OR</u> natural mother? ________________

7. Is your natural father living? _____ yes _______ no

8. Is your father or step-father living with you? ____ yes ____ no

IF YES, is he your step-father <u>OR</u> natural father? ________________

9. Who else lives with you at home?

Brother(s)________ How many?________ Ages? ________________
Sister(s)________ How many?________ Ages? ________________
Step-Brother(s)______ How many?______ Ages? ______________
Step-Sister(s)______ How many?________ Ages? ________________
Half-Brother(s)______ How many?________ Ages? ______________
Half-Sister(s)______ How many?________ Ages? ________________
Cousin(s)________ How many?________ Ages? ________________
Niece(s)________ How many?________ Ages? ________________
Nephew(s)________ How many?________ Ages? ________________
Grandmother________
Grandfather_________
Aunt ________ Uncle ________
Friends of the family _______ How many?________ Ages? ________
Others (who?) ____

1. If your home was broken by death of a parent, divorce, or separation, how old were you when it happened? ______________

2. If one of your parents re-married, how old were you when your parent re-married? ____________________

3. What does your mother do for a job (or step-mother, if your step-mother lives with you):? ____

4. What does your father do for a job (or step-father, if your step-father lives with you):? ____

INSTRUCTIONS

We have some sentences here and, as you can see from the top of the next page where it says, "What I am like", we are interested in what each of you is like, what kind of a person you are like, and how you think and feel about different things. This is not a test. There are no right or wrong answers. Since kids are very different from one another, each of you will be putting down something different.

Let us explain how these questions work. For each question you need to follow these directions.

1. First, you need to decide which kind of "kid" you are most like, the one described on the left or the one described on the right.
2. Next, after you have decided what kind of kid is most like you, you have to decide whether that is only sort of true for you, or really true. If it's only sort of true, then put an X in the box under sort of true; if it's really true for you, then put an X under really true.
3. For each question you only check one box. Sometimes it will be on one side of the page, and at other times it will be on the other side of the page, but you can only check one box for each question.

What I Am Like

Name ______________________ Age ______ Birthday ______________ Group ______
Month Day

Boy or Girl (circle which)

SAMPLE SENTENCE

	Really True for me	Sort of True for me				Sort of True for me	Really True for me
(a)	☐	☐	Some kids would rather play outdoors in their spare time	BUT	Other kids would rather watch T.V.	☐	☐
1.	☐	☐	Some kids feel that they are very *good* at their school work	BUT	Other kids *worry* about whether they can do the school work assigned to them.	☐	☐
2.	☐	☐	Some kids find it *hard* to make friends	BUT	Other kids find it's pretty *easy* to make friends.	☐	☐
3.	☐	☐	Some kids do very *well* at all kinds of sports	BUT	Other kids *don't* feel that they are very good when it comes to sports.	☐	☐
4.	☐	☐	Some kids are *happy* with the way they look	BUT	Other kids are *not* happy with the way they look.	☐	☐
5.	☐	☐	Some kids often do *not* like the way they *behave*	BUT	Other kids usually *like* the way they behave.	☐	☐
6.	☐	☐	Some kids are often *unhappy* with themselves	BUT	Other kids are pretty *pleased* with themselves.	☐	☐
7.	☐	☐	Some kids feel like they are *just as smart* as as other kids their age	BUT	Other kids aren't so sure and *wonder* if they are as smart.	☐	☐
8.	☐	☐	Some kids have *alot* of friends	BUT	Other kids *don't* have very many friends.	☐	☐

	Really True for me	Sort of True for me				Sort of True for me	Really True for me
9	☐	☐	Some kids wish they could be alot better at sports	BUT	Other kids feel they are good enough at sports.	☐	☐
10.	☐	☐	Some kids are *happy* with their height and weight	BUT	Other kids wish their height or weight were *different.*	☐	☐
11.	☐	☐	Some kids usually do the *right* thing	BUT	Other kids often *don't* do the right thing.	☐	☐
12.	☐	☐	Some kids *don't* like the way they are leading their life	BUT	Other kids *do* like the way they are leading their life.	☐	☐
13.	☐	☐	Some kids are pretty *slow* in finishing their school work	BUT	Other kids can do their school work *quickly.*	☐	☐
14.	☐	☐	Some kids would like to have alot more friends	BUT	Other kids have as many friends as they want.	☐	☐
15.	☐	☐	Some kids think they could do well at just about any new sports activity they haven't tried before	BUT	Other kids are afraid they might *not* do well at sports they haven't ever tried.	☐	☐
16.	☐	☐	Some kids wish their body was *different*	BUT	Other kids *like* their body the way it is.	☐	☐
17.	☐	☐	Some kids usually *act* the way they know they are *supposed* to	BUT	Other kids often *don't* act the way they are supposed to.	☐	☐
18.	☐	☐	Some kids are *happy* with themselves as a person	BUT	Other kids are often *not* happy with themselves.	☐	☐
19.	☐	☐	Some kids often *forget* what they learn	BUT	Other kids can remember things *easily.*	☐	☐
20.	☐	☐	Some kids are always doing things with *alot* of kids	BUT	Other kids usually do things *by themselves.*	☐	☐

	Really True for me	Sort of True for me				Sort of True for me	Really True for me
21.	☐	☐	Some kids feel that they are *better* than others their age at sports	BUT	Other kids *don't* feel they can play as well.	☐	☐
22.	☐	☐	Some kids wish their physical appearance (how they look) was *different*	BUT	Other kids *like* their physical appearance the way it is.	☐	☐
23.	☐	☐	Some kids usually get in *trouble* because of things they do	BUT	Other kids usually *don't* do things that get them in trouble.	☐	☐
24.	☐	☐	Some kids *like* the kind of *person* they are	BUT	Other kids often wish they were someone else.	☐	☐
25.	☐	☐	Some kids do *very well* at their classwork	BUT	Other kids *don't* do very well at their classwork.	☐	☐
26.	☐	☐	Some kids wish that more people their age liked them	BUT	Other kids feel that most people their age *do* like them.	☐	☐
27.	☐	☐	In games and sports some kids usually *watch* instead of play	BUT	Other kids usually *play* rather than just watch.	☐	☐
28.	☐	☐	Some kids wish something about their face or hair looked *different*	BUT	Other kids *like* their face and hair the way they are.	☐	☐
29.	☐	☐	Some kids do things they know they *shouldn't* do	BUT	Other kids *hardly ever* do things they know they shouldn't do.	☐	☐
30.	☐	☐	Some kids are very *happy* being the way they are	BUT	Other kids wish they were *different*.	☐	☐
31.	☐	☐	Some kids have *trouble* figuring out the answers in school	BUT	Other kids almost *always* can figure out the answers.	☐	☐
32.	☐	☐	Some kids are *popular* with others their age	BUT	Other kids are *not* very popular.	☐	☐

	Really True for me	Sort of True for me				Sort of True for me	Really True for me
33.	☐	☐	Some kids *don't* do well at new outdoor games	**BUT**	Other kids are *good* at new games right away.	☐	☐
34.	☐	☐	Some kids think that they are good looking	**BUT**	Other kids think that they are not very good looking.	☐	☐
35.	☐	☐	Some kids behave themselves very well	**BUT**	Other kids often find it hard to behave themselves.	☐	☐
36.	☐	☐	Some kids *are* not very happy with the way they do alot of things	**BUT**	Other kids think the way they do things is *fine*.	☐	☐

Susan Harter, Ph.D., University of Denver, 1985

FACES III

David H. Olson, Joyce Portner, and Yoav Lavee

1	2	3	4	5
ALMOST NEVER	ONCE IN AWHILE	SOMETIMES	FREQUENTLY	ALMOST ALWAYS

DESCRIBE YOUR FAMILY <u>NOW</u>:

_____ 1. Family members ask each other for help.

_____ 2. In solving problems, the children's suggestions are followed.

_____ 3. We approve of each other's friends.

_____ 4. Children have a say in their discipline.

_____ 5. We like to do things with just our immediate family.

_____ 6. Different persons act as leaders in our family.

_____ 7. Family members feel closer to other family members than to people outside the family.

_____ 8. Our family changes its way of handling tasks.

_____ 9. Family members like to spend free time with each other.

_____ 10. Parent(s) and children discuss punishment together.

_____ 11. Family members feel very close to each other.

_____ 12. The children make the decisions in our family.

_____ 13. When our family gets together for activities, everybody is present.

_____ 14. Rules change in our family.

_____ 15. We can easily think of things to do together as a family.

_____ 16. We shift household responsibilities from person to person.

_____ 17. Family members consult other family members on their decisions.

_____ 18. It is hard to identify the leader(s) in our family.

_____ 19. Family togetherness is very important.

_____ 20. It is hard to tell who does which household chores.

FAMILY SOCIAL SCIENCE, 290 McNeal Hall, University of Minnesota, St. Paul, MN 55108

KIDCOPE

Now we would like you to think of a problem that you have had that was related to your Spina Bifida (MM). Try to think of some problem that you had within the last 6 months. This has to be something related to the Spina Bifida. It could have happened at home, at school, at the doctor's, with your family, or with your friends. It could have been an embarrassing situation you got in because of your Spina Bifida. It could have had something to do with your braces or with your catheter (if you use one). It may have involved a shunt malfunction or anything else having to do with your Spina Bifida. You only need to think of ONE problem.

We would first like you to write what the problem was in the space below:

____

____

____

Now we would like you to think about this problem and tell us what you did when you had this problem. First, you answer "yes" or "no" for whether or not you did each of the things below. Then, if you used one of these things, tell us how much it helped you.

	Did you do this? (CIRCLE ONE)		IF YES, how much did it help?		
			Not at all	A little	A lot
1. I just tried to forget it.	YES	NO	1	2	3
2. I did something like watch TV or played a game to forget it.	YES	NO	1	2	3
3. I stayed by myself.	YES	NO	1	2	3
4. I kept quiet about the problem.	YES	NO	1	2	3
5. I tried to see the good side of things.	YES	NO	1	2	3
6. I blamed myself for causing the problem.	YES	NO	1	2	3
7. I blamed someone else for causing the problem.	YES	NO	1	2	3

KIDCOPE (continued)

	Did you do this? (CIRCLE ONE)		IF YES, how much did it help? Not at all	A little	A lot
8. I tried to fix the problem by thinking of answers.	YES	NO	1	2	3
9. I tried to fix the problem by doing something or talking to someone.	YES	NO	1	2	3
10. I yelled, screamed, or got mad.	YES	NO	1	2	3
11. I tried to calm myself down.	YES	NO	1	2	3
12. I wished the problem had never happened.	YES	NO	1	2	3
13. I wished I could make things different.	YES	NO	1	2	3
14. I tried to feel better by spending time with others like family, grownups, or friends.	YES	NO	1	2	3
15. I didn't do anything because the problem couldn't be fixed.	YES	NO	1	2	3

APPENDIX B

MEASURES ADMINISTERED TO MOTHERS

ID # ____________________

Informed Consent (for Parental Participation)

I, ________________________________, the parent or guardian of my child,
(name of parent or legal guardian)
____________________________________, voluntarily agree to participate in this study entitled: "Developmental Factors, Family Functioning, and Psychosocial Adjustment in Adolescents with Myelomeningocele (MM)." This study is being carried out under the supervision of Dr. Grayson N. Holmbeck from the Department of Psychology at Loyola University of Chicago and Dr. Karen E. Wills from Medical Psychology at Children's. The purpose of this study is to determine why some adolescents with MM have difficulties with their behavior and why others do not. Adolescence is a stage of life that brings with it certain challenges and the researchers involved in this study would like to understand better how adolescents with MM and their families deal with these challenges. They are also interested in whether there are differences in the parenting styles used in families where there is a child with MM than in families where there is no child with a disability. My participation will help researchers learn more about adolescents with MM so that they may provide the proper services for those in need.

I understand that I will complete about 60 minutes of questionnaires about my family. That is, I will be asked about my feelings toward other family members and will be asked to describe their behavior over the past 6 months. I also understand that I will complete the same questionnaire on two occasions, separated by 6 months. I can complete the questionnaire at home and return it in the pre-stamped envelope provided. I will receive $5.00 as compensation for my participation. I recognize that there are no risks anticipated in this study except that I may become fatigued while completing the questionnaire.

By signing this consent form, I understand that my participation in this study is voluntary. I acknowledge that I have not waived any of my legal rights or released this hospital from liability for negligence.

I may revoke my consent and withdraw from this study at any time without penalty or loss of benefits. My relations with the physician(s) and staff at The Children's Memorial Hospital, now and in the future, will not be affected in any way if I refuse to participate, or if I enter into the program and withdraw later.

I understand that records of this study will be kept confidential with respect to any written or verbal reports making it impossible to identify me individually.

Informed Consent (continued)

If I have any questions about the research procedures, I will contact the principal investigator, Dr. Grayson N. Holmbeck, by calling 312-508-2967 during a workday or 312-871-4718 at night or on weekends.

If I have any questions about my rights as a research subject, I may take them to Mr. Steven B. Pulik, Research Administrator, Children's Memorial Institute for Education and Research, 2300 Children's Plaza, Chicago, Illinois 60614, telephone number (312) 880-4987.

I have read this informed consent document. I understand its contents and I freely consent, without force, reward, or promise of reward, to participate in this study under the conditions described in this document.

______________________	______________________________
Date	Signature of Parent or Guardian
______________________	______________________________
Date	Signature of Parent or Guardian

I certify that I have explained the above to ____________________________ ____________________________ and believe that he/she fully understands its contents and that his/her signature was affixed freely, without duress, reward, or promise of reward. I also agree to answer any questions which may arise.

______________________	______________________________
Date	Signature of Research Assistant

Ms. Joan Faier-Routman
Typed Name of Research Assistant

ID # --------------

PARENT COVER SHEET (MM)

PLEASE NOTE: This page will be detached from the rest of the questionnaire. Do not write your name or your child's name on any pages after this one. We need the information on this page so that we can mail your check to you after we receive the completed questionnaires. Should you have any questions about anything in this packet, please call Grayson N. Holmbeck at 312-508-2967. If the call is long distance, you will be reimbursed.

Your CHILD'S Name: ____________________

YOUR Full Name (first name, last name): ____________________

Relationship to Child: ____________________

Your SPOUSE'S Full Name (if applicable): ____________________

Relationship to Child: ____________________

Home Address: ____________________
____
____

City: ____________________

State: ____________________

Zip Code: ____________________

Home Phone Number: (   ) ____________________

Work Phone Number: (   ) ____________________

ID # ______________

P. Demographics Questionnaire

1. Today's Date: ______________________________
Month Day Year

2. Your Birthdate: ______________________________
Month Day Year

3. Your Age: ________

4. Your child's grade: ____________________

5. Your child's school: ____

6. Are you this child's?:

1. ______ mother
2. ______ father
3. ______ step-mother
4. ______ step-father
5. ______ grandmother
6. ______ grandfather
7. ______ other who? ____________________________

7. Your race: ____________________

8. Please list the FIRST name, sex, and age of all other individuals living in your home. Also, include their relationship to you (for example, husband, wife, boyfriend, girlfriend, grandmother, son, daughter, step-son, step-daughter, niece, nephew, etc.)

	FIRST NAME	SEX	AGE	RELATIONSHIP
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				
9.				
10.				

1. Have you ever been married? ______ yes _______ no

IF YES, how many times? ________________

IF YOU HAVE BEEN MARRIED MORE THAN ONCE, how did the other marriages end? ____

____

2. Are you currently married? ______ yes _______ no

3. Are you currently separated? ______ yes _______ no

4. IF YOU WERE EVER DIVORCED, was the child being discussed in this questionnaire in the home during that divorce?
______ yes _______ no

5. Was the child being discussed in this questionnaire adopted?
______ yes _______ no

6. Check the highest level of education that you completed:

1. ___ some grade school
2. ___ finished grade school
3. ___ some high school
4. ___ finished high school
5. ___ some college
6. ___ finished college
7. ___ attended graduate school or professional school after college
8. ___ received a professional degree

7. Check the highest level of education you expect your child to complete:

1. ___ some grade school
2. ___ finish grade school
3. ___ some high school
4. ___ finish high school
5. ___ some college
6. ___ finish college
7. ___ attend graduate school or professional school after college
8. ___ receive a professional degree

1. IF YOU WORK full-time or part-time, what do you do for job?
____

What are your duties on this job? ____________________
____

Is your work: ______ full-time ______ part-time

Are you:

1. _____ self-employed
2. _____ working for salary or wages

Do you own your own business? _____ yes _____ no

2. What is your family's total yearly income?

1. ______ under $10,000
2. ______ 10,000-20,000
3. ______ 20,000-30,000
4. ______ 30,000-40,000
5. ______ 40,000-50,000
6. ______ 50,000-60,000
7. ______ 60,000-70,000
8. ______ 70,000-80,000
9. ______ 80,000-90,000
10. ______ 90,000-100,000
11. ______ over 100,000
12. ______ I don't know

3. What is your religion (if any)? ____________________

4. Has the child being discussed in this questionnaire had any serious medical problems (other than those related to Spina Bifida)?
_____ yes _____ no

IF YES, what were they? ____________________
____

5. Has the child being discussed in this questionnaire had any learning disabilities problems? _____ yes _____ no

IF YES, did he/she receive any special educational services?
_____ yes _____ no

1. Has the child being discussed in this questionnaire ever received mental health services?
   _____ yes _____ no

2. Has anyone else in your family ever received mental health services?
   _____ yes _____ no

3. Does your child have a shunt? _____ yes _____ no

   IF YES, has the shunt been infected? _____ yes _____ no

   IF YES, has the shunt been revised? _____ yes _____ no

4. Does your child have seizures? _____ yes _____ no

5. Does you child use a catheter? _____ yes _____ no

6. Does you child have leg braces? _____ yes _____ no

   IF YES, what type?
   _____ knee-ankle-foot
   _____ ankle-foot
   _____ reciprocating brace
   _____ full control brace

7. Does you child use crutches? _____ yes _____ no

8. Does your child use a walker? _____ yes _____ no

9. Does you child use a wheelchair? _____ yes _____ no

   IF YES, does your child use it part-time or continuously?
   _____ part-time _____ continuously

10. Please list your child's medications: ______________________________
____
____

11. Hospitalizations: (Please List <u>Dates and Duration</u>)

   a. Shunt Revision ______________________________
   b. Orthopedic ______________________________
   c. Urological (UTI, etc.) ______________________________
   d. Other ______________________________

RATING SCALE OF CHILD'S ACTUAL BEHAVIOR

Please indicate what you feel to be your child's actual competence on each question, in your opinion. First decide what kind of child he or she is like, the one described on the left or right, and then indicate whether this is just sort of true or really true for that individual. Thus, for each item, check <u>one</u> of four spaces.

	Really True	Sort of True				Sort of True	Really True
1.	_____	_____	My child is really good at his/her school work.	<u>OR</u>	My child can't do the school work assigned.	_____	_____
2.	_____	_____	My child finds it hard to make friends.	<u>OR</u>	For my child it's pretty easy.	_____	_____
3.	_____	_____	My child does really well at all kinds of sports.	<u>OR</u>	My child isn't very good when it comes to sports.	_____	_____
4.	_____	_____	My child is good-looking.	<u>OR</u>	My child is not very good-looking.	_____	_____
5.	_____	_____	My child is usually well-behaved.	<u>OR</u>	My child is often not well-behaved.	_____	_____
6.	_____	_____	My child often forgets what he/she learns.	<u>OR</u>	My child can remember things easily.	_____	_____
7.	_____	_____	My child has alot of friends.	<u>OR</u>	My child doesn't have many friends.	_____	_____
8.	_____	_____	My child is better than others his/her age at sports.	<u>OR</u>	My child can't play as well.	_____	_____

	Really True	Sort of True				Sort of True	Really True
9.	______	______	My child has a nice physical appearance.	<u>OR</u>	My child doesn't have such a nice physical appearance.	______	______
10.	______	______	My child usually acts appropriately.	<u>OR</u>	My child would be better if he/she acted differently.	______	______
11.	______	______	My child has trouble figuring out the answers in school.	<u>OR</u>	My child almost always can figure out the answers.	______	______
12.	______	______	My child is popular with others his/her age.	<u>OR</u>	My child is not very popular.	______	______
13.	______	______	My child doesn't do well at new outdoor games.	<u>OR</u>	My child is good at new games right away.	______	______
14.	______	______	My child isn't very attractive.	<u>OR</u>	My child is pretty attractive.	______	______
15.	______	______	My child often gets in trouble because of things he/she does.	<u>OR</u>	My child usually doesn't do things that get him/her in trouble.	______	______

CHILD BEHAVIOR CHECKLIST

For office use only
ID #

[illegible]

SEX ☐ Boy ☐ Girl

AGE

ETHNIC GROUP OR RACE

TODAY'S DATE Mo ________ Day ________ Yr ________

CHILD'S BIRTHDATE Mo. ________ Day ________ Yr ________

GRADE IN SCHOOL

PARENT'S TYPE OF WORK *(Please be specific — for example, auto mechanic, high school teacher, homemaker, laborer, lathe operator, shoe salesman, army sergeant, even if parent does not live with child.)*

FATHER'S TYPE OF WORK: ________________

MOTHER'S TYPE OF WORK ________________

THIS FORM FILLED OUT BY:

☐ Mother (name) ________________

☐ Father (name) ________________

☐ Other — name & relationship to child ________________

I. Please list the sports your child most likes to take part in. For example: swimming, baseball, skating, skate boarding, bike riding, fishing, etc.

☐ None

	Compared to other children of the same age, about how much time does he/she spend in each?				Compared to other children of the same age, how well does he/she do each one?			
	Don't Know	Less Than Average	Average	More Than Average	Don't Know	Below Average	Average	Above Average
a. ________	☐	☐	☐	☐	☐	☐	☐	☐
b. ________	☐	☐	☐	☐	☐	☐	☐	☐
c. ________	☐	☐	☐	☐	☐	☐	☐	☐

II. Please list your child's favorite hobbies, activities, and games, other than sports. For example: stamps, dolls, books, piano, crafts, singing, etc. (Do not include T.V.)

☐ None

	Compared to other children of the same age, about how much time does he/she spend in each?				Compared to other children of the same age, how well does he/she do each one?			
	Don't Know	Less Than Average	Average	More Than Average	Don't Know	Below Average	Average	Above Average
a. ________	☐	☐	☐	☐	☐	☐	☐	☐
b. ________	☐	☐	☐	☐	☐	☐	☐	☐
c. ________	☐	☐	☐	☐	☐	☐	☐	☐

III. Please list any organizations, clubs, teams, or groups your child belongs to.

☐ None

	Compared to other children of the same age, how active is he/she in each?			
	Don't Know	Less Active	Average	More Active
a. ________	☐	☐	☐	☐
b. ________	☐	☐	☐	☐
c. ________	☐	☐	☐	☐

IV. Please list any jobs or chores your child has. For example: paper route, babysitting, making bed, etc.

☐ None

	Compared to other children of the same age, how well does he/she carry them out?			
	Don't Know	Below Average	Average	Above Average
a. ________	☐	☐	☐	☐
b. ________	☐	☐	☐	☐
c. ________	☐	☐	☐	☐

3-81 Edition

V. 1. **About how many close friends does your child have?** ☐ None ☐ 1 ☐ 2 or 3 ☐ 4 or more

2. **About how many times a week does your child do things with them?** ☐ less than 1 ☐ 1 or 2 ☐ 3 or more

---

VI. **Compared to other children of his/her age, how well does your child:**

	Worse	About the same	Better
a. Get along with his/her brothers & sisters?	☐	☐	☐
b. Get along with other children?	☐	☐	☐
c. Behave with his/her parents?	☐	☐	☐
d. Play and work by himself/herself?	☐	☐	☐

VII. 1. **Current school performance—for children aged 6 and older:**

☐ Does not go to school

	Failing	Below average	Average	Above average
a. Reading or English	☐	☐	☐	☐
b. Writing	☐	☐	☐	☐
c. Arithmetic or Math	☐	☐	☐	☐
d. Spelling	☐	☐	☐	☐
Other academic subjects—for example: history, science, foreign language, geography. e. ____________	☐	☐	☐	☐
f. ____________	☐	☐	☐	☐
g. ____________	☐	☐	☐	☐

---

2. **Is your child in a special class?**

☐ No ☐ Yes—what kind?

---

3. **Has your child ever repeated a grade?**

☐ No ☐ Yes—grade and reason

---

4. **Has your child had any academic or other problems in school?**

☐ No ☐ Yes—please describe

When did these problems start?

Have these problems ended?

☐ No ☐ Yes—when?

VIII. Below is a list of items that describe children. For each item that describes your child now or within the past 6 months, please circle the 2 if the item is very true or often true of your child. Circle the 1 if the item is somewhat or sometimes true of your child. If the item is not true of your child, circle the 0. Please answer all items as well as you can, even if some do not seem to apply to your child.

0 = Not True (as far as you know)   1 = Somewhat or Sometimes True   2 = Very True or Often True

0 1 2 1. Acts too young for his/her age 16
0 1 2 2. Allergy (describe): ____________

____

0 1 2 3. Argues a lot
0 1 2 4. Asthma

0 1 2 5. Behaves like opposite sex 20
0 1 2 6. Bowel movements outside toilet

0 1 2 7. Bragging, boasting
0 1 2 8. Can't concentrate, can't pay attention for long

0 1 2 9. Can't get his/her mind off certain thoughts; obsessions (describe): ____________

____

0 1 2 10. Can't sit still, restless, or hyperactive 25

0 1 2 11. Clings to adults or too dependent
0 1 2 12. Complains of loneliness

0 1 2 13. Confused or seems to be in a fog
0 1 2 14. Cries a lot

0 1 2 15. Cruel to animals 30
0 1 2 16. Cruelty, bullying, or meanness to others

0 1 2 17. Day-dreams or gets lost in his/her thoughts
0 1 2 18. Deliberately harms self or attempts suicide

0 1 2 19. Demands a lot of attention
0 1 2 20. Destroys his/her own things 35

0 1 2 21. Destroys things belonging to his/her family or other children
0 1 2 22. Disobedient at home

0 1 2 23. Disobedient at school
0 1 2 24. Doesn't eat well

0 1 2 25. Doesn't get along with other children 40
0 1 2 26. Doesn't seem to feel guilty after misbehaving

0 1 2 27. Easily jealous
0 1 2 28. Eats or drinks things that are not food (describe): ____________

____

0 1 2 29. Fears certain animals, situations, or places, other than school (describe): ____________

____

0 1 2 30. Fears going to school 45

0 1 2 31. Fears he/she might think or do something bad

0 1 2 32. Feels he/she has to be perfect
0 1 2 33. Feels or complains that no one loves him/her

0 1 2 34. Feels others are out to get him/her
0 1 2 35. Feels worthless or inferior 50

0 1 2 36. Gets hurt a lot, accident-prone
0 1 2 37. Gets in many fights

0 1 2 38. Gets teased a lot
0 1 2 39. Hangs around with children who get in trouble

0 1 2 40. Hears things that aren't there (describe): ____________

____

____________ 55

0 1 2 41. Impulsive or acts without thinking

0 1 2 42. Likes to be alone
0 1 2 43. Lying or cheating

0 1 2 44. Bites fingernails
0 1 2 45. Nervous, highstrung, or tense 60

0 1 2 46. Nervous movements or twitching (describe): ____________

____

0 1 2 47. Nightmares

0 1 2 48. Not liked by other children
0 1 2 49. Constipated, doesn't move bowels

0 1 2 50. Too fearful or anxious 65
0 1 2 51. Feels dizzy

0 1 2 52. Feels too guilty
0 1 2 53. Overeating

0 1 2 54. Overtired
0 1 2 55. Overweight 70

56. Physical problems without known medical cause:
0 1 2 a. Aches or pains
0 1 2 b. Headaches
0 1 2 c. Nausea, feels sick
0 1 2 d. Problems with eyes (describe): ____________

____

0 1 2 e. Rashes or other skin problems 75
0 1 2 f. Stomachaches or cramps
0 1 2 g. Vomiting, throwing up
0 1 2 h. Other (describe): ____________

____

Please see other side

0 = Not True (as far as you know) **1 = Somewhat or Sometimes True** **2 = Very True or Often True**

0 1 2 57. Physically attacks people

0 1 2 58. Picks nose, skin, or other parts of body (describe): ______

______ 80

0 1 2 59. Plays with own sex parts in public 16

0 1 2 60. Plays with own sex parts too much

0 1 2 61. Poor school work

0 1 2 62. Poorly coordinated or clumsy

0 1 2 63. Prefers playing with older children 20

0 1 2 64. Prefers playing with younger children

0 1 2 65. Refuses to talk

0 1 2 66. Repeats certain acts over and over; compulsions (describe): ______

______

0 1 2 67. Runs away from home

0 1 2 68. Screams a lot 25

0 1 2 69. Secretive, keeps things to self

0 1 2 70. Sees things that aren't there (describe):

______

______

0 1 2 71. Self-conscious or easily embarrassed

0 1 2 72. Sets fires

0 1 2 73. Sexual problems (describe):

______

______ 30

0 1 2 74. Showing off or clowning

0 1 2 75. Shy or timid

0 1 2 76. Sleeps less than most children

0 1 2 77. Sleeps more than most children during day and/or night (describe): ______

______

0 1 2 78. Smears or plays with bowel movements 35

0 1 2 79. Speech problem (describe): ______

______

0 1 2 80. Stares blankly

0 1 2 81. Steals at home

0 1 2 82. Steals outside the home

0 1 2 83. Stores up things he/she doesn't need (describe):

______ 40

0 1 2 84. Strange behavior (describe): ______

______

0 1 2 85. Strange ideas (describe):

______

0 1 2 86. Stubborn, sullen, or irritable

0 1 2 87. Sudden changes in mood or feelings

0 1 2 88. Sulks a lot 45

0 1 2 89. Suspicious

0 1 2 90. Swearing or obscene language

0 1 2 91. Talks about killing self

0 1 2 92. Talks or walks in sleep (describe):

______

0 1 2 93. Talks too much 50

0 1 2 94. Teases a lot

0 1 2 95. Temper tantrums or hot temper

0 1 2 96. Thinks about sex too much

0 1 2 97. Threatens people

0 1 2 98. Thumb-sucking 55

0 1 2 99. Too concerned with neatness or cleanliness

0 1 2 100. Trouble sleeping (describe):

______

0 1 2 101. Truancy, skips school

0 1 2 102. Underactive, slow moving, or lacks energy

0 1 2 103. Unhappy, sad, or depressed 60

0 1 2 104. Unusually loud

0 1 2 105. Uses alcohol or drugs (describe):

______

0 1 2 106. Vandalism

0 1 2 107. Wets self during the day

0 1 2 108. Wets the bed 65

0 1 2 109. Whining

0 1 2 110. Wishes to be of opposite sex

0 1 2 111. Withdrawn, doesn't get involved with others

0 1 2 112. Worrying

113. **Please write in any problems your child has that were not listed above:**

0 1 2 ______ 70

0 1 2 ______

0 1 2 ______

PLEASE BE SURE YOU HAVE ANSWERED ALL ITEMS.

UNDERLINE ANY YOU ARE CONCERNED ABOUT.

CHIP

The following questionnaire was developed to record what parents find helpful or not helpful to them in the management of family life when one of its members has a medical condition which calls for continued medical care. For the following items, we would like you to tell us how helpful each of the items has been when attempting to cope with your child's Spina Bifida (MM) throughout your child's life.

	Has this helped you in dealing with your child's Spina Bifida?			
	Not Helpful	Minimally Helpful	Moderately Helpful	Extremely Helpful
1. Trying to maintain family stability.	0	1	2	3
2. Engaging in relationships and friendships which help me to feel important and appreciated.	0	1	2	3
3. Trusting my spouse (or former spouse) to help support me and my child(ren).	0	1	2	3
4. Sleeping.	0	1	2	3
5. Talking with the medical staff (nurses, social worker, etc.) when we visit the medical center.	0	1	2	3
6. Believing that my child will get better.	0	1	2	3
7. Working, outside employment.	0	1	2	3
8. Showing that I am strong (emotionally).	0	1	2	3
9. Purchasing gifts for myself and/or other family members.	0	1	2	3
10. Talking with other individuals/ parents in my same situation.	0	1	2	3
11. Taking good care of all the medical equipment/supplies at home.	0	1	2	3

CHIP (continued)

	Has this helped you in dealing with your child's Spina Bifida?			
	Not Helpful	Minimally Helpful	Moderately Helpful	Extremely Helpful
12. Eating.	0	1	2	3
13. Getting other members of the family to help with chores and tasks at home.	0	1	2	3
14. Getting away by myself.	0	1	2	3
15. Talking with the Doctor about my concerns about my child.	0	1	2	3
16. Believing that the medical center/hospital has my family's best interest in mind.	0	1	2	3
17. Building close relationships with people.	0	1	2	3
18. Believing in God.	0	1	2	3
19. Developing myself as a person.	0	1	2	3
20. Talking with other parents in the same type of situation and learning about their experiences.	0	1	2	3
21. Doing things together as a family (involving all members of the family).	0	1	2	3
22. Investing time and energy in my job.	0	1	2	3
23. Believing that my child is getting the best medical care possible.	0	1	2	3
24. Entertaining friends in our home.	0	1	2	3
25. Reading about how other persons in my situation handle things.	0	1	2	3

CHIP (continued)

	Has this helped you in dealing with your child's Spina Bifida?			
	Not Helpful	Minimally Helpful	Moderately Helpful	Extremely Helpful
26. Doing things with family relatives.	0	1	2	3
27. Becoming more self-reliant and independent.	0	1	2	3
28. Telling myself that I have many things that I should be thankful for.	0	1	2	3
29. Concentrating on hobbies (art, music, jogging, etc.).	0	1	2	3
30. Explaining our family situation to friends and neighbors so they will understand us.	0	1	2	3
31. Encouraging my child to be more independent.	0	1	2	3
32. Keeping myself in shape and well groomed.	0	1	2	3
33. Involvement in social activities (parties, etc.) with friends.	0	1	2	3
34. Going out with my spouse on a regular basis.	0	1	2	3
35. Being sure prescribed medical treatments for my child are carried out at home on a daily basis.	0	1	2	3
36. Building a closer relationship with my spouse.	0	1	2	3
37. Allowing myself to get angry.	0	1	2	3
38. Investing myself in my child.	0	1	2	3
39. Talking to someone (<u>not</u> professional counselor/doctor) about how I feel.	0	1	2	3

CHIP (continued)

	Has this helped you in dealing with your child's Spina Bifida?			
	Not Helpful	Minimally Helpful	Moderately Helpful	Extremely Helpful
40. Reading more about the medical problem (Spina Bifida).	0	1	2	3
41. Talking over personal feelings and concerns with my spouse.	0	1	2	3
42. Being able to get away from the home care tasks and responsibilities for some relief.	0	1	2	3
43. Having my child seen at the clinic/hospital on a regular basis.	0	1	2	3
44. Believing that things will always work out.	0	1	2	3
45. Doing things with my children.	0	1	2	3

PARENTCOPE

Now we would like you to think of a problem that you had that was related to your child's Spina Bifida (MM). Try to think of some problem that occurred within the last 6 months. This has to be something related to the Spina Bifida. It could have happened at home, at your child's school, at the doctor's, with your family, or with your child's friends. It could have been an embarrassing situation that involved your child's Spina Bifida. It could have had something to do with his/her braces or catheter (if he/she uses one). It may have involved a shunt malfunction or anything else having to do with your child's Spina Bifida. You only need to think of ONE problem.

We would first like you to write what the problem was in the space below:

Now we would like you to think about this problem and tell us what you did about it. First, you answer "yes" or "no" for whether or not you did each of the things below. Then, if you used one of these things, tell us how much it helped you.

	Did you do this? (CIRCLE ONE)		IF YES, how much did it help?				
			Not at all	A little	Some-times	Pretty much	Very Much
1. I thought about something else; tried to forget it; and/or went and did something like watch TV or play a game to get it off my mind.	YES	NO	0	1	2	3	4
2. I stayed away from people; kept my feelings to myself; and just handled the situation on my own.	YES	NO	0	1	2	3	4
3. I tried to see the good side of things and/or concentrated on something good that could come out of the situation.	YES	NO	0	1	2	3	4
4. I realized I brought the problem on myself and blamed myself for causing it.	YES	NO	0	1	2	3	4

PARENTCOPE (continued)

	Did you do this? (CIRCLE ONE)		IF YES, how much did it help?				
			Not at all	A little	Sometimes	Pretty much	Very Much
5. I realized that someone else caused the problem and blamed them for making me go through this.	YES	NO	0	1	2	3	4
6. I thought of ways to solve the problem; talked to others to get more facts and information about the problem and/or tried to actually solve the problem.	YES	NO	0	1	2	3	4
7a. I talked about how I was feeling; yelled, screamed, or hit something.	YES	NO	0	1	2	3	4
7b. Tried to calm myself by talking to myself, praying, taking a walk, or just trying to relax.	YES	NO	0	1	2	3	4
8. I kept thinking and wishing this had never happened; and/or that I could change what had happened.	YES	NO	0	1	2	3	4
9. Turned to my family, friends, or other adults to help me feel better.	YES	NO	0	1	2	3	4
10. I just accepted the problem because I knew I couldn't do anything about it.	YES	NO	0	1	2	3	4

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VITA

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The final copies have been examined by the director of the dissertation and the signature which appears below verifies the fact that any necessary changes have been incorporated and that the dissertation is now given final approval by the Committee with reference to content and form.

The dissertation is therefore accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

11/20/94
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