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Disease Severity and Psychosocial Adjustment in Pre-Adolescents with Spina Bifida

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DISEASE SEVERITY AND PSYCHOSOCIAL ADJUSTMENT IN PRE-ADOLESCENTS WITH SPINA BIFIDA

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CHAPTER 1

INTRODUCTION

Numerous studies indicate that physically disabled and chronically ill children are at increased risk for experiencing psychosocial adjustment problems (Breslau, 1985; Wallander, Feldman, & Varni, 1989; Wallander, Varni et al., 1989). Moreover, several investigators have begun to examine factors that may be associated with various levels of adjustment in these populations (e.g., see Holmbeck & Faier-Routman, 1995; Wallander, Pitt, & Mellins, 1990; Wallander, Feldman et al., 1989; Wallander, Varni et al., 1989). This study will examine the association between one factor, disease severity, and psychosocial adjustment in pre-adolescents with spina bifida. The following discussion will be subdivided as follows: 1) the medical aspects of spina bifida will be reviewed, 2) past research findings on the psychosocial adjustment of children with spina bifida will be summarized, 3) disease parameters will be defined and their relationship to psychosocial adjustment will be discussed, and 4) the "marginality" and "severity" hypotheses as well as their relationship to the hypotheses proposed in the present study will be examined.

Medical Aspects of Spina Bifida

Spina bifida is the most frequently occurring central nervous system (CNS) malformation (Varni & Wallander, 1988; Wallander, Feldman, & Varni, 1989) and the second most common birth defect, after cerebral palsy (Charney, 1992). This common congenital disorder occurs in approximately 1 in 1,000 births and is caused by an incomplete closure of one or more vertebrae during the fifth to sixth week of gestation (Charney, 1992; Varni & Wallander, 1988). Depending on the level of the lesion on the spine and the associated abnormalities of the brainstem and the cerebellum, a variety of medical problems can result, including urinary, orthopedic, and neurological difficulties (Holmbeck & Faier-Routman, 1995; Wallander, Feldman et al., 1989). Such physical problems may include lower-extremity paralysis, hydrocephalus, CNS infections, and neurogenic incontinence (McLone, 1984; Wills, 1993).

Spina bifida is expressed in one of three forms, classified as lipomeningocele, meningocele, or myelomeningocele (McLone, 1984). Lipomeningocele is characterized by a skin covered lipoma or fatty tumor located over the spine. These children may experience problems with urinary control and musculoskeletal function of the lower extremities. In meningocele, the membranes covering the spinal cord (meninges) are exposed as a fluid-filled sac through an opening in the spinal column. Because this sac

does not include the nerves of the spinal cord, the neurological deficits associated with this type of spina bifida are limited. However, in some cases, sensory and motor handicaps may be present (Williamson, 1987). The most common condition is myelomeningocele, which occurs in 70% of the cases (Varni & Wallander, 1988; Wills, 1993). Myelomeningocele is the most severe form of spina bifida and is typified by a noticeable protrusion (the spinal cord in its membrane sac) on the back of the newborn (McLone, 1984; Varni & Wallander, 1988; Wills, 1993). This lesion is closed shortly after birth through neurosurgery to help ensure survival and preserve physical function (McLone, 1984; Varni & Wallander, 1988; Wills, 1993). Although the spinal lesion is usually at the waist (lumbar level), it may occur at the cervical, thoracic, or sacral levels (Wills, 1993). The higher the lesion level is on the spine, the more that locomotion and other bodily functions will be severely affected (McLone, 1984; Wills, 1993).

Most children with spina bifida are born with a deformity of the brain known as the Arnold-Chiari Type II malformation (Wills, 1993). This malformation of the brainstem and the cerebellum often results in motor difficulties, including problems with hand-eye coordination (McLone, 1984; Wills, 1993). Additionally, the malformed cerebellum may contribute to the development of hydrocephalus (McLone, 1984). Hydrocephalus occurs when there is an

obstruction of the system responsible for draining cerebrospinal fluid (CSF) from the brain (McLone, 1984; Wills, 1993). Hydrocephalus is treated by implanting a valve or shunt in the ventricle as a means of draining excess CSF into another body cavity. Approximately 85% of children born with myelomeningocele develop hydrocephalus and are shunted within the first year of life (McLone, 1984; Wills, 1993). However, it is not uncommon for a shunt to become obstructed or disconnected, and thus, most children require several shunt revisions during their lifetime (McLone, 1984).

The degree of the brain malformation and the level of the lesion vary considerably among children with spina bifida and thus, every child will experience a variety of secondary orthopedic and neurological difficulties (Varni & Wallander, 1988). For example, whereas children with sacral level lesions may have only impaired ankle and foot movement, those with thoracic level lesions usually have no leg movement (McLone, 1984). While the former group of children may only need to wear braces to walk, the latter usually ambulates with a wheelchair. Additionally, the etiology, course, and severity of hydrocephalus along with the presence of a shunt, of complications, revisions, and changes in ventricular distention will vary markedly among children with spina bifida (Wills, 1993). Thus, the spina bifida population should be viewed as a diverse group, comprised of individuals

presenting with a wide range of physical and psychological abilities.

Psychosocial Adjustment of Children with Spina Bifida

Evidence suggests that chronically ill and physically disabled children are at increased risk for evidencing psychological adjustment problems (Breslau, 1985; Wallander, Feldman et al., 1989; Wallander, Varni et al., 1989). Although the majority of physically disabled and chronically ill children experience no more psychosocial adjustment problems than their nondisabled peers, the incidence of clinical maladjustment among the disabled population has been determined to be approximately twice that found in children in general (Wallander, Feldman et al., 1989; Wallander, Varni, Babani, Banis, & Wilcox, 1988).

In their study of 270 chronically ill and disabled children, Wallander et al. (1988) found that children with spina bifida were reported by their mothers to display a significantly higher level of behavioral adjustment difficulties than found in a normative sample. However, their level of adjustment was similar to that of children with other chronic physical disorders and better than that of children referred for mental health services. Similarly, in a study by Wallander, Feldman et al. (1989), children with spina bifida were reported by their mothers to evidence poorer psychosocial adjustment than found for a normative sample. Yet, the adjustment levels of the sample tended to

vary, with many children exhibiting no more behavioral or social adjustment problems than were found in a normative sample, and only a small portion of the subjects were considered clinically maladjusted. Thus, although children with physical handicaps and chronic illness are at risk for higher rates of internalizing and externalizing symptoms, there is considerable variability in the degree to which such children evidence adjustment problems (Holmbeck & Faier-Routman, 1995; Wallander, Feldman et al., 1989; Wallander, Pitt, & Mellins, 1990). Several studies have investigated factors that may be associated with various levels of adjustment in children with spina bifida. For example, investigators have examined the association between adjustment and child temperament (e.g., Wallander, Hubert, & Varni, 1988), child's perceived stress (e.g., Murch & Cohen, 1989), family functioning (e.g., Lavigne, Nolan, & McLone, 1988; Murch & Cohen, 1989), and parental temperament (e.g., Wallander, Hubert et al., 1988). Additional factors associated with various disease parameters have also been investigated in relation to child adjustment (Holmbeck & Faier-Routman, 1995; Wallander, Feldman et al., 1989; Wallander, Varni et al., 1989). Before examining the research on disease severity and adjustment in more detail, an integrative, theoretical model of psychosocial adjustment in children with chronic physical conditions will be presented.

Theoretical Models of Psychosocial Adjustment

As indicated above, there appears to be multiple purported influences on adjustment in children with chronic illness and physical disabilities. Moreover, theorists have begun to construct models in order to better explain the complexity of psychosocial adjustment in these populations. One integrative model, Wallander and Varni's disability-stress-coping model (Wallander & Varni, 1992), organizes several variables hypothesized to influence adjustment into a risk-and-resistance framework. Although the model suggests that condition parameters (e.g., diagnosis, visibility, cognitive involvement, and severity) may directly influence child adjustment outcomes, the factor hypothesized to be primarily responsible for increasing the risk of maladjustment is stress. While a portion of this stress is thought to arise from the chronic illness or disability, other stressors indirectly or not at all associated with the condition (e.g., moving to a new school) are also purported to influence adjustment. Moreover, the model suggests that the effect of various risk factors (e.g., condition parameters, functional independence, and psychosocial stress) on psychosocial adjustment is moderated by resistance factors (e.g., personal, social, and coping processes). Thus, although the present study is solely focused upon the association between disease parameters and child adjustment, in light of the disability-stress-coping model, the potential

psychosocial stress emanating from various condition parameters may be more strongly associated with adjustment outcomes than the disability parameter itself.

Similarly, Thompson (1985) has proposed a stress and coping model to explain the relationship between illness parameters and child adjustment. Specifically, this model suggests that child and family adaptational processes mediate the relationship between illness parameters and child adjustment. Hypothesized adaptational processes include methods of coping (e.g., adaptive versus palliative), cognitive processes (e.g., stress appraisal; self-esteem; health locus of control), and family functioning (e.g., supportive, conflictual, and/or controlling). Moreover, based upon the model, child adjustment outcomes affect and are affected by maternal adjustment. Thus, in light of Thompson's stress and coping model of adjustment (Thompson, 1985), the influence of disease parameters on child psychological adjustment may be explained in part by the mediational contribution of adaptational processes.

Disease Parameters

Although several researchers have investigated the relationship between disease severity and adjustment outcomes, often times, very weak and nonsignificant relationships have been found. However, the majority of these studies are not comprehensive in the sense that (1) they may use only maternal reports of children's psychosocial

adjustment, (2) most studies do not examine multiple severity parameters, and (3) many of the studies fail to examine parameters independently (some utilize composite scores). Prior to examining these studies in more detail, the types of disease parameters assessed in these investigations will be described.

In past research on children with spina bifida, such disease or disability parameters have included spinal cord lesion level (Fletcher et al., 1995; Holmbeck & Faier-Routman, 1995; Wallander, Feldman et al., 1989), shunt status (Fletcher et al., 1995; Holmbeck & Faier-Routman, 1995), number of surgeries (Fletcher et al., 1995; Wallander, Feldman et al., 1989), ambulation status (Fletcher et al., 1995; Holmbeck & Faier-Routman, 1995; Wallander, Feldman et al., 1989), bladder control (Fletcher et al., 1995; Wallander, Feldman et al., 1989), and the child's intellectual functioning (Wallander, Varni et al., 1989). Information on various physical status variables has been obtained from medical charts (Holmbeck & Faier-Routman, 1995; Wallander, Feldman et al., 1989), maternal reports (Holmbeck & Faier-Routman, 1995), teacher reports (Wallander, Varni et al., 1989), and/or interviews with both mother and child (Wallander, Varni et al., 1989). There are several advantages to utilizing one or more of these methods over others based upon the specific information being collected. For example, more accurate information regarding types and

numbers of surgeries would be obtained from medical charts that have been cross checked with maternal reports than would be gathered from maternal report alone. Similarly, maternal and teacher reports regarding the percentage of time a child utilizes a particular ambulation device are likely to be more accurate than those obtained via medical charts.

Measurement of Disease Parameters

Disability parameters have been measured as a composite score (Wallander, Feldman et al., 1989; Wallander, Varni, et al., 1989) and/or as a set of discrete variables (Fletcher et al., 1995; Holmbeck & Faier-Routman, 1995; Wallander, Feldman, et al., 1989). Wallander, Varni, et al. (1989) assessed physical disability by rating children on the 5-point Severity of Physical Handicap (SPH) (Rutter, Tizard, & Whitmore, 1970) scale. Ratings were based on information obtained via interviews with mothers and children. Wallander, Feldman, et. al. (1989) computed an index of overall disability, the Disability Composite score, by adding scores assigned to various disability parameters. These authors cautioned, however, that in the absence of prior guidelines or indications from past results (see next section), it is difficult to know whether disability parameters should be weighed differentially and/or whether some should be included and others excluded. In the absence of such information, it may make more sense to examine parameters separately rather than to combine them.

Holmbeck and Faier-Routman (1995) measured lesion level and shunt status separately. Lesion level was divided into sacral, lumbar, and thoracic groups, while shunt status was defined by the existence or nonexistence of a shunt. Similarly, prior to calculating a Disability Composite score, Wallander, Feldman, et al. (1989) measured a number of disability parameters independently. Lesion level was divided into sacral, lumbar, and thoracic groups. The second parameter, shunt surgeries, was categorized as either zero, one, or two or more surgeries. Surgeries for ulcers below the waist were measured as either zero or one or more surgeries. Overall surgeries were grouped as either zero, one to two, or three or more surgeries. Ambulation status was divided into no aids, braces, or wheelchair/carried. Bladder function was grouped according to whether the child was continent, utilized a catheter, or used a collection device. Similarly, Fletcher et al. (1995) investigated a number of categorical variables including hydrocephalus (progressive, arrested, absent), shunt status (yes, no), number of shunt revisions (0, 1, 2, $\geq$ 3), level of spinal lesion (actual level), ambulatory status (ambulatory, nonambulatory, ambulates with assistance), and neurogenic bladder (yes, no). Finally, Wallander, Varni, et al. (1989) estimated child's intellectual functioning by using four data sources: performance on the Wechsler Intelligence Scale for Children-Revised (WISC-R; Wechsler, 1974) Block Design

subtest, the WISC-R Picture Arrangement subtest, the Peabody Picture Vocabulary Test-Revised; PPVT-R (Form L) (Dunn & Dunn, 1981), and any school-administered intelligence test.

Disease Parameters and Psychosocial Adjustment

The majority of studies examining the relationship between disease parameters and psychosocial adjustment have relied exclusively on maternal reports of children's psychosocial adjustment, including internalizing behavior problems, externalizing behavior problems, and social competence (Wallander, Feldman et al., 1989, Wallander, Varni et al., 1989). For example, Fletcher et al. (1995) investigated behavioral adjustment of children with hydrocephalus and found that these children were more likely than nonhydrocephalic children to display behavior problems, obtained lower scores on measures of adaptive behavior, and perceived themselves as less physically competent. However, very weak and nonsignificant relationships have generally been obtained between children's status with regard to various disease parameters and their behavioral and social adjustment (Wallander, Feldman et al., 1989, Wallander, Varni et al., 1989). Thus, some have concluded that variation in physical status per se does not account for much of the observed differential adjustment in children with spina bifida.

In their study of 65 children and adolescents with spina bifida, Holmbeck and Faier-Routman (1995) examined whether

family functioning and child psychosocial adjustment were associated with spinal lesion level and shunt status. Information on lesion level was obtained from the child's medical chart, while information regarding shunt status was based on maternal report and medical chart data. The list of adjustment outcomes not only included internalizing behavior problems, externalizing behavior problems, and social competence, but also included measures of self-concept and school grades. Unlike most studies in this literature, Holmbeck and Faier-Routman (1995) assessed the responses of both parents and children. Specifically, mothers reported on the nature of family relationships, while both children and mothers reported on the child's psychosocial adjustment.

Children with shunts exhibited lower levels of scholastic competence, more thought problems, and poorer school grades than children without shunts (Holmbeck & Faier-Routman, 1995). While shunt status was associated with outcomes related to cognitive functioning, it was not related to family functioning or other measures of psychosocial adjustment (Holmbeck & Faier-Routman, 1995).

Lesion level, however, tended to be associated with family atmosphere (Holmbeck & Faier-Routman, 1995). Findings revealed that mothers of children with higher lesion levels reported more attachment to their children, less family conflict, and a greater willingness to grant autonomy to their offspring. Thus, the least physically-impaired

children with spina bifida exhibited the greatest family difficulties. The investigators suggest that the "marginality hypothesis" may explain why children with less impairment can exhibit more difficulties (Bruhn, Hampton, & Chandler, 1971; Holmbeck & Faier-Routman, 1995; McAnarney, Pless, Satterwhite, & Friedman, 1974; Pless & Pinkerton, 1975).

The Marginality Hypothesis

There is evidence which suggests that less severely affected children, whose disability is "marginal," may evidence more psychological problems than children who are more severely affected (Bruhn et al., 1971; Holmbeck & Faier-Routman, 1995; McAnarney et al., 1974; Pless & Pinkerton, 1975). For example, in their study of 42 children with chronic arthritis, McAnarney et al. (1974) found that those children whose disease had produced no significant disability had more psychosocial problems than their disabled peers. Pless and Pinkerton (1975) offer one possible explanation for such findings:

> ... it would seem, paradoxically, that the less disabling the lesion and the more marginal its effect, the greater the challenge it may pose for the child in attempting to keep abreast of competitive society. These children are neither so handicapped as to drop out automatically nor yet well enough equipped to compete on an equal footing. They, therefore, fall between two stools. (p. 171)

Although children with spina bifida who have lower lesion levels may appear no different than their nondisabled peers,

they typically evidence a number of invisible difficulties such as a neurogenic bladder and learning disabilities (Holmbeck & Faier-Routman, 1995). Thus, these children may have a difficult time fitting in with both their nonimpaired peers and with more severely disabled children (Faier-Routman, 1994).

The Severity Hypothesis

On the other hand, other studies have reported a negative association between disease severity and psychosocial adjustment (Billings, Moos, Miller, & Gottlieb, 1987; Cadman, Boyle, Szartmari, & Offord, 1987; Daniels, Miller, Billings, & Moos, 1987; Steinhausen, Schindler, & Stephan, 1983). That is, several investigators have found that children with more severe forms of a given disorder are at higher risk for poor psychological adjustment than those with milder forms. For example, Steinhausen et al. (1983) found that cystic fibrosis patients with more severe symptomatology displayed higher levels of psychopathology than those children with more mild symptoms. Similarly, Billings et al. (1987) investigated psychosocial functioning of children with severe rheumatic disease as compared to that of children with milder forms of the disease. Compared to the mild patient group, the severe patient group showed more parent-reported psychological and physical problems. Additionally, children in the severe group missed more days of school due to illness than those children in the mild

group. In contrast to the marginality hypothesis, if findings consistent with the severity hypothesis were applied to the spina bifida population, it would be expected that those children with more severe forms of the disease (e.g., higher lesion levels) would be at higher risk for poor psychological adjustment than those with milder forms of the disease (e.g., lower lesion levels).

Rationale for Current Study

The present study will investigate further the relationship between psychosocial adjustment and disease severity. The set of physical status variables employed in Holmbeck and Faier-Routman's (1995) study (e.g., lesion level and shunt status) will be expanded to include those investigated in past research (e.g., spina bifida classification; number of shunt surgeries; shunt infection status; ambulation status; child's receptive vocabulary level). In light of Holmbeck and Faier-Routman's (1995) findings, these parameters will be examined independently as each one may be associated with different outcomes. Additionally, comprehensiveness of reported outcomes will be increased by utilizing not only parent and child reports, but also available teacher responses.

Hypotheses

Marginality versus Severity Hypotheses

One of the current study's objectives was to evaluate the competing hypotheses presented above. Thus, in this section, hypotheses were as follows:

1) It was hypothesized that if the marginality hypothesis is supported, those children with lower lesion levels, whose disability is "marginal," would display lower perceived self-concepts [as measured by the 6-item subscales of Harter's (1985) Self-Perception Profile for Children] and more internalizing behavior problems than those children with higher lesions (i.e. thoracic). In contrast, if the severity hypothesis is supported, those children with higher lesion levels would display lower perceived self-concepts and more internalizing behavior problems than those children with lower lesions.

2) If the marginality hypothesis is supported, those children diagnosed with lipomeningocele would display more internalizing behavior problems and lower perceived self-concepts as compared to those diagnosed with myelomeningocele. In contrast, if the severity hypothesis is supported, children diagnosed with myelomeningocele would display more internalizing behavior problems and lower perceived self-concepts as compared to those diagnosed with lipomeningocele.

3) If the marginality hypothesis is supported, children who ambulate with less visible forms of aid [i.e. ankle-foot orthoses (AFOs) or no aid] would display more internalizing behavior problems and lower perceived self-concepts than those who ambulate with more visible forms of aid (i.e. a wheelchair). In contrast, if the severity hypothesis is supported, those children who ambulate with more visible forms of aid would display more internalizing behavior problems and lower perceived self-concepts than those who ambulate with less visible forms of aid.

Additional Hypotheses

In addition to the hypotheses consistent with the competing theories, a number of additional hypotheses were investigated. It was hypothesized that 1) children with a shunt would demonstrate less self-perceived scholastic competence as compared to those children without shunts; 2) children with reported shunt infection(s) would demonstrate less scholastic competence as compared to those with no history of infection; 3) children with more shunt surgeries would display less scholastic competence as compared to those with fewer surgeries; and 4) children with higher levels of receptive vocabulary skills would display fewer internalizing behavior problems and higher levels of scholastic competence and perceived self-concept than those with lower receptive vocabulary levels.

CHAPTER 2

METHOD

Sample

Subjects were 67 families with 8- and 9-year-old pre-adolescents with spina bifida [37 males, 30 females; *M* (age) = 8.33 years] who were participants in a larger study on the transition to adolescence in families with children who have spina bifida. Table 1 provides complete demographic information on the sample. As illustrated in Table 1, this sample is representative of a wide range of family incomes and maternal and paternal ages. The majority of the subjects were White (77%; this rate is consistent with the prevalence rate for spina bifida in the general population; Hynd & Willis, 1988). Natural mothers from all of the families participated in the study.

Information on a number of physical status variables was obtained from children's medical charts and/or from maternal reports. As can be seen in Table 2, most of the children had spina bifida myelomeningocele (*N* = 57; lipomeningocele, *N* = 8). Additionally, there was considerable variability with respect to lesion level (sacral, *N* = 20; lumbar, *N* = 36; thoracic, *N* = 7) and child

TABLE 1

DEMOGRAPHIC CHARACTERISTICS OF SAMPLE (*N* = 67)

Demographic Characteristics	Full Sample
Child age (years)	
M	8.33
SD	.47
Child grade	
M	2.60
SD	.68
Child gender (*n*)	
Male	37
Female	30
Ethnicity of child (*n*)	
White	52
Hispanic	5
African American	4
Other	4
Missing	2
Maternal age (years)	
M	37.63
SD	2.20
Paternal age (years)	
M	40.94
SD	5.39
Family Structure (*n*)	
Two parents	56
One parent	11
Family Income *	
M	6.20
SD	2.56

* Family income is based on a scale that is divided into $10,000 increments: Level 1 = $10,000 or less per year; Level 2 = $10,000 - $20,000 per year; and so on to Level 11 = over $100,000 per year.

TABLE 2

PHYSICAL STATUS OF SAMPLE (N = 67)

Physical Status Variables	Full Sample
Lesion level (n)	
Sacral	20
Lumbar	36
Thoracic	7
Missing	4
Spina bifida classification (n)	
Lipomeningocele	8
Myelomeningocele	57
Missing	2
Shunt status (n)	
Shunted	48
Unshunted	19
Shunt surgeries	
M	2.13
SD	3.07
Shunt infections (n)	
Yes	7
No	59
Missing	1
Ambulation status *	
No assistance and/or AFOs	28
KAFOs and/or HKAFOs	25
Wheelchair	12
Missing	2
Receptive vocabulary level	
M	91.70
SD	19.22

* AFOs = ankle-foot orthoses; KAFOs = knee-ankle-foot orthoses; HKAFOS = hip-knee-ankle-foot orthoses.

receptive language abilities (based on the PPVT-R; Dunn & Dunn, 1981). Consistent with other studies, the mean PPVT-R score was in the average range (e.g., Wills, Holmbeck, Dillon, & McLone, 1990). Most of the children had a shunt (71%) and ambulated with no assistance or AFOs (43%).

Procedure

Families participating in the study were originally recruited from lists provided from three sources: (1) a children's hospital, (2) a hospital that cares exclusively for children with physical disabilities, and (3) a state-wide spina bifida association. Letters were sent to parents of children from the aforementioned sources who were 8- or 9-years-old as a means of recruiting families to participate. Within a month, letters were followed-up with phone calls. Out of 310 child names obtained from the three sources, 86 families lived too far away to be contacted (more than 120 miles from our laboratory), 55 could not be contacted due to incorrect addresses and/or phone numbers, 63 declined to participate, 11 had children who were not diagnosed with spina bifida, 16 had parents and/or children who did not speak English, and 11 could not participate for miscellaneous reasons. Thus, this left 68 families to participate in the study. An additional family was dropped after the home visit was conducted because the child was too old for the study (13-years-old).

All family assessments were conducted by trained research assistants during a three hour session at each family's home. During training, research assistants were familiarized with the data protocol, information on interviewing techniques, informed consent issues, and strategies for insuring consistency across administrations. During the family assessment, the assistants provided instructions to the family for all procedures. Additionally, the assistants were responsible for the videotaping and for taking care of all non-participating children in the home. After the parents and children had signed informed consent blanks, the parents and children were asked to complete a set of questionnaires. After all family members had completed the questionnaires, they were asked to sit together in a location where they can all be comfortable. They were then asked to complete one hour of family interaction tasks that were videotaped and audiotaped. Upon completion of the interaction tasks, the family was paid $50.00. In addition, parents were asked to sign release of information forms for the child's teacher, for a health professional from the child's spina bifida clinic, and for a medical chart review. After the family visit, a questionnaire packet was sent to the child's teacher. After the completed teacher packet was received, the teacher was compensated with $5.00 (return rate = 92%; N = 62). A questionnaire was also sent to each child's health care professional, for which the professionals

were compensated with $2.00 (return rate = 94%; *N* = 63). This study involves analyses of mother, father, child, and teacher questionnaire data along with information obtained from medical chart reviews.

Measures

Child Psychological Adjustment

Behavioral Adjustment. Parent and teacher reports on the Child Behavior Checklist (CBCL; Achenbach, 1991a) were used to evaluate behavioral adjustment. The CBCL consists of 138 items which have been normed on a large sample of community and clinic-referred children between the ages of 4 to 16. This measure is comprised of eight common scales and two second-order scales representing internalizing behavior problems and externalizing behavior problems. Since the primary goal was to identify internalizing behavioral problems, only scales associated with withdrawal, somatic complaints, and anxiety/depression were used in this study. The teacher report version that was utilized is referred to as the Teacher Report Form (TRF; Achenbach, 1991b). Achenbach (1991a, 1991b) reports impressive reliability and validity data for both of these measures. According to Perrin, Stein, and Drotar (1991), however, when using these measures with children and adolescents with chronic illness, investigators should be aware of a possible bias in interpreting data concerning physical symptoms. Children with chronic illnesses are likely to have more physical

symptoms than children without such medical conditions. Thus, children with chronic physical disorders may display elevated scores resulting from their medical condition rather than reflecting behavioral or psychological difficulties (Perrin et al., 1991). As a means of determining the impact of physical symptoms on the Internalizing scale score, the Somatic Complaints subscale, which includes the majority of the physical symptom items (Perrin et al, 1991), was examined independently in the present study.

Perceived Self-Competence. Perceived self-concept was assessed with child, parent, and teacher report on Harter's (1985) Self-Perception Profile for Children, a 36-item multidimensional measure of child self-concept and self-worth, consisting of the following 6-item subscales: scholastic competence, social competence, athletic competence, physical appearance, behavioral conduct, and general self-worth. The shorter, but comparable, 15-item Teacher's Rating Scale of Child's Actual Behavior was adapted for parent-report. This parent-report version is referred to as the Rating Scale of Child's Actual Competence and contains five 3-item scales, which include all six of the previously listed subscales except "general self-worth." Harter (1985) reports impressive psychometric data in support of the reliability and validity of this measure and the subscales. Harter (1990) suggests, however, that the structure of the self-concept may be different among special populations, for

reasons related to either cognitive-developmental levels and/or the unique environments that these children experience. Thus, caution should be taken when utilizing measures standardized for use with normal populations, and such measures should be modified when necessary (Harter, 1990).

Disease Parameters

Information on the following disease parameters was obtained from reviews of medical charts and/or maternal reports. Specified information was obtained from children's medical records by one of three research assistants who were trained prior to conducting the reviews. Reliability was assessed by randomly selecting two assistants to complete the same review every ninth assignment. The percent agreement between raters for the following disease parameters were as follows: lesion level, 83%, spina bifida classification, 92%, and shunt infection status, 96%. Interrater reliability for number of shunt surgeries was r = .97.

Lesion level. Information on lesion level was obtained from orthopedic reports included in the child's medical chart and was cross checked with maternal report. In many cases, multiple orthopedic reports were available, in which case the median of the three most recent reports was recorded. Similarly if only two reports were available, the median lesion level was computed. After recording the specific lesion level from the chart, children were placed into sacral

(N = 20), lumbar (N = 36), or thoracic (N = 7) groups (data was missing on 4 subjects). Several children fell between the sacral and lumbar levels and thus, were classified as lumbosacral. Due to their functional level, these children were placed in the lumbar group, allowing the extreme sacral and thoracic groups to remain as homogeneous as possible.

Spina bifida classification. Information on the classification of spina bifida was obtained from the medical chart and was cross checked with maternal report. Children were either classified as having lipomeningocele or myelomeningocele.

Shunt status. Shunt status was obtained from maternal report. Most of the sample (71%) had shunts (see Table 2). It is important to note that shunt status is not necessarily a proxy for the presence of hydrocephalus (Fletcher et al., 1995). It is possible that some of our participants have compensated hydrocephalus.

Shunt surgeries. Information pertaining to the total number of shunt surgeries was obtained from the child's medical chart and was cross checked with maternal report.

Shunt infection. Shunt infection status was obtained from the child's medical chart and was cross checked with maternal report. Each child was classified as either having had a shunt infection or as not having experienced such an infection.

Ambulation. Ambulation data (see Table 2) was obtained from maternal reports that specified the type of mobility device used and the percentage of time that each device is used. Based upon this information, the children were divided into three categories: 1) those children requiring no assistance or AFOs to ambulate more than fifty percent of the time, 2) those children ambulating with knee-ankle-foot orthoses (KAFOs) or hip-knee-ankle-foot orthoses (HKAFOs) more than fifty percent of the time, or 3) those ambulating with wheelchair assistance more than fifty percent of the time.

Receptive vocabulary level. Standard scores on the PPVT-R (Form L) were used as a measure of receptive vocabulary level. The PPVT-R is a well-normed measure of hearing vocabulary and is used with children who display a wide range of cognitive abilities (Dunn & Dunn, 1981).

Plan of Analysis

Continuous Variables

Scores on Harter's (1985) Self-Perception Profile for Children were based upon mean scores taken across mother, father, teacher, and child reports. The resulting five subscales included scholastic competence, social competence, athletic competence, physical appearance, and behavioral conduct. The general self-worth subscale score was based upon child report. Similarly, scores on the CBCL were based upon mother, father, and teacher means, resulting in three

subscales including withdrawal, somatic complaints, and anxiety/depression. To test the hypotheses, Pearson *r* correlations were conducted between these outcomes and total number of shunt surgeries and receptive vocabulary level.

Categorical Variables

Scores on the Harter were again based upon means taken across mother, father, teacher, and child reports, resulting in five subscales. The general self worth subscale was based upon child report. CBCL scores were determined by means across mother, father, and teacher reports and will result in three subscales. Multivariate analyses of variance (MANOVAs) were conducted for the categorical independent variables including lesion level, spina bifida classification, shunt status, shunt infection status, and ambulation classification.

CHAPTER 3

RESULTS

Marginality versus Severity

MANOVAs (with univariate follow-up analyses) were conducted to assess group differences for the categorical independent variables including lesion level, spina bifida classification, and ambulation classification. In each case, the dependent variables included the Harter (mother, father, teacher, or child reports) and the CBCL (mother, father, or teacher reports). One-way analyses of variance with Duncan post-hoc analysis follow-ups were run for total internalizing behavior problems and total perceived self-competence. See Table 3 through Table 7 for a display of all analyses.

Hypothesis 1

It was predicted that if the marginality hypothesis is supported, children with lower lesion levels would display lower perceived self-concepts and more internalizing behavior problems than those children with higher lesions. In contrast, if the severity hypothesis is validated, it was hypothesized that children with higher lesion levels would demonstrate more internalizing behavior problems and lower perceived self-concepts as compared to those with lower

TABLE 3

ANALYSES CONDUCTED TO TEST HYPOTHESIS 1

Hypothesis 1	Independent Variable	Dependent Variable	One-way/MANOVA Significance
Analysis #1	Lesion Level (3)	Harter-subscales (mother)	$F_{(m)}$ = .92
Analysis #2	Lesion Level (3)	Harter-subscales (father)	$F_{(m)}$ = 1.38
Analysis #3	Lesion Level (3)	Harter-subscales (teacher)	$F_{(m)}$ = 1.88
Analysis #4	Lesion Level (3)	Harter-subscales (child)	$F_{(m)}$ = .93
Analysis #5	Lesion Level (3)	Harter-total (mother)	$F_{(o)}$ = 1.12
Analysis #6	Lesion Level (3)	Harter-total (father)	$F_{(o)}$ = 1.22
Analysis #7	Lesion Level (3)	Harter-total (teacher)	$F_{(o)}$ = .58
Analysis #8	Lesion Level (3)	Harter-total (child)	$F_{(o)}$ = .73
Analysis #9	Lesion Level (3)	CBCL-subscales (mother)	$F_{(m)}$ = .52
Analysis #10	Lesion Level (3)	CBCL-subscales (father)	$F_{(m)}$ = .73
Analysis #11	Lesion Level (3)	CBCL-subscales (teacher)	$F_{(m)}$ = .57
Analysis #12	Lesion Level (3)	CBCL-total (mother)	$F_{(o)}$ = .28
Analysis #13	Lesion Level (3)	CBCL-total (father)	$F_{(o)}$ = .82
Analysis #14	Lesion Level (3)	CBCL-total (teacher)	$F_{(o)}$ = .24

[a] $p < .05$
[b] $p < .01$

Note: (m) = MANOVA; (o) = one-way

TABLE 4

ANALYSES CONDUCTED TO TEST HYPOTHESIS 2

Hypothesis 2	Independent Variable	Dependent Variable	One-way/MANOVA Significance
Analysis #1	Spina Bifida Classification (2)	Harter-subscales (mother)	$F_{(m)} = 3.25^a$
Analysis #2	Spina Bifida Classification (2)	Harter-subscales (father)	$F_{(m)} = 3.05^a$
Analysis #3	Spina Bifida Classification (2)	Harter-subscales (teacher)	$F_{(m)} = 2.93^a$
Analysis #4	Spina Bifida Classification (2)	Harter-subscales (child)	$F_{(m)} = .61$
Analysis #5	Spina Bifida Classification (2)	Harter-total (mother)	$F_{(o)} = 7.78^b$
Analysis #6	Spina Bifida Classification (2)	Harter-total (father)	$F_{(o)} = 13.53^b$
Analysis #7	Spina Bifida Classification (2)	Harter-total (teacher)	$F_{(o)} = 3.70$
Analysis #8	Spina Bifida Classification (2)	Harter-total (child)	$F_{(o)} = .68$
Analysis #9	Spina Bifida Classification (2)	CBCL-subscales (mother)	$F_{(m)} = .43$
Analysis #10	Spina Bifida Classification (2)	CBCL-subscales (father)	$F_{(m)} = .13$
Analysis #11	Spina Bifida Classification (2)	CBCL-subscales (teacher)	$F_{(m)} = .64$
Analysis #12	Spina Bifida Classification (2)	CBCL-total (mother)	$F_{(o)} = .13$
Analysis #13	Spina Bifida Classification (2)	CBCL-total (father)	$F_{(o)} = .02$
Analysis #14	Spina Bifida Classification (2)	CBCL-total (teacher)	$F_{(o)} = .10$

$^a p < .05$
$^b p < .01$

Note: (m) = MANOVA; (o) = one-way

TABLE 5

ANALYSES CONDUCTED TO TEST HYPOTHESIS 3

Hypothesis 3	Independent Variable	Dependent Variable	One-way/MANOVA Significance
Analysis #1	Ambulation Status (3)	Harter-subscales (mother)	$F_{(m)} = .80$
Analysis #2	Ambulation Status (3)	Harter-subscales (father)	$F_{(m)} = .24$
Analysis #3	Ambulation Status (3)	Harter-subscales (teacher)	$F_{(m)} = 2.40^{a}$
Analysis #4	Ambulation Status (3)	Harter-subscales (child)	$F_{(m)} = .96$
Analysis #5	Ambulation Status (3)	Harter-total (mother)	$F_{(o)} = .30$
Analysis #6	Ambulation Status (3)	Harter-total (father)	$F_{(o)} = .21$
Analysis #7	Ambulation Status (3)	Harter-total (teacher)	$F_{(o)} = 1.83$
Analysis #8	Ambulation Status (3)	Harter-total (child)	$F_{(o)} = .16$
Analysis #9	Ambulation Status (3)	CBCL-subscales (mother)	$F_{(m)} = 1.10$
Analysis #10	Ambulation Status (3)	CBCL-subscales (father)	$F_{(m)} = 1.72$
Analysis #11	Ambulation Status (3)	CBCL-subscales (teacher)	$F_{(m)} = 1.04$
Analysis #12	Ambulation Status (3)	CBCL-total (mother)	$F_{(o)} = .39$
Analysis #13	Ambulation Status (3)	CBCL-total (father)	$F_{(o)} = 3.50^{a}$
Analysis #14	Ambulation Status (3)	CBCL-total (teacher)	$F_{(o)} = .11$

$^{a}p < .05$
$^{b}p < .01$

Note: (m) = MANOVA; (o) = one-way

TABLE 6

ANALYSES CONDUCTED TO TEST HYPOTHESIS 4

Hypothesis 4	Independent Variable	Dependent Variable	One-way/MANOVA Significance
Analysis #1	Shunt Status (2)	Harter-subscales (mother)	$F_{(m)} = 2.66^a$
Analysis #2	Shunt Status (2)	Harter-subscales (father)	$F_{(m)} = 2.18$
Analysis #3	Shunt Status (2)	Harter-subscales (teacher)	$F_{(m)} = 2.21$
Analysis #4	Shunt Status (2)	Harter-subscales (child)	$F_{(m)} = .76$
Analysis #5	Shunt Status (2)	Harter-total (mother)	$F_{(o)} = 1.27$
Analysis #6	Shunt Status (2)	Harter-total (father)	$F_{(o)} = 5.52^a$
Analysis #7	Shunt Status (2)	Harter-total (teacher)	$F_{(o)} = 3.50$
Analysis #8	Shunt Status (2)	Harter-total (child)	$F_{(o)} = .26$
Analysis #9	Shunt Status (2)	CBCL-subscales (mother)	$F_{(m)} = .38$
Analysis #10	Shunt Status (2)	CBCL-subscales (father)	$F_{(m)} = .30$
Analysis #11	Shunt Status (2)	CBCL-subscales (teacher)	$F_{(m)} = 1.37$
Analysis #12	Shunt Status (2)	CBCL-total (mother)	$F_{(o)} = .01$
Analysis #13	Shunt Status (2)	CBCL-total (father)	$F_{(o)} = .23$
Analysis #14	Shunt Status (2)	CBCL-total (teacher)	$F_{(o)} = 1.29$

[a] $p < .05$
[b] $p < .01$

Note: (m) = MANOVA; (o) = one-way

TABLE 7

ANALYSES CONDUCTED TO TEST HYPOTHESIS 5

Hypothesis 5	Independent Variable	Dependent Variable	One-way/MANOVA Significance
Analysis #1	Shunt Infection Status (2)	Harter-subscales (mother)	$F_{(m)} = .91$
Analysis #2	Shunt Infection Status (2)	Harter-subscales (father)	$F_{(m)} = .41$
Analysis #3	Shunt Infection Status (2)	Harter-subscales (teacher)	$F_{(m)} = 1.00$
Analysis #4	Shunt Infection Status (2)	Harter-subscales (child)	$F_{(m)} = 1.36$
Analysis #5	Shunt Infection Status (2)	Harter-total (mother)	$F_{(o)} = .02$
Analysis #6	Shunt Infection Status (2)	Harter-total (father)	$F_{(o)} = .80$
Analysis #7	Shunt Infection Status (2)	Harter-total (teacher)	$F_{(o)} = .90$
Analysis #8	Shunt Infection Status (2)	Harter-total (child)	$F_{(o)} = .68$
Analysis #9	Shunt Infection Status (2)	CBCL-subscales (mother)	$F_{(m)} = .53$
Analysis #10	Shunt Infection Status (2)	CBCL-subscales (father)	$F_{(m)} = .56$
Analysis #11	Shunt Infection Status (2)	CBCL-subscales (teacher)	$F_{(m)} = 2.46$
Analysis #12	Shunt Infection Status (2)	CBCL-total (mother)	$F_{(o)} = .28$
Analysis #13	Shunt Infection Status (2)	CBCL-total (father)	$F_{(o)} = 1.57$
Analysis #14	Shunt Infection Status (2)	CBCL-total (teacher)	$F_{(o)} = .32$

[a]$p < .05$
[b]$p < .01$

Note: (m) = MANOVA; (o) = one-way

lesions. Neither hypothesis was supported as lesion level was not significantly associated with psychosocial adjustment. Table 3 displays the analyses that were conducted to test this hypothesis, and Table 8 and Table 9 exhibit mother-, father-, teacher-, and child-reported child adjustment means and standard deviations by lesion level.

Hypothesis 2

It was predicted that if the marginality hypothesis is supported, those children diagnosed with lipomeningocele would display more internalizing behavior problems and lower perceived self-concepts compared to those with myelomeningocele. Alternatively, if the severity hypothesis is supported, children with myelomeningocele would display more psychosocial maladjustment as compared to those with lipomeningocele. Table 4 displays the analyses that were conducted to test this hypothesis, and Table 10 and Table 11 exhibit mother-, father-, teacher-, and child-reported child adjustment means and standard deviations by spina bifida classification. The severity hypothesis was partially supported as father and mother reports indicated that children with lipomeningocele displayed higher perceived self-concepts as compared to those children with myelomeningocele (F [5, 43] = 3.05, $p < .05$; F [5, 52] = 2.93, $p < .05$, respectively). Univariate follow-up tests revealed that the groups differed on two of the variables assessed. Fathers reported that children with

TABLE 8

MOTHER-AND FATHER-REPORTED
CHILD ADJUSTMENT MEANS AND STANDARD DEVIATIONS BY LESION LEVEL

	Mother						Father					
	Sacral		Lumbar		Thoracic		Sacral		Lumbar		Thoracic	
Variable	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
Internalizing behavior problems												
Total internalizing behavior problems	54.19	12.79	53.57	9.89	50.57	11.72	44.91	9.9	49.22	10.55	46.00	3.00
Withdrawal	54.81	6.21	54.11	5.35	52.43	5.22	52.46	3.56	53.22	5.97	50.00	.00
Somatic complaints	60.38	7.97	56.89	7.97	55.29	5.79	52.00	2.37	55.16	7.02	56.00	6.00
Anxiety/depression	56.06	7.83	55.80	7.36	55.29	6.37	52.18	5.17	53.94	6.15	50.67	1.16
Perceived self-competence												
Total perceived self-competence	3.02	.44	2.90	.30	2.83	.24	3.15	.36	2.99	.29	3.00	.18
Scholastic competence	2.82	1.03	2.70	.67	2.24	.79	3.22	.80	2.83	.57	2.56	.51
Social competence	3.33	.54	3.06	.60	3.33	.69	3.58	.41	3.04	.70	3.67	.00
Athletic competence	2.03	.68	1.92	.51	2.24	.69	1.92	.71	2.10	.63	1.89	.39
Physical appearance	3.56	.52	3.51	.50	3.38	.36	3.58	.38	3.51	.49	3.56	.51
Behavioral conduct	3.36	.48	3.30	.59	2.95	.76	3.44	.54	3.49	.47	3.33	.33

[a] $p < .05$
[b] $p < .01$

TABLE 9

TEACHER-AND CHILD-REPORTED CHILD ADJUSTMENT MEANS AND STANDARD DEVIATIONS BY LESION LEVEL

	Teacher						Child					
	Sacral		Lumbar		Thoracic		Sacral		Lumbar		Thoracic	
Variable	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
Internalizing behavior problems												
Total internalizing behavior problems	55.35	12.15	53.22	10.74	52.86	10.12						
Withdrawal	56.24	7.00	55.57	8.05	53.86	7.34						
Somatic complaints	60.24	9.74	56.83	8.64	60.00	8.74						
Anxiety/depression	56.59	9.34	54.74	5.63	53.71	6.50						
Perceived self-competence												
Total perceived self-competence	2.85	.57	2.78	.44	2.62	.33	2.82	.67	2.87	.39	2.56	.89
Scholastic competence	2.51	.81	2.35	.75	1.91	.42	2.87	.85	2.70	.74	2.38	1.14
Social competence	2.67	.86	2.94	.86	3.05	.56	2.89	.92	2.83	.65	2.33	1.28
Athletic competence	2.09	.79	1.70	.62	2.05	.91	2.34	.92	2.57	.77	2.96	.77
Physical appearance	3.37	.60	3.16	.76	3.29	.49	2.76	.81	2.98	.78	2.79	.91
Behavioral conduct	3.61	.64	3.49	.75	2.76	.94	3.09	.49	2.93	.62	3.08	1.13
General self worth							2.97	.92	3.21	.65	2.67	1.10

[a]$p < .05$
[b]$p < .01$

TABLE 10

MOTHER-AND FATHER-REPORTED
CHILD ADJUSTMENT MEANS AND STANDARD DEVIATIONS BY SPINA BIFIDA CLASSIFICATION

	Mother				Father			
	Lipomeningocele		Myelomeningocele		Lipomeningocele		Myelomeningocele	
Variable	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
Internalizing behavior problems								
Total internalizing behavior problems	51.88	10.03	53.35	10.97	47.50	14.46	48.12	9.37
Withdrawal	54.00	4.96	54.02	5.60	53.83	9.39	52.42	4.46
Somatic complaints	58.50	6.89	57.50	8.76	55.00	8.56	54.78	6.15
Anxiety/depression	53.75	5.73	55.96	7.46	54.00	8.85	53.17	5.23
Perceived self-competence								
Total perceived self-competence	3.24	.30	2.89	.34[a]	3.46	.29	2.99	.29[a]
Scholastic competence	3.08	.61	2.60	.79	3.56	.50	2.81	.61[b]
Social competence	3.33	.89	3.15	.55	3.67	.56	3.16	.66
Athletic competence	2.71	.55	1.92	.56[b]	2.61	.98	1.99	.62[a]
Physical appearance	3.71	.49	3.50	.48	3.83	.28	3.51	.47
Behavioral conduct	3.38	.49	3.28	.59	3.61	.53	3.46	.47

[a] $p < .05$
[b] $p < .01$

TABLE 11

TEACHER-AND CHILD-REPORTED
CHILD ADJUSTMENT MEANS AND STANDARD DEVIATIONS BY SPINA BIFIDA CLASSIFICATION

	Teacher				Child			
	Lipomeningocele		Myelomeningocele		Lipomeningocele		Myelomeningocele	
Variable	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
Internalizing behavior problems								
Total internalizing behavior problems	53.25	13.32	54.59	10.66				
Withdrawal	53.00	7.51	56.15	7.70				
Somatic complaints	60.14	8.26	58.46	9.13				
Anxiety/depression	54.14	8.60	55.54	7.08				
Perceived self-competence								
Total perceived self-competence	3.07	.66	2.73	.44	3.01	.71	2.84	.51
Scholastic competence	2.75	.75	2.27	.75	2.96	1.02	2.73	.77
Social competence	3.00	.71	2.84	.87	3.00	1.12	2.83	.72
Athletic competence	2.60	.59	1.75	.66[b]	2.65	1.03	2.57	.81
Physical appearance	3.54	.73	3.18	.68	2.8	1.04	2.95	.76
Behavioral conduct	3.33	.99	3.42	.79	3.21	.43	2.98	.64
General self worth					3.44	.57	3.10	.77

[a] $p < .05$
[b] $p < .01$

lipomeningocele demonstrated higher levels of scholastic competence, F [1, 47] = 8.17, $p < .01$, as compared to those with myelomeningocele. Moreover, based on father, mother, and teacher report, children with lipomeningocele displayed higher levels of athletic competence as compared to those with myelomeningocele (F [1, 47] = 4.49, $p < .05$, F [1, 56] = 11.88, $p < .01$, respectively).

Hypothesis 3

It was predicted that if the marginality hypothesis is supported, then children who ambulate with less visible forms of aid would display more internalizing behavior problems and lower perceived self-concepts than those who ambulate with more visible forms of aid. Conversely, if the severity hypothesis is supported, children who ambulate with more visible forms of aid would display more maladjustment than those who ambulate with less visible forms of aid. Table 5 displays the analyses that were conducted to test this hypothesis, and Table 12 and Table 13 exhibit mother-, father-, teacher-, and child-reported child adjustment means and standard deviations by ambulation status. The severity hypothesis was partially supported as a One-way Analysis of Variance (with Duncan post-hoc analyses) indicated that fathers reported that children who ambulate with KAFOs or HKAFOs more than 50% of the time displayed more internalizing problems, including anxiety and depression, than those who ambulated with no assistance or AFOs more than 50% of the

TABLE 12

MOTHER-AND FATHER-REPORTED
CHILD ADJUSTMENT MEANS AND STANDARD DEVIATIONS BY AMBULATION STATUS

	Mother						Father					
	No Assistance/ AFOs		KAFOs/HKAFOs		Wheelchair		No Assistance/ AFOs		KAFOs/HKAFOs		Wheelchair	
Variable	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
Internalizing behavior problems												
Total internalizing behavior problems	54.33	11.28	51.96	10.34	51.73	10.94	44.95	8.37	52.14	10.78	45.33	6.02[a]
Withdrawal	55.19	5.83	53.38	5.33	52.18	4.22	51.81	3.56	54.18	6.62	50.00	.00
Somatic complaints	57.70	8.50	58.13	9.42	55.36	5.84	53.38	5.89	56.05	6.90	54.33	5.13
Anxiety/depression	56.67	7.69	54.08	6.41	56.36	7.51	51.05	2.42	55.86	7.17	51.83	3.60[a]
Perceived self-competence												
Total perceived self-competence	2.95	.37	2.96	.38	2.87	.23	3.09	.37	3.02	.32	3.07	.23
Scholastic competence	2.87	.80	2.56	.79	2.58	.80	3.03	.75	2.85	.56	2.94	.65
Social competence	3.15	.67	3.19	.62	3.21	.62	3.28	.64	3.21	.63	3.17	.91
Athletic competence	1.94	.66	2.11	.56	2.06	.61	2.15	.78	2.00	.62	2.00	.56
Physical appearance	3.52	.46	3.59	.49	3.36	.51	3.54	.46	3.58	.48	3.56	.40
Behavioral conduct	3.28	.59	3.35	.49	3.12	.70	3.45	.51	3.49	.45	3.67	.42

[a] $p < .05$
[b] $p < .01$

TABLE 13

TEACHER-AND CHILD-REPORTED CHILD ADJUSTMENT MEANS AND STANDARD DEVIATIONS BY AMBULATION STATUS

	Teacher						Child					
	No Assistance/ AFOs		KAFOs/HKAFOs		Wheelchair		No Assistance/ AFOs		KAFOs/HKAFOs		Wheelchair	
Variable	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
Internalizing behavior problems												
Total internalizing behavior problems	53.63	12.44	54.96	10.50	53.58	9.63						
Withdrawal	55.07	6.75	57.30	9.15	54.00	6.35						
Somatic complaints	59.15	9.37	56.74	8.19	60.50	9.66						
Anxiety/depression	55.44	7.08	55.78	8.20	54.00	5.53						
Perceived self-competence												
Total perceived self-competence	2.91	.52	2.65	.47	2.80	.41	2.88	.44	2.87	.57	2.77	.72
Scholastic competence	2.69	.74	2.10	.69	2.06	.71[a]	2.78	.71	2.74	.80	2.79	1.06
Social competence	2.91	.76	2.67	1.01	3.27	.55	2.90	.60	2.87	.87	2.54	.96
Athletic competence	2.02	.76	1.67	.56	2.03	.89	2.33	.76	2.65	.89	3.10	.60
Physical appearance	3.27	.78	3.13	.69	3.42	.50	2.96	.83	2.95	.72	2.83	.92
Behavioral conduct	3.47	.84	3.58	.61	2.97	.99	3.05	.56	2.93	.61	3.06	.83
General self worth							3.23	.78	3.11	.72	2.83	.84

[a] $p < .05$
[b] $p < .01$

time, F [2, 46] = 3.50, p < .05. Similarly, the MANOVA for the teacher-reported self-concept variables was significant, F [10, 106] = 2.40, p <.05. Follow-up analyses revealed that based on teacher report, children who ambulated with no assistance or AFOs more than 50% of the time displayed superior scholastic competence as compared to those using KAFOs, HKAFOs, and wheelchairs, F [2, 59] = 4.97, p < .05.

Additional Results

Hypothesis 1

It was predicted that those children with a shunt would demonstrate less self-perceived scholastic competence as compared to those children without shunts. Table 6 displays the analyses that were conducted to test this hypothesis, and Table 14 and Table 15 exhibit mother-, father-, teacher-, and child-reported child adjustment means and standard deviations by shunt status. This hypothesis was supported as mother, father, and teacher reported self-concept variables were significant or marginally significant (F [5, 59] = 2.66, p <.05, F [5, 45] = 2.18, p = .07, F [5, 53] = 2.12, p = .07, respectively). Univariate follow-up analyses indicated that mothers, fathers, and teachers reported that children without shunts demonstrated higher levels of scholastic competence (F [1, 63] = 6.22. p < .05, F [1, 49] = 7.76, p < .01, F [1, 57] = 5.24. p < .05, respectively) and higher levels of athletic competence (F [1, 63] = 3.57, p = .06, F [1, 49] = 4.83,

TABLE 14

MOTHER-AND FATHER-REPORTED
CHILD ADJUSTMENT MEANS AND STANDARD DEVIATIONS BY SHUNT STATUS

	Mother				Father			
	Shunted		Unshunted		Shunted		Unshunted	
Variable	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
Internalizing behavior problems								
Total internalizing behavior problems	53.02	10.72	52.79	11.12	48.68	9.48	47.20	10.84
Withdrawal	53.65	5.40	54.63	5.60	52.50	4.58	53.00	6.48
Somatic complaints	57.16	8.70	58.11	7.82	55.06	6.41	53.87	6.16
Anxiety/depression	55.74	7.54	55.32	6.45	53.50	5.52	52.87	6.06
Perceived self-competence								
Total perceived self-competence	2.91	.34	3.02	.37	2.99	.31	3.22	.33[a]
Scholastic competence	2.55	.79	3.07	.73[a]	2.79	.61	3.31	.61[b]
Social competence	3.19	.54	3.14	.71	3.19	.65	3.36	.70
Athletic competence	1.94	.55	2.25	.69	1.94	.59	2.38	.81[a]
Physical appearance	3.56	.46	3.42	.51	3.56	.44	3.56	.51
Behavioral conduct	3.31	.57	3.21	.58	3.49	.47	3.49	.49

[a] $p < .05$
[b] $p < .01$

TABLE 15

TEACHER-AND CHILD-REPORTED
CHILD ADJUSTMENT MEANS AND STANDARD DEVIATIONS BY SHUNT STATUS

	Teacher				Child			
	Shunted		Unshunted		Shunted		Unshunted	
Variable	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
Internalizing behavior problems								
Total internalizing behavior problems	55.09	10.28	51.53	12.97				
Withdrawal	56.72	8.05	52.75	5.59				
Somatic complaints	58.80	9.36	57.69	8.00				
Anxiety/depression	55.59	7.25	54.44	7.14				
Perceived self-competence								
Total perceived self-competence	2.72	.44	2.98	.58	2.84	.56	2.91	.50
Scholastic competence	2.22	.72	2.74	.80[a]	2.73	.81	2.84	.76
Social competence	2.82	.90	3.10	.65	2.80	.76	2.93	.79
Athletic competence	1.76	.69	2.27	.72[a]	2.60	.85	2.49	.79
Physical appearance	3.26	.65	3.19	.86	3.00	.75	2.82	.85
Behavioral conduct	3.47	.73	3.26	1.03	2.94	.65	3.13	.51
General self worth					3.06	.82	3.25	.61

[a] $p < .05$
[b] $p < .01$

$p < .05$, F [1, 57] = 5.79, $p < .05$, respectively) as compared to those with shunts.

Hypothesis 2

It was predicted that children with reported shunt infection(s) would demonstrate less scholastic competence as compared to those with no history of such infection. Table 7 displays the analyses that were conducted to test this hypothesis, and Table 16 and Table 17 exhibit mother-, father-, teacher-, and child-reported child adjustment means and standard deviations by shunt infection. While this hypothesis was not supported, the MANOVA for teacher-reported internalizing behavioral variables was marginally significant, F [3, 57] = 2.46, $p = .07$. Univariate follow-up tests, based on teacher report, revealed that children with shunt infections demonstrated increased levels of somatic difficulties as compared to those with no history of shunt infection, F [1, 59] = 3.91, $p < .05$.

Hypothesis 3

It was predicted that children with more shunt surgeries would display less scholastic competence as compared to those with fewer surgeries. To test this hypothesis, Pearson r correlations were conducted (see Table 18). This hypothesis was supported, and a number of additional self-concept and behavioral variables were also significantly associated with number of shunt surgeries. Based on mother and father report, number of shunt surgeries was negatively correlated

TABLE 16

MOTHER-AND FATHER-REPORTED
CHILD ADJUSTMENT MEANS AND STANDARD DEVIATIONS BY SHUNT INFECTION

	Mother				Father			
	Infected		Uninfected		Infected		Uninfected	
Variable	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
Internalizing behavior problems								
Total internalizing behavior problems	50.86	11.08	53.09	10.43	43.00	8.83	48.84	9.93
Withdrawal	52.00	4.12	53.98	5.18	50.00	.00	53.02	5.42
Somatic complaints	57.86	11.11	57.23	8.23	53.20	3.03	54.88	6.64
Anxiety/depression	53.14	5.37	55.81	7.25	52.40	5.37	53.49	5.76
Perceived self-competence								
Total perceived self-competence	2.96	.37	2.94	.34	3.17	.29	3.04	.33
Scholastic competence	2.67	1.07	2.69	.77	2.93	.44	2.92	.66
Social competence	3.19	.42	3.18	.61	3.33	.78	3.22	.66
Athletic competence	1.76	.46	2.07	.61	2.13	.69	2.06	.69
Physical appearance	3.76	.50	3.50	.47	3.80	.30	3.52	.46
Behavioral conduct	3.43	.69	3.28	.56	3.67	.41	3.47	.48

[a] $p < .05$
[b] $p < .01$

TABLE 17

TEACHER-AND CHILD-REPORTED
CHILD ADJUSTMENT MEANS AND STANDARD DEVIATIONS BY SHUNT INFECTION

	Teacher				Child			
	Infected		Uninfected		Infected		Uninfected	
Variable	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
Internalizing behavior problems								
Total internalizing behavior problems	56.38	6.14	54.00	11.64				
Withdrawal	55.25	4.50	55.87	8.08				
Somatic complaints	64.38	8.70	57.79	8.79[a]				
Anxiety/depression	54.13	3.83	55.57	7.59				
Perceived self-competence								
Total perceived self-competence	2.94	.34	2.77	.51	2.70	.42	2.88	.56
Scholastic competence	2.50	.87	2.31	.75	3.06	.75	2.73	.81
Social competence	3.46	.40	2.79	.88	2.64	.59	2.86	.80
Athletic competence	1.92	.68	1.88	.74	2.94	.67	2.54	.85
Physical appearance	3.42	.46	3.24	.71	2.64	.57	2.95	.81
Behavioral conduct	3.42	.77	3.43	.83	2.92	.39	3.02	.64
General self worth					2.71	.46	3.18	.78

[a] $p < .05$
[b] $p < .01$

TABLE 18

PEARSON CORRELATIONS BETWEEN NUMBER OF SHUNT SURGERIES AND CHILD ADJUSTMENT

Variables	Adjustment Respondent: Mother	Father	Teacher	Child
Internalizing behavior problems				
Total internalizing behavior problems	.20	-.06	.02	
Withdrawal	.10	-.18	-.04	
Somatic complaints	.28[a]	.09	.19	
Anxiety/depression	.17	.03	-.08	
Perceived self-competence				
Total perceived self-competence	-.22	-.05	-.01	-.26[a]
Scholastic competence	-.34[b]	-.29[a]	.07	-.18
Social competence	-.10	.11	-.07	-.06
Athletic competence	-.24	-.08	.06	-.11
Physical appearance	.13	.18	.06	-.14
Behavioral conduct	.08	-.01	.06	-.28[a]
General self worth				-.27[a]

[a] $p < .05$
[b] $p < .01$

with scholastic competence (r = -.34, p < .01, r = -.29, p < .05, respectively), and based on mother report, number of shunt surgeries was positively correlated with somatic difficulties, r = .28, p < .05. Moreover, child report indicated that number of shunt surgeries was negatively correlated with perceived self-concept, rt = -.26, p < .05, general self-worth, r = -.27, p <.05, and behavioral conduct, r = -.28, p < .05.

Hypothesis 4

It was predicted that children with higher levels of receptive vocabulary skills would display higher levels of scholastic competence and perceived self-concept and fewer internalizing behavior problems than those with lower receptive vocabulary skills. To test this hypothesis, Pearson r correlations were conducted (see Table 19). Based on teacher report, scholastic competence, r = .44, p = .00, and self-esteem, r = .30, p < .05, were positively correlated with receptive vocabulary level while total internalizing behavior problems were negatively associated with receptive vocabulary level, r = -.26, p < .05.

TABLE 19

PEARSON CORRELATIONS BETWEEN RECEPTIVE VOCABULARY LEVEL AND CHILD ADJUSTMENT

Variables	Adjustment Respondent: Mother	Father	Teacher	Child
Internalizing behavior problems				
Total internalizing behavior problems	.15	-.04	-.26[a]	
Withdrawal	.13	.04	-.17	
Somatic complaints	.02	-.09	-.19	
Anxiety/depression	.24	.01	-.09	
Perceived self-competence				
Total perceived self-competence	.00	.06	.30[a]	.11
Scholastic competence	.13	.07	.44[b]	.00
Social competence	-.18	.03	.16	.01
Athletic competence	-.18	.01	.13	.19
Physical appearance	.17	.13	.03	.08
Behavioral conduct	.05	-.05	.15	.00
General self worth				.10

[a] $p < .05$
[b] $p < .01$

CHAPTER 4

DISCUSSION

Although several investigators have examined the relationship between various disease parameters and children's behavioral and social adjustment, often times, very weak and nonsignificant relationships have been found (e.g., Wallander, Feldman, et al., 1989; Wallander, Varni, et al., 1989). The present investigation investigated further the relationship between several illness parameters and psychosocial adjustment by expanding the set of physical status variables examined in past research and by increasing the comprehensiveness of reported outcomes. Specifically, this study examined the relationship between disease severity and psychosocial adjustment in 67 8- and 9-year-olds with spina bifida. The physical status variables employed in the present investigation included lesion level, spina bifida classification, shunt status, shunt surgeries, shunt infections, and receptive vocabulary level. Information on these disease parameters was obtained from reviews of medical charts and/or by maternal reports. Mother, father, and teacher reports on the Child Behavior Checklist (Achenbach,

1991a, 1991b) were used to evaluate behavioral adjustment, while perceived self-concept was assessed with child, mother, father, and teacher report on Harter's (1985) Self-Perception Profile for Children.

Although results suggest that lesion level was not significantly associated with psychosocial adjustment, the remaining physical status variables were related to various facets of psychosocial functioning. Since lesion level was not significantly associated with adjustment, neither the marginality nor the severity hypothesis was supported in this instance. This finding is consistent with that reported by Holmbeck and Faier-Routman (1995). While these investigators found that lesion level was not associated with child psychosocial adjustment (including behavioral problems and self-competence), they reported that this disease parameter was significantly associated with family atmosphere. Moreover, the nature of the relationship tended to support the marginality rather than the severity hypothesis. Thus, while lesion level does not appear to be associated with psychosocial adjustment, it may be related to different outcomes such as family functioning including, for example, family conflict and issues of autonomy. Additional research is needed to further investigate such relationships.

Although neither the marginality nor the severity hypothesis was supported when examining the relationship between lesion level and child adjustment, the severity

hypothesis was supported over the marginality hypothesis when investigating the relationship between two additional disease parameters (i.e., spina bifida classification and ambulation status) and psychosocial adjustment. In terms of spina bifida classification, results suggest that children with lipomeningocele, as compared to those with myelomeningocele, displayed higher overall levels of self-competence, athletic competence, and scholastic competence across reporters. Moreover, it was found that children who ambulated with KAFOs or HKAFOs more than fifty percent of the time displayed more internalizing problems than those who ambulated with no assistance or AFOs more than fifty percent of the time. Similarly, children who ambulated with no assistance or AFOs displayed superior scholastic competence as compared to those using KAFOs, HKAFOs, and wheelchairs. These results support the severity hypothesis as those children with more severe forms of spina bifida and who require more visible forms of aid appear to be at higher risk for poor psychosocial adjustment than those children with milder forms of spina bifida and those who ambulate with less visible forms of aid. Although this hypothesis has not been supported in previous research with spina bifida samples (e.g., Wallander, Feldman, et al., 1989; Wallander, Varni, et al., 1989), these results are consistent with several studies that have reported a negative association between disease severity and psychosocial adjustment in other pediatric populations,

including children with cystic fibrosis and rheumatic disease (e.g., Billings et al., 1987, Cadman et al., 1987, Daniels et al., 1987, & Steinhausen et al., 1983).

Several hypotheses independent of the marginality and severity hypotheses were examined in addition to those presented previously. For example, the relationship between child psychosocial adjustment and shunt status, shunt infections, and shunt surgeries was investigated. Results indicated that children without shunts demonstrated higher overall levels of self-competence, scholastic competence, and athletic competence. The finding associated with scholastic or cognitive competence is consistent with the predictions of this study and is in line with the reported associations between shunt status and intellectual functioning in past research (e.g., Holmbeck & Faier-Routman, 1995; Wills, 1993). However, in contrast to the present findings, the only other study to investigate the relationship between self-competence and shunt status did not report a significant association between athletic competence and shunt status (Holmbeck & Faier-Routman, 1995). This discrepancy in findings might be explained in part by the use of multiple informants in the present investigation. That is, in the current study, results indicated that fathers and teachers reported that children with shunts demonstrated higher levels of athletic competence. Holmbeck and Faier-Routman (1995) only obtained mother and child reports which may partially account for

their nonsignificant findings. The significant association found in the present investigation may be viewed in light of the literature on visuospatial and motor abilities in shunted, hydrocephalic children with spina bifida. A review of the literature suggests that these children may display impaired visual-motor abilities, abnormal upper extremity and hand functioning, poor tactile-perceptual abilities, and leg paralysis (Wills, 1993). These deficits, in turn, may be associated with impaired athletic abilities and competence.

Consistent with the previous hypothesis, it was predicted that children with shunt infections would demonstrate less scholastic competence as compared to those with no history of such infection. While shunt infection status was not significantly associated with self-competence, it was related to internalizing behavior problems. That is, children with shunt infections demonstrated increased levels of somatic difficulties as compared to those with no history of shunt infections. These results should be interpreted with caution, however, since children with shunt infections may display elevated scores on the somatic complaint scale because of their medical condition rather than reflecting behavioral or psychological difficulties (Perrin et al., 1991). Similarly, somatic difficulties were positively related to number of shunt revisions. This finding is consistent with that reported by Wallander, Feldman et al. (1989). Again, this finding should be interpreted with

caution, however, due to the potential bias in utilizing the somatic scale with children and adolescents with chronic illness.

Moreover, consistent with the predictions of this study and in line with past research, number of shunt surgeries was also significantly associated with various self-competence variables. That is, number of shunt surgeries was negatively correlated with total perceived self-competence, general self-worth, scholastic competence, and behavioral conduct. Finally, scholastic competence and self-concept were positively correlated with receptive vocabulary level, while total internalizing behavior problems appeared to be negatively associated with receptive vocabulary level. While receptive vocabulary level is not a measure of intelligence or academic achievement per se, it may be associated with scholastic performance, especially in verbal domains. Scholastic achievement, in turn, may be positively correlated with self-competence and scholastic competence in particular. Moreover, children displaying poor school performance may be at higher risk for experiencing internalizing problems including withdrawal, somatic complaints, anxiety, and/or depression.

Although the current study reported significant associations between physical status variables and facets of psychosocial functioning not found in previous investigations, the present study is not without its

limitations. For example, while many analyses were conducted to test the various hypotheses, very few significant associations were found. Secondly, consistent with the prevalence rates for spina bifida in the general population, few children in the current study were categorized with thoracic lesion levels or with shunt infections, resulting in small sample sizes (N = 7 and N = 7, respectively). Third, due to the narrow age range targeted in the present investigation (8- and 9-year-olds), the generalizability of these findings to children and adolescents of other ages is limited. Finally, as N = 16 families were excluded from participating in the current study because they could not speak English (most were Spanish-speaking), these results are primarily generalizable to white, English-speaking families. Future studies might include Spanish-speaking families in their samples to attend to this issue of external validity.

In summary, while several investigators have found weak and nonsignificant associations between disease severity and psychosocial adjustment (e.g., Wallander, Feldman et al., 1989; Wallander, Varni et al., 1989), this more comprehensive analysis revealed several significant associations between various illness parameters and adjustment outcomes. As indicated previously, however, the total number of significant associations found was rather limited. Thus, consistent with past research, these findings suggest that

variation in physical status per se does not account for much of the differential adjustment in children with spina bifida.

Additionally, results suggest that disease parameters are differentially associated with various outcome measures. Specifically, findings indicate that severity parameters are more often associated with adjustment outcomes that are directly affected by physical functioning (e.g., athletic and scholastic competence, and somatic complaints) than those related to psychological functioning (e.g., depression/ anxiety and withdrawal). In other words, although children with more severe forms of illness often displayed less athletic and scholastic competence and more somatic complaints than those children with less severe forms of disability, the former group did not demonstrate elevated levels of psychological maladjustment independent of level of physical functioning. Moreover, consistent with past research, it appears that these children are not experiencing maladjustment levels in the clinical range. These results suggest that despite the extent of physical limitations, most of these children are able to psychologically transcend their disabilities.

Theoretical models of psychosocial adjustment in pediatric populations (e.g., Thompson, 1985; Wallander & Varni, 1992) might be used to better explain the findings of the present investigation. First, in light of Wallander and Varni's disability-stress-coping model (Wallander & Varni,

1992), the limited number of significant associations found in the current study may suggest that it is the *stress* emanating from the physical condition rather than the condition parameters themselves that are responsible for elevating the risk for the development of psychosocial problems. Moreover, when severity parameters were significantly associated with child adjustment, the outcomes appeared to be a direct function of the disability (e.g., athletic competence). Although not investigated in the present study, it may be that severity parameters associated with maladjustment of a more psychological nature (e.g., depression/anxiety) are those that increase the risk of psychosocial stress.

Similarly, Thompson's stress and coping model (Thompson, 1985) can be used to better explain the limited number of significant associations found in the present study. According to this model, it is how the child adapts (cognitively and coping-wise) to the chronic physical disability rather than the disability parameters themselves that influence adjustment outcomes. Conceptual models of psychosocial adjustment in pediatric populations (e.g., Thompson, 1985; Wallander & Varni, 1992) should be evaluated and used to guide future research.

Finally, based upon the present study's findings, future research should continue to investigate such disease severity variables independently rather than as composite scores.

Moreover, future investigations might examine the relationship between disease severity and outcomes not targeted in the present study. For example, studies may investigate the association between disease parameters and outcomes of family functioning, such as those employed by Holmbeck & Faier-Routman (1995). It is hoped that the current study will prompt other comprehensive investigations of disease severity not only in the spina bifida population, but in other pediatric populations as well.

REFERENCES

Achenbach, T. M. (1991a). *Manual for the Child Behavior Checklist/4-18 and 1991 Profile*. Burlington, VT: University of Vermont Department of Psychiatry.

Achenbach, T. M. (1991b). *Manual for the Teacher's Report Form and 1991 Profile*. Burlington, VT: University of Vermont Department of Psychiatry.

Billings, A. G., Moos, R. H., Miller, J. J., & Gottlieb, J. E. (1987). Psychosocial adaptation in juvenile rheumatic disease: A controlled evaluation. *Health Psychology, 6,* 343-359.

Breslau, N. (1985). Psychiatric disorder in children with physical disabilities. *Journal of the American Academy of Child Psychiatry, 24,* 87-94.

Bruhn, J. G., Hampton, J. W., & Chandler, B. C. (1971). Clinical marginality and psychosocial adjustment in hemophilia. *Journal of Psychosomatic Research, 15,* 207-213.

Cadman, D., Boyle, M., Szartmari, P., & Offord, D. R., (1987). Chronic illness, disability, and mental and social well-being: Findings of the Ontario Child Health Study. *Pediatrics, 79,* 805-813.

Charney, E. (1992). Neural tube defects: Spina bifida and myelomeningocele. In M. Batshaw, & Y. Perret (Eds.), *Children with disabilities: A medical primer* (3rd ed.; pp. 471-488). Baltimore: Brookes.

Daniels, D., Miller, J. J., Billings, A. G., & Moos, R. H. (1987). Psychosocial functioning of siblings of children with rheumatic disease. *Journal of Pediatrics, 109,* 379-383.

Dunn, L. M., & Dunn, L. M. (1981). *Peabody Picture Vocabulary Test-Revised* (PPVT-R). Circle Pines, MN: American Guidance Service.

Faier-Routman, J. (1994). *Spina bifida: How are pediatric patients and their mothers coping?* Unpublished dissertation, Loyola University, Chicago.

Fletcher, J. M., Brookshire, B. L., Landry, S. H., Bohan, T. P., Davidson, K. C., Francis, D. J., Thompson, N. M., & Miner, M. E. (1995). Behavioral adjustment of children with hydrocephalus: Relationships with etiology, neurological, and family status. *Journal of Pediatric Psychology, 20,* 109-125.

Harter, S. (1990). Issues in the assessment of the self-concept of children and adolescents. In A. M. La Greca (Ed.), *Through the eyes of the child: Obtaining self-reports from children and adolescents* (pp. 292-325). Boston: Allyn and Bacon.

Harter, S. (1985). *Manual for the Self-Perception Profile for Children: Revision of the Perceived Competence Scale for Children.* Denver, CO: University of Denver.

Holmbeck, G. N., & Faier-Routman, J. (1995). Spinal lesion level, shunt status, family relationships, and psychosocial adjustment in children and adolescents with spina bifida. *Journal of Pediatric Psychology, 20,* 817-832.

Hynd, G. W., & Willis, W. G. (1988). *Pediatric neuropsychology.* New York: Grune & Stratton.

Lavigne, J. V., Nolan, P., & McLone, P. G. (1988). Temperament, coping, and psychological adjustment in young children with myelomeningocele. *Journal of Pediatric Psychology, 13,* 363-378.

McAnarney, E. R., Pless, B., Satterwhite, B., & Friedman, S. B. (1974). Psychological problems of children with chronic juvenile arthritis. *Pediatrics, 53,* 523-528.

McLone, D. G. (1984). *An introduction to spina bifida.* Chicago: Children's Memorial Hospital Myelomeningocele Team.

Murch, R. L., & Cohen, L. H. (1989). Relationships among life stress, perceived family environment, and the psychological distress of spina bifida adolescents. *Journal of Pediatric Psychology, 14,* 193-214.

Perrin, E. C., Stein, R. E. K., & Drotar, D. (1991). Cautions in using the Child Behavior Checklist: Observations based on research about children with a chronic illness. *Journal of Pediatric Psychology, 16,* 411-421.

Pless, I. B., & Pinkerton, P. (1975). *Chronic childhood disorder: Promoting patterns of adjustment.* Chicago, IL: Year Book Medical Publishers.

Rutter, M., Tizard, J., & Whitmore, K. (Eds.). (1970). *Education, health, and behavior.* London: Longman.

Steinhausen, H., Schindler, H., & Stephan, H. (1983). Correlates of psychopathology in sick children: An empirical model. *Journal of the American Academy of Child Psychiatry, 22,* 559-564.

Thompson, R. J., Jr. (1985). Coping with the stress of chronic childhood illness. In A. N. O'Quinn (Ed.), *Management of chronic disorders of childhood* (pp. 11-41). Boston: G. K. Hall.

Varni, J. W., & Wallander, J. L. (1988). Pediatric chronic disabilities: Hemophilia and spina bifida as examples. In D. K. Routh (Ed.), *Handbook of pediatric psychology* (pp. 190-221). New York: Guilford.

Wallander, J. L., Feldman, W. S., & Varni, J. W. (1989). Physical status and psychosocial adjustment in children with spina bifida. *Journal of Pediatric Psychology, 14,* 89-102.

Wallander, J. L., Hubert, N. C., & Varni, J. W. (1988). Child and maternal temperament characteristics, goodness of fit and adjustment in physically handicapped children. *Journal of Clinical Psychology, 17,* 336-344.

Wallander, J. L., Pitt, L. C., & Mellins, C. A. (1990). Child functional independence and maternal psychosocial stress as risk factors threatening adaptation in mothers physically or sensorially disabled children. *Journal of Consulting and Clinical Psychology, 58,* 818-824.

Wallander, J. L., & Thompson, R. J. (1995). Psychosocial adjustment of children with chronic physical conditions. In M. C. Roberts (Ed.), *Handbook of pediatric psychology* (2nd ed.; pp. 124-141). New York: Guilford Press.

Wallander, J. L., & Varni, J. W. (1992). Adjustment in children with chronic physical disorders: Programmatic research on a disability-coping-stress model. In A. M. La Greca, L. J. Siegel, J. L. Wallander, & C. E. Walker (Eds.), *Stress and coping in child health* (pp. 279-297). New York: Guilford Press.

Wallander, J. L., Varni, J. W., Babani, L., Banis, H. T., & Wilcox, K. T. (1988). Children with chronic physical disorders: Maternal reports of their psychological adjustment. *Journal of Pediatric Psychology, 13,* 197-212.

Wallander, J. L., Varni, J. W., Babani, L., DeHaan, C. B., Wilcox, K. T., & Banis, H. T. (1989). The social environment and the adaptation of mothers of physically handicapped children. *Journal of Pediatric Psychology, 14,* 371-387.

Wechsler, D. (1974). *Manual for the Wechsler Intelligence Scale for Children-Revised.* New York: Psychological Corporation.

Williamson, G. G. (1987). *Children with spina bifida: Early intervention and preschool programming.* Baltimore: Brookes.

Wills, K. E. (1993). Neuropsychological functioning in children with spina bifida and/or hydrocephalus. *Journal of Clinical Child Psychology, 22,* 247-265.

Wills, K. E., Holmbeck, G. N., Dillon, K., & McLone, D. G. (1990). Intelligence and achievement in children with myelomeningocele. *Journal of Pediatric Psychology, 15,* 161-176.

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The thesis is, therefore, accepted in partial fulfillment of the requirements for the degree of Masters of Arts.

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