The effects of peer social interaction and support on the self-esteem of young people with spina bifida.

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THE EFFECTS OF PEER SOCIAL INTERACTION AND SUPPORT ON THE
SELF-ESTEEM OF YOUNG PEOPLE WITH SPINA BIFIDA

by

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Memorial University of Newfoundland, 1993
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Submitted to the Faculty of Graduate Studies and Research through the Department of Psychology in Partial Fulfilment of the Requirement for the Degree of Master of Arts at the University of Windsor

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1997

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Abstract

The purpose of this study was to assess self-esteem and self-concept in a group of children with spina bifida (mean age 9) before and after involvement in a youth support program which employed and combined social support, and social skills instruction. Ten subjects, 4 in the treatment group, and 6 in the control group, responded to 3 standardized tests: (a) Coopersmith Self-Esteem Inventories (Coopersmith SEI; Coopersmith, 1981), (b) Piers-Harris Children’s Self-Concept Scale (Piers-Harris; Piers & Harris, 1984), and (c) Self-Perception Profile For Children (SPPC; Harter, 1985). The parents of all 10 children responded to the Vineland Adaptive Behavior Scales (Vineland; Sparrow, Balla, & Cicchetti, 1984). There were 2 groups of children, one that was involved in the youth support program (spina bifida organization A, N=2), and one that served as the control group (spina bifida organization B, N=6). The hypotheses were: (a) after 8-10 bi-weekly group meetings there would be an improvement in the children’s self-esteem with respect to various aspects of their self-concept, (b) the control group would be more stable than the treatment group for self-esteem and self-concept, and (c) due to improved self-esteem there would be an improvement on a number of adaptive behaviors. The independent variable in this study was the presence or absence of the youth support program, and the 4 standardized scales, their clusters, and domains served as dependent variables. Due to the attrition rates in the treatment group the focus of this study changed from the hypotheses stated
above to a number of empirical questions. These questions included: (a) were the measures utilized reliable for this sample, (b) were the children in this study similar to or disparate from non-disabled children on the measures, and (c) in a case by case investigation did the children in the treatment group improve their self-esteem as a result of the intervention. The Coopersmith SEI was the only reliable self-esteem measure for the children in this sample, although the Vineland was also reliable. The children in this sample did not differ in their self-esteem scores or in their adaptive behaviors from non-disabled children and it appears that the intervention had positive and negative effects. A number of recommendations for possible changes to the youth support program were generated, and the integration of other programs was suggested.
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## TABLE OF CONTENTS

**ABSTRACT**

**ACKNOWLEDGMENTS**

**LIST OF TABLES**

**CHAPTER**

1. **INTRODUCTION**
   - Definition and Types of Spina Bifida: 2
   - Definition of Self-Esteem and Self-Concept: 3
   - Definition of Social Support and Social Skills: 6
   - Comparison to Other Disabled/Non-Disabled Children: 10
   - Theories of Self: 13
   - Further Conceptualization of Social Support: 17
   - Suggestions for Intervention: 18
   - Summary and Hypotheses: 20

2. **METHOD**
   - Participants: 25
   - Materials: 26
     - Youth Support Program Summary: 26
       - Measures: 29
   - Design and Procedure: 34

3. **RESULTS**
   - Reliability: 42
   - Comparison with Normative Samples: 47
   - Observations of Treatment Group: 48

4. **DISCUSSION**
   - Reliability: 51
   - Comparison with Normative Samples: 54
   - Treatment Program Conclusions: 54
   - Recommendations: 58
   - Conclusions and Future Directions: 60

**REFERENCES**

**VITA AUCTORIS**
LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Standardized Pretest Scores Across Groups for the Coopersmith Self-Esteem</td>
<td>38</td>
</tr>
<tr>
<td></td>
<td>Inventory, Self-Perception Profile for Children, Piers-Harris Children’s</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Self-Concept Scale, and the Vineland Adaptive Behavior Scales (ABC)</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Standardized Posttest Scores Across Groups for the Coopersmith Self-Esteem</td>
<td>40</td>
</tr>
<tr>
<td></td>
<td>Inventory, Self-Perception Profile for Children, Piers-Harris Children’s</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Self-Concept Scale, and the Vineland Adaptive Behavior Scales (ABC)</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Importance Scores for the Control Group (Pretest and Posttest) on the Self-</td>
<td>44</td>
</tr>
<tr>
<td></td>
<td>Perception Profile for Children</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Importance Scores for the Treatment Group (Pretest and Posttest) on the Self-</td>
<td>45</td>
</tr>
<tr>
<td></td>
<td>Perception Profile for Children</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Mean Scores Across Groups on the Self-Perception Profile for Children and</td>
<td>46</td>
</tr>
<tr>
<td></td>
<td>the Coopersmith Self-Esteem Inventory at Pretest and Posttest</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Mean Scores Across Groups on the Piers-Harris Children’s Self-Concept Scale</td>
<td>49</td>
</tr>
<tr>
<td></td>
<td>and the Vineland Adaptive Behavior Scales (ABC) at Pretest and Posttest</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Normative and Pretest Sample Means and Standard Deviations for the Coopers-</td>
<td>50</td>
</tr>
<tr>
<td></td>
<td>smith Self Esteem Inventory and the Vineland Adaptive Behavior Scales (ABC)</td>
<td></td>
</tr>
</tbody>
</table>
CHAPTER I
INTRODUCTION

The objectives of this study were three fold. The first was to assess the self-esteem characteristics of a group of children with spina bifida or myelomeningocele. The second was to evaluate the effects on self-concept and self-esteem of a youth support program which utilizes and integrates social support and social skills instruction. The third was to measure the stability of the children’s self-esteem over a 16 week time period.

Research on self-esteem and spina bifida has incorporated self-esteem as a central aspect of the psychological functioning of children with spina bifida (e.g., King, Shultz, Steel, Gilpin & Cathers, 1993), but lacks consensus as to whether these children actually differ on their levels of self-esteem from non-disabled children. Some researchers report that children with spina bifida (myelomeningocele) have lower levels of self-esteem than non-disabled children (Appleton et al., 1994; Bolding & Llorens, 1991; King et al., 1993; Lord, Varzos, Behrman, Wicks & Wicks, 1990; Riffe, 1981), while others suggest that the self-esteem levels of children with spina bifida (myelomeningocele) are comparable to those of non-disabled children (Murch & Cohen, 1989; Wolman & Basco, 1994).

The children who participated in this study all had spina bifida. To better understand their need for social support and social skills training, and the domains of self-concept in which they feel competent versus those in which they do not feel
competent (i.e., self-esteem), it is necessary to first define spina bifida, its types, and its associated medical problems.

**Definition and Types of Spina Bifida**

Spina bifida is a congenital neural tube defect in the fetus that occurs in the first month of pregnancy (Till, 1975). The covering (meninges) surrounding the spinal cord are damaged, and may be pushed out through an opening (lesion) in the vertebrae. This opening can occur at any of the four divisions (cervical, thoracic, lumbar, and sacral) of the vertebra (Till, 1975).

There are five types of spina bifida: occulta, meningocele, myelomeningocele, encephalocele, and anencephaly. Three of these types have a normal life expectancy: occulta, meningocele and myelomeningocele. The other two types: encephalocele and anencephaly have very low life expectancy (Till, 1975). Occulta is characterized by incomplete joining of the outer part of the vertebrae with meninges undamaged (Till, 1975). Meningocele which can be translated into covering(meningo) and sac(cele) involves a splitting of the outer part of the vertebrae with meninges protruding outward into a fluid filled sac at the lesion site. Myelomeningocele is characterized by a splitting of the outer section of the vertebrae with spinal cord and meninges damaged and pushed out through an opening into a sac at the lesion site (Till, 1975). Children with myelomeningocele usually experience an associated hydrocephalus which involves improper drainage of the cerebrospinal fluid from the brain (Fletcher et al., 1995; Holmbeck & Faier-Routman, 1995)
Myelomeningocele is associated with a number of clinical complications such as pressure sores, bowel and/or bladder incontinence (Bauer, 1994; Leibold, 1993), Arnold Chiari malformation (cerebellum and portions of the brain stem are displaced into the cervical spine; Oakes, 1994), learning disabilities (Lollar, 1993a, 1993b), perceptual problems (Lollar, 1993b), problematic or absence of hip function, and ambulation without braces or a wheelchair (Lindseth, 1995), tethered cord (Venes, 1985), difficult sexual functioning (Sloan, 1993), and a multitude of social problems (Rousso, 1984). Encephalocele (brain is pushed out through a defect in the cranium) and anacephaly (absence of a brain) occur rarely and when they do occur the child does not live long (Till, 1975).

As a result of the numerous complications these children suffer, and the number of hospital stays that are a part of their lives, it is highly likely that on average, their self-esteem is lower than that of non-disabled children. Investigations show, for example that children and adolescents with physical disabilities have lower self-esteem than non-disabled children and adolescents (Appleton et al., 1994; King et al., 1993; Lord et al., 1990).

**Definition of Self-Esteem and Self-Concept**

Self-esteem is a complex concept and is often used interchangeably with self-concept, although the two are typically defined differently. According to Coopersmith (1967), self-esteem can be defined as:
the evaluation a person makes and customarily maintains with respect to him- or herself. Self-Esteem expresses an attitude of approval or disapproval, and indicates the extent to which a person believes him- or herself capable, significant, successful, and worthy. (p. 5)

This definition was later expanded by a number of researchers (Branden, 1969; Epstein, 1985; Pope, McHale, & Craighead, 1988). Pope et al. (1988), for example, qualified Coopersmith’s definition by stating that the evaluation made by the person is "of the information contained in the self-concept, and is derived from a child’s feelings about all the things he is" (p. 2).

Branden (1969) described self-esteem as being composed of interrelated aspects. Epstein (1985) defined self-esteem more specifically by pointing out that there are three hierarchically structured aspects that differentially effect each other and may be more or less visible in the individual at any one time. The levels referred to by Epstein (1985) include: (a) global self-esteem (the most powerful aspect of the self-esteem because once it is established it is always present), (b) the degree of self-esteem a person has in a number of domains of self-esteem (e.g. competence, physical appearance, likability, and moral approval) and (c) an active level of self-esteem which is situationally dependent and is most typically measured (Epstein, 1985).

The term "self-concept" is thus differentiated from the term "self-esteem" in that it typically refers to the cluster of different components or domains a person uses to describe himself
or herself (Epstein, 1985; Harter, 1983; Pope et al., 1988). Self-concept defines what and who a person is (Epstein, 1985; Harter, 1983; Pope et al., 1988). Thus, a child may see himself as a reader, a soccer player, a boy, a friend, and a little brother. It is these things that make up the child's self-concept. A child evaluates each component of his or her self-concept along a continuum that ranges from positive to negative. This type of continuum exists for each domain of the self-concept, thus creating a mirror image hierarchy of self-esteem. A child may see himself as an average reader, a good soccer player, a good boy, a good friend, and a bad little brother. The positive or negative value the child places on each component of the self-concept, and the amount of worth and competence the child feels as a result of their evaluation, is thus translated into the level of self-esteem he or she experiences (Epstein, 1985; Harter, 1983; Mruk, 1995; Pope et al., 1988; Rosenberg, 1965).

Research up to this point has not been conclusive with respect to the domains of self-esteem and self-concept and the manner in which they are ranked or hierarchically structured by a child. There is also no indication of how stable these hierarchies may be once they have been formed. The research is even more ambiguous in terms of children with spina bifida. One of the fundamental questions underlying this research is whether the self-concept and self-esteem hierarchies of disabled children are organized in the same fashion as they are in non-disabled children. A second question is if the self-esteem and self-
concept hierarchies are not organized in the same manner, then what is the most likely basis for this difference. For example, does it stem from their disability alone or are there some other intervening factors in the life of a disabled child that predisposes him or her to a different self-concept or self-esteem hierarchy? Although the differences may not all stem directly from the disability, it is likely that the disability indirectly effects the child's ability to carry out certain developmental tasks that in turn effect the child's self-concept and self-esteem development. One of these developmental tasks, and one that has been stressed by a number of researchers, is the development of social skills and the ability to elicit social support from others. Investigators have correlated self-esteem, self-concept and social support, and have suggested an attempt be made to determine if self-esteem can be improved by social support and social skills training (King et al., 1993; Lindstrom & Kholer, 1991)

Definition of Social Support and Social Skills

Social support can be defined as those functions carried out by significant others in a persons life, such as a close family member, best friend or other relative (Thoits, 1986). Based on the reviews of Cohen and Wills (1985) and Thoits (1986), social support has a number of sub-domains. These include (a) socioemotional support, (b) instrumental support, (c) informational support, and (d) social companionship. Socioemotional support involves providing acceptance, love,
sympathy, caring, esteem, and group belonging, all of which have been shown to improve the distressed person's self-esteem and feeling of worth (Cohen & Wills, 1985; Thoits, 1986). Instrumental support involves providing monetary aid, resources necessary for problem solving, assistance with treatment regimens, and reminders about self-care to the person (La Greca et al., 1995). Informational support involves providing advise and pertinent information (Thoits, 1986). Finally, social companionship involves taking the time to spend with an individual, thereby providing needed social contact with others that will optimally lead to stress reduction (Cohen & Wills, 1985). The types of support which will be the focus of this study are socioemotional support and social companionship. Both involve fulfilling needs to be loved, be cared for, be valued, and belong.

Social skills training involves reinforcement of appropriate interpersonal behavior (King et al., 1993), and providing an environment conducive to peer comparison and acceptance. This training has been suggested by a number of researchers for children with spina bifida so that they may improve their interpersonal skills and competency in social situations. This improvement, in turn, may improve the child’s level of self-esteem with respect to interpersonal skills, and thus give them the social competency that may aid them in dealing with a variety of social scenarios (Appleton et al., 1994; Bolding & Llorens, 1991; Grey, Myron, & Tamborlane, 1980; King et al., 1993;

As noted earlier, some empirical investigations have found that children with spina bifida have low self-esteem, although consistent support for this is not available. For example, some investigators have found little difference in the self-esteem levels of children with spina bifida, and children who have no disability (Murch & Cohen, 1989; Wolman & Basco, 1994). Much of the empirical evidence, however, has come from investigations primarily measuring global self-esteem, rather than particular domains of self-esteem. Such research misses the point that it is the domains (Harter, 1985), how they are ranked for importance by the child, and how that child ranks him- or herself as good or bad, on his or her valued domains, that define the level of self-esteem he or she exhibits.

Thus, we would expect that children with spina bifida would value particular aspects of their self-concept more than others, and as a result, would develop their level of self-esteem based on this evaluation, just as non-disabled children would. For example, a child may have self-concept domains that include his or her height, weight, colour of hair, academic and athletic ability. These may be ranked in a certain order of importance such as athletic ability first, colour of hair second and the others ordered as academic ability, weight, and height. In this simplified example, if the child feels he or she is competent on athletic ability and has a desirable hair colour then this would
translate into high self-esteem. On the other hand, if the child did not feel competent on athletic ability and did not have a desirable hair colour then he or she may have low self-esteem.

Low self-esteem in children with spina bifida generally evolves from a number of factors. They are likely to experience a lower activity level and quality of life (Lindstrom & Kholer, 1991) than their non-disabled peers. They are also more prone to feel socially isolated and depressed than their non-disabled peers which, in turn, is exacerbated by poor communication with parents, increasing awareness of their handicap, and lack of meaningful relationships (Minde, 1978). Children with spina bifida are also predisposed to a variety of emotional and behavioral problems that can have a ripple effect on their social skills, and lead to more prominent isolation from peers (Bryan & Herjanic, 1990). As a result, children with disabilities such as spina bifida may be less able to deal effectively with their everyday problems (Bryan & Herjanic, 1990; Minde, 1978).

Self-esteem models, such as Epstein’s Cognitive-Experiential View, would suggest, in this case, that a lack of competence in functioning and dealing with everyday problems, in addition to the problems associated with a disability, will lead to lowered self-esteem (Epstein, 1985). Thus, a social support group addressing these issues may be an important resource in helping children with spina bifida develop an overall feeling of competency.
Comparison with Other Disabled/Non-Disabled Children

Children with spina bifida have been compared to children with other disabilities (e.g. cystic fibrosis, cerebral palsy, diabetes) in a number of studies (Bolding & Llorens, 1991; Lindstrom & Kholer, 1991; Magill & Hurlbut, 1986) and in these circumstances children with spina bifida have been found to experience lower levels of self-esteem than children with other disabilities. Lindstrom and Kholer (1991) have found when youths with spina bifida were compared to those with cystic fibrosis, the spina bifida youths had significantly lower self-esteem and a lower activity level than either the cystic fibrosis youths or a normative sample. Overall, it was suggested that the spina bifida youths tended not to do well in the personal, psychological sphere of their lives, and had lower quality of life than either the normative sample or the Cystic Fibrosis youths (Lindstrom & Kholer, 1991).

Magill and Hurlbut (1986) examined the self-esteem of children with cerebral palsy with respect to aspects of the physical and social self. Although children with cerebral palsy did not differ from controls on global measures of self-esteem, they did score lower on measures of physical and social self-esteem, with females placing more emphasis on social interaction and attractiveness, both of which were negatively affected by their disability. The difference found on emphasis of attractiveness in girls did not become apparent until about age 8 (Magill & Hurlbut, 1986). These emphases were not found in boys.
Other empirical evidence that disabled or chronically ill children are more prone to lower self-esteem than non-disabled children has been provided by Grey et al. (1980) who used a number of standardized tests to show that children and adolescents with diabetes experienced lower self-esteem and psychosocial maladjustment when compared with children without diabetes. They suggest that lowered self-esteem on the part of these children stems from an interference with school and other activities, and a constant threat of complications due to their illness (Grey et al., 1980). The work of Grey et al. (1980) may possibly be generalized to children with spina bifida as both illnesses/disabilities involve some social isolation, and time missed in association with peers and other significant others (Riffey, 1981, La Greca et al., 1995).

Lord et al. (1990), compared the self-esteem of non-disabled adolescents and adolescents with spina bifida. Each subject was measured on a battery of academic, loneliness, self-esteem, and personality measures. These test scores were compared to a sample of non-disabled adolescents and it was found that adolescents with spina bifida experienced stronger feelings of loneliness and performed less favourably than controls on tests of academic and social skills, but did not experience lower self-esteem overall (Lord et al., 1990).

Studies by King et al. (1993) examined self-esteem and its importance in determining independence and persistence in interpersonal relationships by comparing the results of children
with spina bifida on a number of standardized tests to a normative sample. They found that children with spina bifida experienced significantly lower competence levels on athletics and romantic appeal, and scored lower on measures of social acceptance, independence, and persistence in relationships (King et al., 1993).

The most recent and, arguably, strongest evidence to date in favour of the assumption that children suffering from spina bifida experience low self-esteem, and a sense of loneliness due to social isolation comes from Appleton et al. (1994). They suggested that children with spina bifida will likely experience areas of difficulty in the domains of their self-concept that in turn will have deleterious effects on their self-esteem (Appleton, et al.,). They investigated the domains of self-concept that have surfaced as those most likely to cause difficulties, such as social acceptance, athletic competence, academic competence, and physical appearance. Using a number of standardized measures representing several self-concept domains and global self-esteem, they found clear evidence that children with spina bifida report lower levels of competence than able bodied children on academic, athletic and social domains. They also found that females with spina bifida were lower than males with spina bifida on all domains. On measures of global self-esteem there were no significant differences between children with spina bifida and non-disabled children (Appleton, et al.,).

Although a large number of studies have focused on the
difference in self-esteem levels of disabled and non-disabled children, few have investigated specific reasons for this difference. Bolding and Llorens (1991) investigated the effects of habilitative hospital stays on the self-esteem of children with spina bifida and juvenile arthritis and found that all of these children, although reaching their habilitative goals, experienced lower self-esteem after their release. Other studies have also shown that hospitalization alone can lead to a decrease in self-esteem in the child after his or her release (Wilkinson, 1978), and that hospitalization for a surgical reason also affects the child's self-esteem levels (Riffee, 1981). Children with spina bifida are often hospitalized and experience surgeries for shunt removal and replacement (Fletcher et al., 1995; Holmbeck & Faier-Routman, 1995). The loss of attention, leading to a feeling of abandonment (Bolding & Llorens, 1991; Riffee, 1981), is compounded in these children due to the vulnerability they feel as a result of their disability (Rousso, 1984).

Theories of Self

The majority of the literature discussed above describes what Pope et al. (1988) have referred to as the "perceived self." The "perceived self" is the self that takes an objective view of our own abilities, characteristics, and qualities. On the other hand, there is also a self that we would most like to be based on our personal and cultural ideals. This self, according to Pope, et al. (1988) is the "ideal self" and is an "image of the person one would like to be - not in a frivolous manner... but rather a
sincere desire to possess certain attributes" (p.2). When the perceived self (self-concept) and the ideal self have a small discrepancy between them, the result is positive self-esteem. Thus, a child who has high global self-esteem places value on the domains of his or her self-concept in which he or she is highly competent (Pope, et al., 1988). In contrast, a child who has negative self-esteem may have a perceived self and an ideal self that are highly discrepant.

There are a number of theories that aid the investigation of how the self-concept of children and adolescents with spina bifida may differ from children with no disability, if self-esteem is defined as the feeling of worth arising from discrepancies between the perceived self and the ideal self (Pope et al., 1988). The first of these theories is based on the work of Cooley (1902) and Mead (1934). Cooley’s theory of self is most often referred to as the "looking glass self" and explains that an individual’s self-concept is based on how other persons in their environment regard and see him or her (Cooley, 1902).

Mead (1934) took Cooley’s theory a step further by stating that self-awareness develops as people become more conscious of themselves in society. He felt that children gradually develop a sense of self as they begin to see themselves as others see them (Mead, 1934). Because others may use certain labels to describe the child that are not necessarily positive (Crocker & Major, 1989), these labels may gradually be integrated into the child’s self-concept (Mead, 1934). According to Mead (1934) these
negative interactions would serve to shape the child’s self-concept, and may influence the competence he or she assigns to his or her most salient domains (Lord et al., 1990; Pope et al., 1988). As a result, his or her perceived self will be highly discrepant from his or her ideal self and his or her resulting self-esteem will be low.

Another important theory that suggests differences in individual self-concepts stemming from how others perceive us is the self-fulfilling prophecy. This theory suggests that once a person realizes how he or she is perceived by others, then he or she will begin to behave accordingly (Merton, 1957). Therefore, if a child with spina bifida is continually seen by others as physically unattractive, slower in academics, and socially inept, then he or she will have integrated these negative aspects into his or her existing self-concept, and eventually will begin to interact with others in a fashion that is consistent with his or her self-concept (Merton, 1957; Pope et al., 1988). In turn, when the child is observed by others behaving in a negative fashion this will serve to promulgate the stereotype and lead to further negativity from the observer. This negativity again will fold back onto the child’s self-concept and in time lower the child’s self-esteem. Of course, if a child experiences negativity in certain domains of his or her self-concept, then he or she will feel less competent than other children in those domains. As was mentioned previously, the worth a person feels based on how that person values different aspects of his or her self-concept can be
assumed to affect the level of self-esteem he or she experiences (Epstein, 1985; Harter, 1993; Mruk, 1995; Pope et al., 1988; Rosenberg, 1965).

A child or adult that has spina bifida or any other type of long term disability (Mattsson, 1972) may possibly be a target for social stigma (Crocker & Major, 1989), may be at risk for psychological problems (Boyle, diSant’ Agnese, Sack, Millican, & Kulczycki, 1976), may have difficulty with establishing friendships due to long hospital stays (Bolding & Llorens, 1991), and may possibly suffer from a lack of social support from peers (Lord et al., 1990; Minde, 1978). Other problems may include impaired social skills (Lord, et al.,), and lower activity levels (Lindstrom & Kohler, 1991).

A number of studies have noted that negativity, especially in the form of insults towards appearance, speech or mental ability, can produce lower self-esteem in its target (Cohen & Wills, 1985; Crocker & Major, 1989; Thoits, 1986), and can cause a stressful response in the person which leaves them questioning the best method to deal effectively with this stress. Thoits (1986) has suggested that any type of close relationship with others can significantly lower an individual’s risk of psychological problems in response to this stress. The next logical step in this sequence would include the distressed person’s involvement in some type of relationship that provides him or her with much needed social support.
Further Conceptualization of Social Support

Although I have previously defined social support, Thoits (1986) further conceptualizes social support as an aid in coping with stress. She has shown that a number of types of support and coping have strikingly similar functions, and speculates that the type of support offered by a peer, can be and often is similar in type to the coping strategies an individual implements on his or her own (Thoits, 1986). She also suggests that social support can be reconceptualized as coping assistance (Thoits, 1986) and may be used to reduce stress and bolster the self-esteem of the individual in need of support. It is important to note that Cohen and Wills (1985) also consider social support as a coping resource, such that when a person feels stressed, helpless, and lonely, a low sense of self-esteem will stem from this perceived inability to cope. Social support or coping assistance (Thoits, 1986) from a friend may help improve the person's appraisal of his or her own coping ability, thus changing his or her perception of the event. Support can also provide an intervention between the stress experienced, and the outcomes, one of which may include reduced self-esteem. Thoits (1986) and Cohen and Wills (1985), therefore, agree that the support provided by a friend or significant other can meet the coping requirements of the distressed person so he or she may successfully stave off the stress he or she is experiencing.

Crocker and Major (1989) take the social support issue one step further by investigating whether social support coming from
a similar versus a dissimilar person has differential effects on the effectiveness of the support. They point out that persons in disadvantaged groups, disabled groups included, prefer to compare themselves with individuals in their own group (Crocker & Major, 1989). This is based on Leon Festinger's theory of social comparison (Festinger, 1954), which postulates that when a person finds him or herself to be in some way discrepant from his or her surroundings, he or she will strive to change the discrepancy by changing his or her environment, changing the opinions of others, changing his or her own opinions, or making a decision that certain others are not suitable as comparison persons. Disabled persons would most likely, then, compare themselves with other disabled persons because they encounter them often, are similar in appearance, and experience the same relevant life events. As a result, this type of comparison could be instrumental in protecting their self-concept and self-esteem.

Suggestions for Intervention

Bolding and Llorens (1991) suggest that maintenance of contact with school, and other friends can be helpful in dealing with the sense of isolation children with spina bifida experience when they are hospitalized. This point of view is shared by Riffey (1981), who stresses the importance of maintaining peer contacts before, during, and after the hospital stay. This contact could be an important variable in lessening the experience of lowered self-esteem as a result of having a chronic disability that requires frequent and lengthy hospital stays.
often in the company of infants and younger children (Riffee, 1981). An intervention program to counteract the negative effects on the child when in the hospital would likely include exposure to effective strategies for dealing with social and environmental problems, and education as to their physical limitations (Bolding & Llorens, 1991). If these important issues were better understood by the child it could lead to increased acceptance by peers (Bolding & Llorens, 1991) and higher self-esteem.

A better understanding of, and acceptance of the disability could also lead to an improved sense of independence and persistence in social relationships, positive school experiences, and an increased sense of self-esteem (Wolman & Basco, 1994). In addition, an opportunity for social relationships at school or in special settings can lead to an improvement in self image, and development of social skills important in improving peer interactions for the child with spina bifida (Wolman & Basco, 1994). Other research suggests that social support may serve to influence the child’s self-esteem, and other relevant outcomes by providing sources of coping assistance that put the child with spina bifida at a lesser risk for social isolation and loneliness (Kronenberger & Thompson, 1992).

A sense of loneliness usually increases as the child reaches adolescence (Bryan & Herjanic, 1990), and thus an intervention at an earlier age is highly recommended (Magill & Hurlbut, 1986) as it can improve the development of interpersonal skills, and lead to the development of friendships (Parker & Asher, 1993), which
children with spina bifida need (Hayden, Davenport, & Campbell, 1979). Intervention may also lead to an improved understanding of their disability and may lead to feelings of acceptance and worth (Magill & Hurlbut, 1986). Lord et al. (1990) point out that forming a special class or group in which the disabled child can interact and begin to feel comfortable may help the child decrease his or her loneliness and social isolation (Lord et al., 1990). This, in turn, may improve his or her sense of competence in social situations and lead to an improvement in the domains of self-concept with which he or she needs the most help (Lord et al., 1990). Contact with children similar to themselves can present optimal situations for social comparison (Festinger, 1954), thus improving the child’s self-esteem because he or she is now seeing himself or herself as the other disabled children see him or her (Cooley, 1902).

Summary and Hypotheses

The evidence just presented, and its theoretical bases, clearly indicates that there is a problem with particular domains of self-concept, self-esteem, and social skills of children and adolescents who were born with spina bifida. The majority of these investigators suggest some form of intervention integrating social skills training and social support. Such an intervention may serve to improve the domains of self-concept with which these children experience trouble and in turn improve their resulting levels of self-esteem, peer acceptance, and overall quality of life (Appleton et al., 1994; Bolding & Llorens, 1991; Grey et
al., 1980; King et al., 1993; Lindstrom & Kholer, 1991; Lord et al., 1990; Magill & Hurlbut, 1986; Riffee, 1981; Wolman & Basco, 1994). This intervention almost always involves some type of social group that will serve to provide social support for these children who, due to attendance difficulties, may be missing this opportunity at school, and other organized events. Appleton et al. (1994) suggest that this type of intervention and social skills training can be focused specifically on the young person with spina bifida, their views, interests, plans, and wishes. They also point out that peer acceptance and social comparison are key issues in developing a program that effectively deals with social skills improvement and, in turn, will fulfil the need to belong in these children (Appleton et al., 1994).

Currently, a number of interventions have been documented for use with children with spina bifida. These programs involved teaching self-help skills, providing personal objectives, and encouraging social development in children with spina bifida. Unfortunately, research as to their effectiveness seems to be lacking (Engelman, Loomis, & Klieback, 1994; Flynn, 1989; Lollar, 1994).

The intervention utilized in this study involved communicating to the children, by way of a facilitator, and their peers, that the highly ranked domains of their self-concept can be idiosyncratic, and that other aspects, possibly more in their reach, could be ranked as the top domains. It was assumed that, by spending time with children like themselves, and an accepting
and knowledgable facilitator, it may have been possible for these children to focus on, and place more value on their different abilities and the coinciding domains of their self-esteem. Thus, as rankings of domains alter, some may be more in reach, and may lead to an overall improved level of competence (self-esteem).

The assumption underlying the intervention used here was that children with spina bifida experience lower self-esteem than non-disabled children (King et al., 1993). As was previously stated, however, some evidence exists suggesting children with spina bifida are no different on measures of global self-esteem than non-disabled matched controls (Kronenberger & Thompson, 1992; Murch & Cohen, 1989; Wolman & Basco, 1994). The discrepancy in the literature as to the differences and/or similarities in the self-concept and self-esteem hierarchies of disabled, and non-disabled children is difficult to interpret particularly since there is little discussion as to the stability of self-esteem over a period of time.

In the current study, an opportunity was provided for these children to improve their social competence and peer interaction by participating in, as King et al. (1993) suggested, a group that provided "successful experiences with peers, reinforcement of appropriate interpersonal behaviour and encouraged realistic expectations" (p. 388). The youth support program conducted by the Spina bifida and Hydrocephalus Association of Ontario attempted to provide an environment in which children with spina bifida could comfortably voice their concerns, learn about
themselves and their disability, interact with children of a similar age, develop important interpersonal skills, build up a sense of confidence and competence in all their abilities, receive the respect they deserve, and the guidance of the other children. It was thought that this would provide the social support they needed to help them cope effectively with the everyday stressors of their disability.

Thus, the intentions of this study were to provide a comprehensive investigation of the self-esteem levels of children with spina bifida, and to determine if peer groups specialized to provide social support, coping assistance and social skills change the child's self-esteem and abilities related to a feeling of pride in ones self.

In the present study it was hypothesized that after 8 - 10 bi-weekly group meetings, in which the children choose and participate in group discussion with their peers there would be an improvement in their self-esteem as reflected by their total-self score and subscale scores on the Coopersmith Self-esteem Inventory. Second, there would be a change in their self-concept reflected by their total score, and cluster scores on the Piers-Harris Self Concept Scale. Third, Harter's Importance, Competence, and Total Discrepancy scores, which tap the child's self-perceptions, would improve. Fourth, there would be an overall stability in the scores of children in the control group on all measures but an overall instability in these scores for the children in the treatment group. Finally, as a result of
their improved self-esteem and changed self-concept, which have been suggested to improve their self-care responsibilities and overall independence (Bolding & Llorens, 1991; King et al., 1993), there would be an improvement in their standard score on the Adaptive Behavior Composite measured by the Vineland Adaptive Behavior Scales which was administered to parents.

A number of empirical questions were also investigated. The first was whether or not the self-esteem level of children with spina bifida in this sample was comparable to or discrepant from those of children with no disabilities. A second and final question focused on the stability of self-esteem and self-concept in children with spina bifida over a 16 week period.
Chapter II

METHOD

Participants

Ten preteens and their parents, four females and six males, with varying degrees of spina bifida participated in this study. Their mean age was 9 years with a range of ages from 8 to 12 years. Participants were placed into their respective groups based on their geographical location. All participants were recruited from the registration of the Spina bifida and Hydrocephalus Association of Ontario (SBHAO) and letters of invitation were mailed to each participant. Four of the preteens were drawn from those registered with SBHAO (organization A) with the other six from SBHAO (organization B). Those preteens from Organization A served as the experimental group with the criterion that they attend at least four of the eight sessions. Those from Organization B served as the control group. All of the preteen participants had spina bifida, and eight also had an associated hydrocephalus. Each preteen and either their mother or father, were interviewed. Participation in the study was completely voluntary, and consent forms were issued to the parent for the child’s participation, and for their own participation.

It should be noted here that although the experimental group began with four children the attrition rate for this group was high. The most common reasons for this attrition were health complications, and time constraints. As a result, the final experimental group consisted of two children, while the control
group remained the same with six children.

**Materials**

**Youth Support Program Summary.** The youth support program was held every second Friday evening, beginning at 7:00 p.m., and continued until 8:30 p.m.. The group began with the facilitator introducing herself to the children, and explaining some of the topics they may be talking about over the next few meetings. She encouraged some discussion among the children as to their days activities, and then began to lead into the topics she had chosen for the first week. The facilitator for the youth group evaluated in this study was a female adult who had experience in conducting similar groups with teens. Her acceptability for the position was approved by SBHAO, and the author observed her while she conducted a similar teen group on a number of different occasions.

Each session followed a similar type of procedure as that explained above, but the children were encouraged to begin topic discussion on their own. It should be stressed that although particular topics were chosen before the group began, the children decided what topics actually were discussed. Specifically, the group consisted of eight sessions which utilized the following exercises and topics. Session one was an introductory session in which the children got to know one another by playing a game in which they removed a number of tissues from a box, and then had to share one thing about themselves with the group for each tissue they had (Stapleford,
1996). Session one was also a time for the children to generate a list of topics for future sessions, and choose some ground rules. Some rules suggested by Stapleford (1996) involved attempting to listen to others when they speak, being prompt for the meeting, not disturbing the session with any type of disruptive behavior, and not attending the session while taking non-prescription drugs and/or alcohol. It was also suggested that the reasons for group attendance be discussed, and a question box be utilized (Stapleford, 1996). The question box aided the facilitator in dealing effectively with questions that the children may have had but were concerned about asking in a group setting.

Session Two and Three focused on what spina bifida is, and some of the complications of the disease. Specifically, it was suggested that the types of spina bifida, shunts, and the importance of personal care be explained (Stapleford, 1996). During this session the children were asked to draw their conceptualization of spina bifida. This drawing was then shared with the group and any comments were invited. In addition, a doll and video were utilized in order to help the children visualize the spinal lesion, the shunt system, and other complications of spina bifida (Stapleford, 1996).

Stapleford (1996) suggests that during sessions four and five the group members should be made aware of some of the less visible issues that coincide with spina bifida. These sessions focused on school difficulties, learning disabilities, and why the children may perform better on certain topics but not all
topics taught in their school. It was also suggested that the impossibility of particular academic topics, feelings that stem from difficulties with academics, and methods by which the children may deal and cope with these difficulties, be discussed (Stapleford, 1996). Finally, an attempt was made to discuss the practical aspects of learning disabilities, which are a common characteristic of children with spina bifida (Lollar, 1993a, 1993b), and to teach the children how to incorporate such a disability into their daily lives (Stapleford, 1996).

The sixth session provided instruction on relationship skills, coping with loneliness, social skills training, and what makes one friend more preferable than another friend. This session involved an exercise in which each group member was asked to give a compliment to one other person in the group, and then to give themselves a compliment (Stapleford, 1996). Reasons why the former task was easier than the latter task were then discussed, in addition to some more general questions dealing with friendship, starting conversations, desirable characteristics of a friend, and whether it is better to have many friends or a few close friends (Stapleford, 1996).

Session seven and eight were designed to pass on information with respect to sexuality, sexual functioning, emotions, feelings, boundaries, and belonging (Stapleford, 1996). An emotions exercise involving the use of colored pencils to list all of the emotions each child could think of was utilized during this session. The children were then asked to match each emotion
they had written with a color, and then to imagine or think of a situation in their lives when they felt a certain emotion (Stapleford, 1996). Each paper was then compared with the others, and an example situation was generated that matched each emotion (Stapleford, 1996). Finally, it was ensured that each child had dealt with any feelings that may have surfaced during the session, they were informed that the group would be ending, and party plans were made.

It must be stressed here that the topics for each week were decided the previous week in order to provide the children with some time to think about them. The children were active in leading their discussions and their choice of topic was not discouraged if it did not follow the pre-decided line of discussion. This group continue bi-weekly for 16 weeks (i.e., 8 meetings).

Measures

Self-esteem/self-concept/adaptive behavior measures. Four standardized tests were used to measure self-esteem, self-concept and a number of adaptive behaviors that may be related to the child’s level of self-esteem. These include: (a) Coopersmith Self-Esteem Inventories (Coopersmith, 1981), (b) Piers-Harris Children’s Self-Concept Scale (The Way I Feel About Myself (Piers, 1984), (c) Self-Perception Profile For Children (Harter, 1985), and (d) Vineland Adaptive Behavior Scales.

Coopersmith Self-Esteem Inventories (SEI). These are the most widely used of the self-esteem measures (Mitchell, 1985),
and include three questionnaires requiring self-reports. These are used to measure self-esteem or the person's evaluation of him- or herself. Thus, the questionnaires present favorable or unfavorable statements to which the respondent must indicate "like me" or "unlike me." The School Form, for children 8 to 15, was used in this study and consisted of 58 items broken down into four sub-scales (peers, parents, school and personal interest), and an integrated Lie scale used to assess defensiveness. The SEI was scored in such a way that the unfavorable items were correct if the child answers "unlike me" and the favorable items were correct if the child answers "like me." The scale was internally consistent with a KR-20 range from .87 to .92. Test-retest reliabilities range from .70 to .88. Construct validity seemed to be adequate.

**Piers-Harris Children's Self-Concept Scale (The Way I Feel About Myself).** This scale consisted of 80 declarative statements describing how a child feels about him- or herself to which the child responds either "yes" or "no" (Piers, 1984). This scale contained a total score and a score for 6 cluster scales (behavior, intellectual and school status, physical appearance and attributes, anxiety, popularity, happiness and satisfaction). A total raw score, range 0-80, and cluster raw scores were calculated with items being scored in the direction of positive self-concept. The higher the total raw score, the more positive the child's assessed self-concept would be. The total raw score was the total number of responses marked in a positive direction.
The cluster score was the sum of positively marked responses for that cluster. A high total score indicated a positive self-esteem, and cluster scores were used to identify weakness or strength in the self-concept domains of individual children. Internal consistency was adequate at a KR-20 ranging from .88 to .93. Test-retest reliability coefficients range from .42 to .93. Construct validity estimates were acceptable.

**Self-Perception Profile For Children (SPPC).** This scale was used to tap the perceptions children grades three to eight have of themselves by using a domain-specific approach in addition to a more global judgement approach (Harter, 1985). In addition, the SPPC had a method of scoring which resulted in a profile of the child's competency/adequacy and provided six subscale means with each subscale corresponding to one of the five domains and global self-worth. The importance of the domains to the child or how the child saw himself on the domains could be determined by using the subscale scores, and a separate measure of the child's importance judgements.

These importance judgements were used in conjunction with the Competency score from the SPPC to determine how important the importance/competence relationship was to the child's global self-worth. Harter (1985) provided a Discrepancy score for this reason. This score involved subtracting the Importance score from the Competency score for each test item in a particular domain. If the Total Discrepancy Score (discrepancy scores added for each domain) had a high negative value, then the child's importance
rating had exceeded his competency score. This type of result was associated with low self-worth. A low negative, zero, or positive score was associated with high self-worth.

This method of determining importance, competence and discrepancy separately aided in the investigation of how the domains were ranked for importance by the child, how competent the child felt on the domain and, how these related to the child's feeling of global self-worth. The importance and discrepancy scores were calculated for each child before and after his or her involvement in the youth group. How he or she ranked each domain, how competent he or she felt on that domain, and its effect on his or her global self-worth was determined at these two time periods.

There were 36 items that asked the child to decide which child described in two sentences was most like him or her. The child was then asked to further differentiate his or her likeness to this child by indicating whether the child he or she had chosen as most similar to him- or herself was really true for him or her or only sort of true for him or her. According to Harter (1985), this question format served to provide more accurate self-perceptions rather than more socially desirable ones. There were six subscales (a) Scholastic Competence, (b) Social Acceptance, (c) Athletic Competence, (d) Physical Appearance, (e) Behavioral Conduct, and (f) Global Self-Worth. Each of these subscales had six items with the first three items reflecting high competency and the last three reflecting low competency.
These items were scored from one (low perceived competence) to four (high perceived competence). An additional measure, was also used in conjunction with the Self Perception Profile. It was titled, How Important are These Things to How You Feel About Yourself as a Person. This measured the child’s judgement of the importance of each of the subscales in the Self Perception Profile and was used to determine a discrepancy score which reflected how competent a child feels on the domains or subscales he or she deemed important. Internal consistency reliabilities ranged from .75 to .86 and subscale reliabilities were consistent and acceptable with reliabilities around .85.

*Vineland Adaptive Behavior Scales (Vineland) Survey Form.* This form was used to "assess personal and social sufficiency of individuals" (Sparrow et al., 1984, p. 1) with spina bifida. The VABS required that a parent or caregiver familiar with the child’s behavior respond to a series of 297 items. These were used to assess adaptive behavior useful to determine strengths and weaknesses of the individual in question. Persons from birth to 18 years 11 months or low functioning adults may be assessed on five domains: Communication, Daily Living Skills, Socialization, Motor Skills, and Maladaptive Behavior.

Each domain was scored based on the normalized domain standard scores. The standard scores of these domains, excluding the Maladaptive Behavior domain, were summed to determine the Adaptive Behavior Composite (ABC) standard score. Internal consistency reliabilities for the ABC ranged from .89 to .98
(median .94). Test-retest reliability coefficients for the domains and the ABC ranged from .83 to .92. The Vineland also showed adequate construct validity.

**Design and Procedure**

The self-esteem and self-concept of these children was assessed using the SEI, Piers-Harris, and the SPPC, while the domains of self-concept were most adequately assessed using the SPPC. The self-esteem characteristics (measured by the Coopersmith SEI) under investigation included:

1. General Self
2. Social Self
3. Home and Parents
4. School and Academic

Also investigated were the domains of self-concept as measured by the SPPC and the Piers-Harris. These domains were:

1. Scholastic Competence (SPPC) or Intellectual and School Status (Piers-Harris)
2. Social Acceptance (SPPC) or Popularity (Piers-Harris)
3. Athletic Competence (SPPC)
4. Physical Appearance (SPPC) or Physical Appearance and Attributes (Piers-Harris)
5. Behavioral Conduct (SPPC) or Behavior (Piers-Harris)
6. Anxiety (Pier-Harris)
7. Happiness and Satisfaction (Piers-Harris)
8. Global Self-Worth (SPPC) or Total Self (Piers-Harris)

The independent variable was the presence (experimental
group), or absence (control group) of the intervention. The four standardized measurement scales, and their subscales, as described above, served as the dependent variables.

Letters were written to the parents in order to inform them of the study and to solicit their consent for their own and their child's involvement in the study. Once the parents had consented, they were given a choice of a number of appointment dates and times, and given the approximate length of time their participation required. The average participation time for parents was 2 hours for the pretest and posttest combined. Each child's participation time was 1.5 hours. For children in the experimental group, their participation was more extensive, that is, 1.5 hours every two weeks in addition to their pre- and posttest. All 10 children were administered the three self-esteem/self-concept scales over a period of two to three weeks. Their parents were administered the Vineland over the same time period. The pretest and posttest included the Vineland (administered by the author) and the SPPC, SEI, and Piers-Harris (administered by two qualified volunteers). Volunteers consisted of two graduate students, one of which tested the treatment group while the other tested the control group. The volunteer conducting treatment testing was a fourth year graduate student in a clinical psychology program, while the volunteer conducting control testing was a second year graduate student in the same clinical psychology program. Both students were instructed in how to administer the tests by the author. All test administration
took place either in the home of the participants or at the offices of spina bifida organization A. Children were offered the opportunity of rest periods between the administration of each test but even with rest periods the administration time was approximately 45 minutes.

Once tested, the children in Spina bifida organization A began to participate in a peer interaction and support group in which they discussed topics important to them and experienced positive interactions with their peers. The children in Spina bifida organization B continued with their normal lifestyles with no intervention for the 16 week period. Once the 16 weeks had passed the children in both spina bifida organizations and their parents were again administered the four standardized tests as a posttest. The second administration of these tests conformed to the time and method of administration of the pre-test. Children in spina bifida organization B were offered the opportunity to attend a similar youth support group in the following year.
CHAPTER III

RESULTS

The measures described in the previous section were utilized in the analyses used in this study. Due to high rates of attrition in the treatment group, however, it was difficult to investigate the effects of the youth support program on the two children that remained. A support group is best conceptualized as one in which persons sharing common characteristics meet together, form friendships and choose to identify with a person of their choice (Stainback, Stainback, East, & Sapon-Shevin, 1994). Only two children completed the youth support program which constituted a primary focus of this study. Therefore, opportunities to choose another child with which to identify were obviously limited. As a result, the two remaining children were not considered to constitute a group. Consequently, group comparisons were not made and the focus of the study changed.

The pretest and posttest data obtained in this study are presented in Tables 1 & 2. In the following material three sets of analyses are presented. First, reliability of the measures utilized was examined. Second, a comparison between the pretest data for the ten children in this sample and the normative data provided by the Coopersmith SEI and Vineland norms was conducted. Third, a comparison of the pretest and posttest scores of the two children completing the youth support program was conducted.
Table 1

Standardized Pretest Scores Across Groups for the Coopersmith Self-esteem Inventory, Self-Perception Profile for Children, Piers-Harris Children’s Self-Concept Scale, and the Vineland Adaptive Behavior Scales (ABC)

<table>
<thead>
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<th>Variables</th>
<th>Control</th>
<th>Treatment</th>
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<td>1  2  3  4  5  6</td>
<td>7  8  9  10</td>
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<tr>
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<tr>
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<tr>
<td>Soc. Self</td>
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<td>4</td>
</tr>
<tr>
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<td>3</td>
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<tr>
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<td>3.3</td>
</tr>
<tr>
<td>Soc. Acc.</td>
<td>1.8</td>
<td>2.8</td>
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Ath. Comp. 1.2 2.3 1.2 3.6 3.5 2.0 2.3 1.6 2.6 3.5
Phys. App. 2.0 2.5 2.2 1.6 3.3 2.0 2.3 2.5 4.0 2.8
Beh. Cond. 1.6 2.8 1.8 2.3 3.6 2.8 3.0 2.5 2.5 2.8
Global SW 3.2 2.6 1.0 2.5 3.5 2.6 3.3 2.8 3.0 2.3
Total Dis -1.2 -.2 -2.0 -1.7 -.7 -.7 -.9 -.5 -.4 -.7

<table>
<thead>
<tr>
<th>Piers-Harris Children's Self-Concept Scale (Percentile scores)</th>
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<td>Happ/Satis</td>
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<tr>
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</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Vineland Adaptive Behavior Scales</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABC</td>
</tr>
</tbody>
</table>

Note. Long form of the above abbreviated variable and cluster names can be found on page 32-36. Maximum scores for the Coopersmith are: total score=100, general self=26, social self=8, home/parents=8, and school/academic=8.
Table 2

**Standardized Posttest Scores Across Groups for the Coopersmith Self-esteem Inventory, Self-perception Profile for Children, Piers-Harris Children's Self-Concept Scale, and the Vineland Adaptive Behavior Scales (ABC)**

<table>
<thead>
<tr>
<th>Subject Numbers</th>
<th>Control</th>
<th>Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Variables</td>
<td>1 2 3 4 5 6</td>
<td>8 9</td>
</tr>
</tbody>
</table>

---

**Demographics**

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>SB</th>
<th>SBH</th>
<th>SBH</th>
<th>SB</th>
<th>SBH</th>
<th>SBH</th>
<th>SBH</th>
<th>SBH</th>
<th>SBH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lesion</td>
<td>S</td>
<td>L</td>
<td>L</td>
<td>S</td>
<td>L</td>
<td>L</td>
<td>L</td>
<td>L</td>
<td>L</td>
</tr>
<tr>
<td>Age</td>
<td>10</td>
<td>9</td>
<td>8</td>
<td>10</td>
<td>10</td>
<td>9</td>
<td>9</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>F</td>
<td>F</td>
<td>M</td>
<td>M</td>
<td>M</td>
<td>F</td>
<td>F</td>
<td>M</td>
<td></td>
</tr>
</tbody>
</table>

---

**Coopersmith SEI**

| Gen. Self | 17 9 6 6 23 19 | 9 22          |
| Soc. Self | 6 5 2 2 7 7    | 4 5           |
| Home/Parent | 7 6 2 6 8 7 | 3 8           |
| School/Ac.  | 8 3 1 2 8 6    | 4 5           |
| Total      | 76 46 22 32 92 78 | 40 80         |

---

**Self Perception Profile for Children**

<p>| Sch. Comp | 3.8 2.8 1.0 1.0 2.6 3.5 | 2.5 2.6 |
| Soc. Acc. | 3.2 3.2 1.5 1.0 2.3 2.6 | 2.5 2.6 |</p>
<table>
<thead>
<tr>
<th>Ath. Comp.</th>
<th>1.5</th>
<th>3.2</th>
<th>1.5</th>
<th>3.3</th>
<th>2.8</th>
<th>2.8</th>
<th>2.5</th>
<th>2.3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phys. App.</td>
<td>2.8</td>
<td>3.3</td>
<td>1.0</td>
<td>1.2</td>
<td>3.0</td>
<td>2.5</td>
<td>2.5</td>
<td>3.5</td>
</tr>
<tr>
<td>Beh. Cond.</td>
<td>2.5</td>
<td>3.2</td>
<td>2.0</td>
<td>1.2</td>
<td>3.3</td>
<td>3.2</td>
<td>2.5</td>
<td>3.3</td>
</tr>
<tr>
<td>Global SW</td>
<td>3.3</td>
<td>3.2</td>
<td>1.0</td>
<td>1.8</td>
<td>3.2</td>
<td>3.5</td>
<td>2.5</td>
<td>2.8</td>
</tr>
<tr>
<td>Total Dis</td>
<td>-.4</td>
<td>-.1</td>
<td>0</td>
<td>-2.2</td>
<td>-.7</td>
<td>-.5</td>
<td>0</td>
<td>-.7</td>
</tr>
</tbody>
</table>

**Piers-Harris Children's Self-Concept Scale (Percentile scores)**

<table>
<thead>
<tr>
<th>Behavior</th>
<th>65</th>
<th>18</th>
<th>25</th>
<th>5</th>
<th>81</th>
<th>65</th>
<th>13</th>
<th>65</th>
</tr>
</thead>
<tbody>
<tr>
<td>Int/Sch.</td>
<td>81</td>
<td>38</td>
<td>1</td>
<td>1</td>
<td>70</td>
<td>60</td>
<td>60</td>
<td>30</td>
</tr>
<tr>
<td>Phys. Att.</td>
<td>60</td>
<td>91</td>
<td>1</td>
<td>5</td>
<td>84</td>
<td>91</td>
<td>97</td>
<td>60</td>
</tr>
<tr>
<td>Anxiety</td>
<td>70</td>
<td>1</td>
<td>1</td>
<td>11</td>
<td>90</td>
<td>37</td>
<td>6</td>
<td>58</td>
</tr>
<tr>
<td>Popular.</td>
<td>27</td>
<td>9</td>
<td>2</td>
<td>13</td>
<td>86</td>
<td>86</td>
<td>13</td>
<td>38</td>
</tr>
<tr>
<td>Happ/Satis.</td>
<td>72</td>
<td>39</td>
<td>1</td>
<td>9</td>
<td>56</td>
<td>90</td>
<td>56</td>
<td>72</td>
</tr>
<tr>
<td>Total</td>
<td>71</td>
<td>27</td>
<td>2</td>
<td>3</td>
<td>94</td>
<td>74</td>
<td>33</td>
<td>55</td>
</tr>
</tbody>
</table>

**Vineland Adaptive Behavior Scales**

| ABC         | 85 | 70 | 73 | 88 | 106 | 75 | 113 | 95 |

**Note.** Long form of the above abbreviated clusters can be found on page 32-36. Maximum scores for the Coopersmith are: total score=100, general self=26, social self=8, home/parents=8, and school/academic=8.
Reliability

To assess the reliability of the measures used in this study, for this sample, the pretest and posttest scores of the 6 children in the control group who completed both test sessions were compared. Reliability was assessed in terms of the number of children who experienced a one standard deviation change (based on the normative standard deviation) in their score from pretest to posttest. A reliable subscale, domain, cluster or total score was one on which fewer than two children changed their score by one standard deviation. Thus, if two or more children changed by one standard deviation in these subscales, domains, clusters and total scores then the scale was deemed unreliable.

When the reliability of the children’s responses was reviewed over the 16-week period, only their responses on the self-esteem measure (Coopersmith SEI) were reliable from pretest to posttest. On the Coopersmith Self-Esteem Inventory (SEI), none of the children changed (beyond one standard deviation) on the total score and general self cluster. On the home/parent and school/academic subscales, only one child changed his/her score. In the social self subscale, however, three children’s scores changed by one standard deviation from pretest to posttest. Therefore, the social self subscale was the least reliable of the Coopersmith SEI scores for the children in this sample.

The Self Perception Profile for Children (SPPC) gave both importance scores and competency scores for each of the six children who participated in this study at posttest. Both types
of scores were investigated for their retest reliability. When evaluating importance scores it appeared that the domains that children with spina bifida place importance on, and thus may have allowed to influence their self-esteem level, were quite variable across time. None of the children viewed the same domains and same number of domains as important on both occasions (See Table 3 & Table 4). Thus, importance scores on the SPPC were not reliable for the children in this sample. Competency scores showed a similar pattern (See Tables 1, 2, & 5). Generally, scores on the SPPC for the children in this sample demonstrated little reliability over a period of 16 weeks. It is likely, however, that some of this variability stemmed from administration difficulties. For example, the children in this sample seemed to have great difficulty understanding the question format.

Responses to the Piers-Harris clusters were also quite variable over the 16-week period for the six children in the control group. For all of the Piers-Harris clusters there were score fluctuations greater than one standard deviation. These clusters include: behavior (three children), intellectual and school status (two children), physical appearance and attributes (two children), anxiety (two children), popularity (five children), happiness and satisfaction (four children), and the total score (three children). In contrast, the Vineland Adaptive Behavior Scale (Vineland) Adaptive Behavior Composite (ABC) seemed to be stable for the children in this sample (See Tables
Table 3
Importance Scores for the Control Group (Pretest and Posttest) on the Self-Perception Profile for Children

<table>
<thead>
<tr>
<th>Variable</th>
<th>Pretest</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th>Posttest</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Scholastic Competence</td>
<td>-</td>
<td>3.5</td>
<td>4.0</td>
<td>3.5</td>
<td>4.0</td>
<td>3.5</td>
<td>3.0</td>
<td>-</td>
<td>4.0</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Social Acceptance</td>
<td>4.0</td>
<td>-</td>
<td>3.0</td>
<td>-</td>
<td>-</td>
<td>3.5</td>
<td>-</td>
<td>-</td>
<td>4.0</td>
<td>-</td>
<td>3.5</td>
</tr>
<tr>
<td>Athletic Competence</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>4.0</td>
<td>-</td>
<td>3.5</td>
<td>4.0</td>
<td>-</td>
<td>3.0</td>
</tr>
<tr>
<td>Physical Appearance</td>
<td>3.5</td>
<td>3.0</td>
<td>-</td>
<td>-</td>
<td>4.0</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Behavioral Conduct</td>
<td>-</td>
<td>4.0</td>
<td>4.0</td>
<td>-</td>
<td>3.5</td>
<td>3.5</td>
<td>3.0</td>
<td>-</td>
<td>-</td>
<td>4.0</td>
<td>-</td>
</tr>
</tbody>
</table>

*Note.* Each dash (-) signifies a domain that was deemed unimportant by the child.
Table 4

**Importance Scores for the Treatment Group (Pretest and Posttest) on the Self-Perception Profile for Children**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Pretest</th>
<th>Posttest</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>7  8  9 10</td>
<td>8  9</td>
</tr>
<tr>
<td><strong>Treatment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Scholastic Competence</td>
<td>4.0</td>
<td>- 3.0</td>
</tr>
<tr>
<td>Social Acceptance</td>
<td>4.0</td>
<td>- 4.0</td>
</tr>
<tr>
<td>Athletic Competence</td>
<td>- 3.0</td>
<td>- 4.0</td>
</tr>
<tr>
<td>Physical Appearance</td>
<td>3.0 3.0</td>
<td>- 3.5</td>
</tr>
<tr>
<td>Behavioral Conduct</td>
<td>4.0 3.0</td>
<td>- 4.0</td>
</tr>
</tbody>
</table>

**Note.** Each dash (−) signifies a domain that was deemed unimportant by the child.
Table 5

Mean Scores Across Groups on the Self Perception Profile for Children and the Coopersmith SEI at Pretest and Posttest

<table>
<thead>
<tr>
<th>Variable</th>
<th>Normative Data</th>
<th>Control</th>
<th>Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Pre</td>
</tr>
<tr>
<td>Coopersmith SEI</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gen. Self</td>
<td>15.2</td>
<td>3.8</td>
<td>13(1.5)</td>
</tr>
<tr>
<td>Soc. Self</td>
<td>5.2</td>
<td>1.6</td>
<td>4(1.4)</td>
</tr>
<tr>
<td>Home/Par.</td>
<td>4.8</td>
<td>2.0</td>
<td>5(1.7)</td>
</tr>
<tr>
<td>Sch/Aced.</td>
<td>5.2</td>
<td>1.7</td>
<td>4(1.3)</td>
</tr>
<tr>
<td>Total</td>
<td>60.2</td>
<td>13.8</td>
<td>56(7.3)</td>
</tr>
</tbody>
</table>

Self-Perception Profile for Children

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
<th>Pre</th>
<th>Post</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sch. Comp.</td>
<td>2.7</td>
<td>.71</td>
<td>2.6(.83)</td>
<td>2.4(.83)</td>
</tr>
<tr>
<td>Soc. Acc.</td>
<td>2.9</td>
<td>.84</td>
<td>2.3(.95)</td>
<td>2.3(.95)</td>
</tr>
<tr>
<td>Ath. Comp.</td>
<td>3.0</td>
<td>.72</td>
<td>2.3(.62)</td>
<td>2.5(.62)</td>
</tr>
<tr>
<td>Phys. App.</td>
<td>3.0</td>
<td>.78</td>
<td>2.3(.80)</td>
<td>2.3(.80)</td>
</tr>
<tr>
<td>Beh. Cond.</td>
<td>2.9</td>
<td>.56</td>
<td>2.5(.69)</td>
<td>2.5(.69)</td>
</tr>
<tr>
<td>GlobalSW</td>
<td>3.0</td>
<td>.77</td>
<td>2.6(.58)</td>
<td>2.6(.58)</td>
</tr>
<tr>
<td>Total</td>
<td>-1.1</td>
<td>-.6</td>
<td>-.6</td>
<td>-.3</td>
</tr>
</tbody>
</table>

Note. Numbers in parentheses are the standard deviations.
In summary, of the three measures used to identify self-esteem and self-concept only the Coopersmith SEI proved to be reliable using the criteria stated above. The Vineland ABC was also reliable for this sample. As a result, the SPPC and Piers-Harris were excluded from all other investigations conducted.

Comparison with Normative Samples

A t-test was utilized to compare the responses of the 10 children in this sample at the outset of the study to the normative data of non-disabled children provided by the Coopersmith SEI. No significant differences were found on the social self ($t = .46, p > .05$), general self ($t = .15, p > .05$), home/parents ($t = .05, p > .05$), school/academic ($t = .06, p > .05$), and total score ($t = .03, p > .05$). It appears that the children in this sample are not particularly different in levels of self-esteem as measured by the Coopersmith SEI relative to profiles of non-disabled children (see Table 7).

A t-test was also used to compare the responses of the 10 children in this sample on the Vineland ABC to the normative data of non-disabled children provided by this measure. No significant differences were found between the responses of children in this sample and those of the normative sample ($t = 1.3, p > .05$). As a consequence, the children in this sample appear to be functioning adaptively in the daily living, communication, and socialization skills represented by the ABC (see Table 7).
Observations of Treatment Program

While it is quite clear that there are not enough data in this study to make any generalizations as to the effectiveness of the youth support program for the two children who participated, there is an opportunity to view these data in a case by case fashion. Comparisons were made between the pre- and posttest data of both children who participated in the youth support program. Again, a criteria was utilized to determine improvements and decrements for each of the children, thus, if the score of the child changed by one standard deviation (either increase or decrease) then an improvement or decrement was recorded.

For the Coopersmith SEI, one child in the treatment group dropped further below the norm by one standard deviation on the total self-esteem score while the other child improved his/her score. Both children experienced decreases in their scores on the social self, home/parents, and school/academic subscales of the Coopersmith SEI. Therefore, it appears that neither of the children who participated in the youth support program made any major positive gains in their self-esteem and may have actually experienced a decline.
Table 6

Mean Scores Across Groups on the Piers-Harris Children’s Self-Concept Scale and the Vineland Adaptive Behavior Scales (ABC) at Pretest and Posttest

<table>
<thead>
<tr>
<th>Variable</th>
<th>Normative Data</th>
<th>Control</th>
<th>Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Pre</td>
</tr>
<tr>
<td><strong>Vineland Adaptive Behavior Scales</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ABC</td>
<td>101</td>
<td>15.6</td>
<td>76(9.1)</td>
</tr>
<tr>
<td><strong>Pier-Harris Children’s Self-Concept Scale</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavior</td>
<td>11.4</td>
<td>3.2</td>
<td>11.2(2.2)</td>
</tr>
<tr>
<td>Int/Sch</td>
<td>11.6</td>
<td>3.6</td>
<td>11.3(2.7)</td>
</tr>
<tr>
<td>Phys. Att.</td>
<td>8.3</td>
<td>3.0</td>
<td>8.3(4.3)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>9.5</td>
<td>3.1</td>
<td>7.8(2.1)</td>
</tr>
<tr>
<td>Popular.</td>
<td>8.2</td>
<td>2.7</td>
<td>6.5(3.1)</td>
</tr>
<tr>
<td>Happiness</td>
<td>8.0</td>
<td>2.0</td>
<td>7.3(3.7)</td>
</tr>
<tr>
<td>Total</td>
<td>51.8</td>
<td>11.9</td>
<td>51.5(15.6)</td>
</tr>
</tbody>
</table>

*Note. The numbers in parentheses are the standard deviations.*
Table 7

Normative and Pretest Sample Means and Standard Deviations for the Coopersmith Self-Esteem Inventory and the Vineland Adaptive Behavior Scales (ABC)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Normative Data</th>
<th>Pretest Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Coopersmith SEI</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gen. Self</td>
<td>15.2</td>
<td>3.8</td>
</tr>
<tr>
<td>Soc. Self</td>
<td>5.2</td>
<td>1.6</td>
</tr>
<tr>
<td>Home/Par.</td>
<td>4.8</td>
<td>2.0</td>
</tr>
<tr>
<td>Sch/Aced.</td>
<td>5.2</td>
<td>1.7</td>
</tr>
<tr>
<td>Total</td>
<td>60.2</td>
<td>13.8</td>
</tr>
</tbody>
</table>

Vineland Adaptive Behavior Scales

<table>
<thead>
<tr>
<th>ABC</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>101</td>
<td>15.6</td>
</tr>
<tr>
<td></td>
<td>80.5</td>
<td>12.3</td>
</tr>
</tbody>
</table>
CHAPTER IV
DISCUSSION

Due to the high attrition rate in the treatment group of this study, none of the hypotheses were testable. The focus of the study was thus changed in order to answer three questions. First, were the self-esteem and self-concept measures utilized reliable for this sample of children with spina bifida? Second, were the self-esteem scores of this sample similar to or discrepant from those of the normative sample? Third, were there any changes in the self-esteem of the treatment group after the intervention when investigated in a case by case fashion?

Although the definitions of self-esteem and self-concept are often used interchangeably, their behavioral referents are quite different. Self-concept refers to the various ways in which a person views himself or herself. Thus, he or she may utilize a number of different components in his or her "self" definition (Epstein, 1985; Harter, 1993; Pope et al., 1988). Self-esteem, on the other hand, is an expression of the value, and the degree of approval or disapproval an individual feels towards each interrelated aspect of his or her self-concept (Branden, 1969; Coopersmith, 1967; Pope et al., 1988). Since self-esteem is an evaluation of the components of self-concept, it has been referred to as a mirror image of the self-concept (Epstein, 1985; Harter, 1993; Mruk, 1995; Pope et al., 1988; Rosenberg 1965).

Reliability

All of the self-esteem and self-concept measures utilized in
this study had acceptable levels of reliability according to the psychometric properties reported in their test manuals. In this study, however, the only reliable self-esteem/self-concept measure was the Coopersmith SEI. This reliability of scores was somewhat surprising when heterogeneity of function in this sample was considered. Although these 10 children all had spina bifida, their lesion levels, degree of ambulation and paralysis, respiratory functioning, bowel and bladder control, and degree of understanding of instructions were all different. When these differences are taken into account, the reliability of the Coopersmith SEI gathers even more support, thus, this measure will likely be reliable with other groups of children with spina bifida in other research and therapeutic settings.

The SPPC and the Piers-Harris were excluded from the second and third phases of the analyses due to their variability when used with this sample. The difficulty with the SPPC may have been due to its question format. Each question required the children to first understand two discrepant statements from which they had to choose one that was most similar to themselves. Then they had to decide whether the statement they had chosen was really similar or only sort of similar to themselves. Therefore, the children may not have responded as accurately to the SPPC due to difficulties in fully comprehending the question being asked. These difficulties may have stemmed from learning disabilities and perceptual problems on the part of the children given their relatively common occurrence in children with spina bifida.
(Lollar, 1993a, 1993b). Consequently, the lack of reliability of the SPPC was not surprising. The Piers-Harris has a yes-no style but was still unreliable for this sample. Because it was the last of three assessments administered to these children, participant fatigue and boredom may have been reasons for its low level of reliability.

Based on these observations, use of the SPPC is not highly recommended with children who have learning or perceptual difficulties coupled with spina bifida or other physical disabilities. Future researchers may opt for a measure that is less linguistically complex and requires only a single response from the child (e.g., the Coopersmith yes-no format). Use of the Piers-Harris for children with spina bifida is also questionable, but the reliability of this measure should be investigated again with a second sample. In addition, therapists and counsellors of children with spina bifida who may want to utilize either of these measures should consider other data about the child’s self-esteem and self-concept rather than developing a treatment based on these measures alone.

The Vineland was a reliable measure of adaptive behaviors for the children in this sample. Again, when the degree of heterogeneity of function in this sample is taken into account, the reliability of the Vineland accumulates additional support. Thus, the Vineland would probably be a reliable measure with other groups of children with spina bifida in a variety of research and therapeutic settings.
Comparison with Normative Samples

It has been suggested by some researchers that children with spina bifida and other disabilities have lower self-esteem than non-disabled children (Appleton et al., 1994; Bolding & Llorens, 1991; King et al., 1993; Lord et al., 1990; Riffe, 1981). Other researchers cite evidence to suggest that self-esteem levels are similar to those of non-disabled children (Murch & Cohen, 1989; Wolman & Basco, 1994). This study supported the latter conclusion.

Utilizing the normative data provided for the Coopersmith SEI, it appeared that the children in this sample had self-esteem levels that were within the normative range, and thus, comparable to non-disabled children (i.e., within one standard deviation of the mean). In addition, the children in this sample were also similar to non-disabled children with respect to adaptive behaviors. Because this sample’s responses were comparable to the norm, these children could probably function just as effectively in a self-esteem program for both disabled and non-disabled children. It should be noted here that the responses of the children in this sample were highly variable and although statistical analysis supports the previous conclusions, the variability of the children’s self-esteem and adaptive abilities should be investigated in the future.

Treatment Program Conclusions

In order to better define the components of self-concept for children with spina bifida and improve their self-esteem, a
number of investigators have suggested that social skills training, and social support may be of value (Appleton et al., 1994; Bolding & Llorens, 1991; Grey et al., 1980; King et al., 1993; Lindstrom & Kohler, 1991; Lord et al., 1990; Magill & Hurlbut, 1986; Riffie, 1981; Wolman & Basco, 1994). The current study provided such an opportunity for a sample of these children.

However, when the pretest and posttest self-esteem scores of the two children in the treatment group were investigated on an individual basis, these children did not appear to benefit from the social skills training and social support provided by the "youth support program." Of some concern was the observation that both children in the treatment group decreased their scores (i.e., by more than one standard deviation) in the social self, home/parents, and school/academic domains of the Coopersmith SEI. Similar decreases in the control group were not observed. One of the two children did, however, show an increase of more than one standard deviation in his/her overall self-esteem at posttest.

There are a number of possible reasons for the mixed results in the changes in the Coopersmith SEI score of the two children who participated in the youth support program. Given the very small sample, however, it must be stressed that these are very tentative and intended only to form the basis for future research in this area.

Changes in the Coopersmith SEI scores of the two children who completed the youth support program may have been due to a
gender bias. The gender of the facilitator of the youth support program (an adult female) may have had a different influence on the female and male child who participated.

Although peer interactions are important, it may also be important to focus on social relationships as a whole, taking into account the emotional support that is provided by peers (with and without spina bifida) and family (Wolman & Basco, 1994). The suggestion here is that a group such as this should also focus on the families and friends of children with spina bifida and what the child brings to any relationship he or she may have, not just the relationships he or she has with other disabled children. Therefore, self-esteem training should perhaps begin with disabled and non-disabled peers as well as family members in order to support the disabled child’s positive interactions with other individuals.

It is important to realize that there are many aspects to the child’s "self," and that the physical disability is only one of those aspects (Arnold & Chapman, 1992). That is, a focus on the child’s every day friendships, relationships with family, and what these experiences do for those involved, should probably be emphasized when considering the self-esteem of children with spina bifida. The children in this study may already have rich relationships in their lives, and may have established a sense of autonomy that has improved their ability to create positive experiences for themselves. If this is so, then these relationships and experiences should be explored. If not, then
such relationships, abilities, and experiences should be developed.

In addition, the parents of these children may have already realized that "body-image" should be placed in its proper perspective, as an element of the individual’s self-cognition and perception rather than an exclusive entity in itself" (Yuker, 1965, p.18). Having noted the above, one possibility that needs consideration is that the sample of children who participated in the youth support program had acceptable levels of self-esteem initially and may not have warranted intervention.

Some families declined the invitation to participate in the youth group, but typically not because they felt their children’s self-esteem level was acceptable. The most common reason involved time constraints. Parents had the demands of work, home, caring for their children, and providing extra care for their child with spina bifida in the form of administering treatments, aiding with personal care needs, providing respiratory care, physical therapy, and many other activities. An article titled "I’m an RN, respiratory therapist, and surgeon" stressed the extent to which the parents become the primary health providers for their child with spina bifida. The heading "home becomes hospital" reinforces the reality of just how much the entire life of the family revolves around the child’s health care needs (Dorean, 1989). With these types of demands on families, compounded with the stress and difficulties that the child has to face throughout his or her life, the thought of adding one more
appointment on top of it all may have seemed unbearable.

**Recommendations**

Some recommendations that may improve the youth support program include, two (two hour) sessions that are focused on one simplified topic that the children can recall over a period of time. This should enable them to better understand, remember, and draw on what they have learned during each session. With the responsibilities and activities that coincide with having spina bifida it is quite possible that the children are not remembering what they have learned in previous groups, and thus are unable to utilize their new skills in their daily lives. Perhaps social skills workbooks, handouts, and other activities the children could complete at home would be beneficial in the future.

A second recommendation for the program involves making directions and goals linguistically simple and more explicit. Children with spina bifida often have learning disabilities, perceptual difficulties, and difficulties with discourse (Lollar, 1993a, 1993b). The former is characterized by much better performance with concrete than abstract language (Culatta & Young, 1992). The current goals and expectations of the program seem to be difficult to understand because they are so linguistically abstract. They may also be somewhat unrealistic and overly ambitious to carry through due to their psychosocial complexity.

A third recommendation is to focus less on the issues of sexuality, and medical terminology in the final two sessions of
the program. It is highly probable that children with spina bifida are inundated with medical information from nurses, doctors, parents, and various therapists. In addition, many schools now integrate instruction on strangers, sexual abuse, and boundaries in their curriculum. If these issues must be addressed with respect to their practical applications to children with spina bifida (e.g., boundary issues), then a separate group should be conducted to deal specifically with these issues. If the youth support program is a social skills and support program then each session should cover a major aspect of socialization and supportive behavior.

A fourth recommendation is concerned with instructions within the manual for the facilitator. There appears to be very little direction for the facilitator on exactly how to meet many of the goals outlined. Some valuable activities are provided for the children, but exactly how these activities are to be explained to the children, and how the activities are expected to produce the ultimate goal, should be included in the program manual for use by the facilitator. An example of such a goal, and its lack of clarity can be observed in one of the session introductions. This "Introduction" mentions that children should be made aware of why they may be having difficulty at school, and should be taught selection strategies with respect to what they need to achieve academic success (Stapleford, 1996). This sounds appropriate, but there is no further direction for the facilitator on how to do this. Furthermore, this goal seems
almost impossible to reach within the time allotted, as it would require teaching a child skills that will enable him or her to pinpoint difficulties, and then choose the appropriate strategies to overcome them. Perhaps, the goals for each session should be more modest so the children can actually reach them throughout the session or throughout the following week. Overall, the youth support program could be re-worked stressing goals and topics that will benefit, as soon as possible, the socialization, support, and coping skills of the children who chose to participate.

Conclusions and Future Directions

Due to the small sample size it is difficult to make definitive conclusions. One child in this study did not appear to have benefited from his/her participation in the youth support program while the other child does appear to have benefitted when total self-esteem score on the Coopersmith SEI is taken into account. Because both children did not benefit from the youth support program, it is possible that other programs that stress social skills, communication, supportive behaviors, and competence issues could be beneficial in the future. Some valuable ideas and suggestions are provided by Lollar (1994) on the development of social skills in young people with spina bifida. A number of sessions from the program developed by Engelman, Loomis, and Klieback (1994) also focus on social skills, self-esteem, friendships, and other relationships that children with spina bifida experience. An integration of the
current program, and these programs would perhaps be the best combination to reach the ultimate goal of supporting children with spina bifida in feeling good about themselves, creating the best life experiences, and living the best life they can.
References


Bryan, D. P., & Herjanic, B. (1990). Depression and suicide among adolescents and young adults with selective handicapping conditions. EEO/Adolescents and Young Adults, 12, 57-65.


Klieback, LK: Authors.


Occupational Therapy, 47(2), 132-140.


Mead, G. H. (1934). Mind, self and society. Chicago:
University of Chicago Press.


guide to successful groups for children and youth with physical disabilities. Unpublished manuscript.


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