

A HOSPITAL-BASED CAMP FOR PROMOTING
INDEPENDENCE IN ADOLESCENTS WITH SPINA BIFIDA

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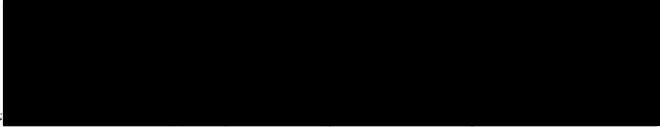
Susan Cooper Labhard, B.S.N., R.N.

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APPROVED:




Shirley Hanson, R.N., PhD., Professor, Research Advisor, School of Nursing,
The Oregon Health Sciences University



Marsha Heims, R.N., Ed.D., Associate Professor, Committee Member, School of
Nursing, The Oregon Health Sciences University



Deborah Becker, R.N., M.S., Director of Patient Care Services, Committee Member,
Shriners Hospital for Crippled Children, Portland, Oregon



Sheila Kodadek, R.N., PhD., Associate Professor, Department Chairperson, School
of Nursing, The Oregon Health Sciences University

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The foresight of the administrator, medical staff and Shriners, allowed the first hospital-based camp at Shriners Hospital, Portland Unit to exist. By advocating clinical nursing research, Camp SPIRIT was created. The eight adolescents in the control group permitted me to contact them by telephone several times and their honesty is appreciated. The eight adolescents in the experimental group taught me more about physically challenged adolescents than I ever could find in the literature. Through their cooperation and trust, the experimental group allowed me to understand the impact of being an adolescent with myelomeningocele. Our final "moonlight roll" will always be special to me. This group made Camp SPIRIT a success!

In memory of Nola, a little girl with myelomeningocele that will never be able to attend a camp, your outlook on life was inspirational and your spirit lives on. I dedicate the concept of Camp SPIRIT to you.

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ABSTRACT

TITLE: A Hospital-based Camp for Promoting Independence in
Adolescents with Spina Bifida

AUTHOR: Susan Cooper Lebbord

APPROVED: _____
Shirley Hanson, R.N., PhD., Advisor

This study explored the benefits of a hospital-based camp for promoting independence in adolescents with spina-bifida. The purposes of this treatment were: 1) to increase knowledge of socialization, and future goals; 2) to improve self-esteem; and 3) improve independence in activities of daily living (ADL's) of adolescents with spina bifida.

A quasiexperimental, equivalent control-group, interrupted time series design was used. The sample consisted of 16 subjects with spina bifida, eight experimental and eight control group subjects, who were between 13 and 19 years of age. The experimental subjects volunteered to spend one week at Shriners Hospital in the treatment program and the controls were contacted by telephone. Three instruments: 1) Socialization and Goals Questionnaire (SGQ); 2) Piers-Harris Children's Self-Concept Scale (PHCSCS); and 3) Functional Independence Measure (FIM), were given over three interrupted time intervals and analyzed by analysis of variance of pre-camp, post-camp, and follow-up. The p value was significant at the .05 level. The research hypothesis was supported in that socialization and goals can be significantly improved for individuals and group by a hospital-based camp, as shown by the SGQ. Self-Concept was difficult to measure as it changes over time and there

are many variables involved in self-esteem. Total self-esteem scores for individuals and group can improve, seen in the one month follow-up in areas of: intellectual/school status, anxiety, popularity, and happiness/satisfaction. The FIM was an accurate measure of ADL's. The experimental group had relatively high independence function for their disability, so did not dramatically improve in ADL's as a group. Individually, clinical improvement in three subjects was shown.

Nurses are in a unique position to improve socialization and goals, self-esteem, and independence in adolescents with spina bifida. A variety of instruments should be utilized to record results of interventions over time, as all benefits may not be evident immediately following the treatment. Factors limiting generalizability of results include the small sample size, wide age range, diagnosis, time frame, and instruments used. The clinical significance of the findings are apparent in the need to assess all adolescent's knowledge of socialization, independence in ADL's, and setting mutual goals for the future. This study signified the need for more research on camps for promoting independence in children/adolescents with disabilities.

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Chapter I

Introduction

Spina bifida (myelomeningocele) refers to a congenital neural tube defect (NTD) involving the spinal cord which may result in neurological deficits affecting extremities and bowel/bladder functions. Spina bifida remains a prevalent birth defect. However, in the past decade encouraging new statistics have emerged. Nationally, the incidence of NTD's (most commonly spina bifida and anencephaly), has declined "to 0.6 per 1000 births in 1989" (Yen et al., 1992, p. 857). There are reported decreases in the rates of children born with spina bifida and corresponding increases in the numbers of adults now living with spina bifida. Rauen and Aubert (1992) reported that most children born with myelomeningocele, can be expected to become adults. Individuals with spina bifida commonly have loss of sensation and "muscle weakness/paralysis below the spinal defect" (Knowlton, Peterson, & Putbrese, 1985, p. 259). Socialization and recreation which were frequently altered in childhood, can manifest themselves as deficits in peer relationships and social activities in the adolescent years. These problems frequently affect the care that nurses give adolescents with spina bifida and their families. Even though social, educational, and recreational aspects of living are not always direct concerns of the nurse, disturbances in these areas are so significant to the patients' medical conditions that the nurse inevitably must deal with them. The few hospital-based camps for medical, social and recreational concerns demonstrate the need for further development in this area. An extraordinary (not typical) nursing intervention would

be the development of a hospital-based camp using a multidisciplinary approach, to increase independence.

Statement of Problem and Purpose

Adolescents that come to health care facilities often have no close friends; they do not participate in physical activities or sports. They miss normal peer relationships and opportunities to explore their sexuality. This study focused on adolescents, because the crisis concerning socialization and independence was current for them. Increasing social activities and encouraging independence, in a concentrated manner may help improve peer relationships and promote self-esteem for adolescents with spina bifida.

According to Strax (1988), there are four major tasks that all maturing adolescents must face: vocational, identity, independence, and peer acceptance. Reaching these goals can be a particular problem to physically handicapped adolescents due to altered mobility, social isolation from peers, and dependence on their family (Sherman, Berling, & Oppenheimer, 1985). Another problem is that nursing and medical needs often detract from social, recreational, and educational needs. According to available research, parents received more information from health professionals on the physical aspects of disabilities than on psychosocial issues. The psychosocial dimensions of normal development received even less consideration. Social and recreational needs of adolescents have been neglected (Rinck, Berg, & Hafeman, 1989; Sherman et al., 1985). A few hospital-based camping experiences reported in the literature appeared effective in meeting goals for independence and

socialization. The few studies in the literature on camps for adolescents or adolescents with spina bifida all demonstrate the need for more self-help programs and research on this topic (Bodzioch, Roach, & Schkade, 1986; Bolding & Llorens, 1991). Programs for affected children could help prevent the problems adolescents now face.

The purposes of this study were to demonstrate specific outcomes of a treatment program designed to help adolescents with myelomeningocele: 1) to increase knowledge of socialization and future goals; 2) to improve in self-esteem; and 3) improve independence in activities of daily living (ADL's). The benefits of a hospital-based program such as Camp SPIRIT (S: Socialization/Self-Esteem; P: Programs in vocational goals; I: Independence; R: Recreation; I: Improvement; T: Teamwork), were explored. Background information and summary of research supported the importance of socialization, education, and recreation for the physically challenged adolescent.

Chapter II

Review of the Literature

The review of literature consists of five different sections: (1) socialization/independence, (2) peer relationships, (3) recreation, (4) camping experiences, and (5) the conceptual framework. Each area of the literature will be discussed concluding with the conceptual framework. Orem's self-care theory demonstrates how nurses can empower adolescents with disabilities to become more independent, through supportive-educational opportunities.

Socialization/independence. During the family nursing assessment, socialization and independence of adolescents are important dimensions to review in adolescents with myelomeningocele. Blum, Resnick, Nelson, and St Germaine (1991) emphasized that health care professionals work closely with children and parent support groups, "to help normalize the social experiences of those children developing with spina bifida...to reduce the social isolation and its associated sequelae both during adolescence and beyond" (p. 280). Many physically disabled adolescents rely on family members to assist with activities of daily living (ADL's). According to Murch and Cohen (1989), becoming independent is more difficult for handicapped individuals. Blum et al. (1991) found that even though friends were important to children with physical handicaps, out-of-school relationships and social activities were limited. Adolescents often assumed sedentary lifestyles and parents were unable to completely meet the need for socialization with peers, education regarding sexuality, and future vocational concerns (Rinck et al., 1989). As Blum et al. (1991) stated, to

help adolescents reach their potential, we must assist them and their families in achieving independence.

Peer relationships. Adolescent peer relationships is another area of importance in the family nursing assessment. The literature on peer relationships revealed studies which focused on friendships and development of personal identity. Rosenbaum, Armstrong, and King, (1987) reported that "failure to establish successful peer friendships is emerging as a significant factor distinguishing disabled from able-bodied children" (p. 327). Misunderstandings regarding handicapped peers can hamper opportunities for friendships (Rosenbaum et al, 1987). Strax (1988) contended that disabled individuals usually have a prolonged adolescence due to being sheltered by their families and also having limited peer access. For the disabled, the "identity crisis is even more profound because of a dearth of appropriate role models" (Strax, 1988, p. 756). Wallander and Varni (1989) reported that adolescents with "high social support from both family and peers showed significantly better adjustment than those with high social support from only one of these sources" (p. 185). A study of seventh to eleventh graders found that the children "chose as friends, nondisabled first, wheelchair bound next..." (Strax, 1988, p. 758).

It can be difficult for physically challenged children to initiate interaction with peers. Strax (1988) revealed, "it is agonizing for physically disabled or uncoordinated children who have trouble dancing, conversing, or participating in sports activities to join in with other teenagers," (p. 759). Unfortunately, in spina bifida, "nonhandicapped friends of preadolescents were lost during adolescence"

(Strax, 1988, p. 759). Blum et al. (1991), also noted that, while peers were starting to date, "heterosexual social contacts were infrequent" for physically handicapped adolescents (p. 280). Current literature agreed that physically disabled adolescents had fewer social relations with peers than non-disabled. This decrease in social activity was attributed to rejection by peers or lack of opportunities for socialization. A special hospital-based camp can offer experiences with peers not possible before.

Recreation. In the family nursing assessment, it is important to include recreation. Physical activities are important to adolescents but can be a special challenge to adolescents with physical disabilities, making rewards appear remote. According to Biddle and Fox (1989) "there is evidence suggesting that the process of exercise can bring about both short- and long-term psychological enhancement, which may be important factors in exercise motivation and also contribute significantly to mental well-being" (p. 206). There are a wide range of sports options for handicapped adolescents that improve "stamina, strength, and skill" (Jackson, 1987, p. 302). The mastery of a specialized sport (like downhill snow skiing) can make other ADL's seem easy. Current literature on exercise supports the hypothesis that "those who pursue a physical lifestyle, have a better mental outlook and a better acceptance of their disability, than those who are relatively inactive" (Jackson, 1987, p. 302). Recreation is important for all, "but for the handicapped, it is a significant factor in eliminating the web of obstacles that restrict a person with a disability... skiing can mean adventure, exercise, growth, development, self-respect and independence" (O'Leary, 1987, p. 8).

Research by Hayden, Davenport, and Campbell (1979) compared adolescents with myelodysplasia to nondisabled adolescents in order to investigate physical, psychological and social characteristics of both groups. Adolescents in both groups made friends easily, but those with spina bifida had fewer close friends than the control subjects. They participated in, "fewer team sports, group and extra curricular activities" (Hayden et al., 1979, p. 55). Rinck et al. (1989) also found, that adolescents with myelomeningocele had fewer close friends, attended sporadic outside activities, and had not been out with a friend for a year. Recommendations from these studies illustrated the need for group activity for networking adolescents, focusing on problems and solutions, which can be initiated in hospital-based camping experiences.

Camping experiences. The literature on socialization/independence, peer relationships, and recreation for adolescents with disabilities was reviewed. This section summarizes material on specialized camping experiences for the disabled. Camping experience in this context, refers to planned overnight experiences outside of the patient's home. Several hospitals in the Portland area have rehabilitation programs in which the adolescent is admitted to the hospital for the sole purpose of learning activities of daily living (ADL's). The focus of this proposal is to expand this idea to a camp program that includes the socialization component so important to adolescents. Documentation in the literature concerning programs for adolescents with physical handicaps focused on camping experiences and activities (Bodzioch et al., 1986; Bolding & Llorens, 1991; Dorman, 1989; Lollar, Reinoehl, Leverette,

Martin, & Posid, 1989; Sahler & Carpenter, 1989; Sherman et al., 1985; Swensen, 1988). Only four articles dealt specifically with spina bifida (Bodzioch et al., 1986; Bolding & Llorens; Lollar et al., 1989; Sherman et al., 1985).

Bodzioch et al. (1986), reported on a hospital-based camp for paraplegic adolescents that lasted two weeks and was designed to, "improve their self-esteem, independence, and eventual employability," (p. 198). The Piers-Harris Self-Concept Scale (PHSCS) was used as a measure of self-esteem. This study showed some improvement in ADL's, self-concept, and social skills as a result of the camp experience.

Sherman et al. (1985) described a program utilizing a multidisciplinary team, to promote social growth and development of adolescents in a spina bifida treatment program. Clear objectives focused on independence for the adolescent with spina bifida, realistic goal setting, and reliable measurement tools. Strengths of the program were noted to be, "socialization and support among the teenagers" (Sherman et al., 1989, p. 13). Recommendations were to increase "vocational and prevocational activities" (Sherman et al., 1989, p. 13).

There were few instruments used for evaluating hospital programs. Lollar et al. (1989) utilized an instrument entitled the "Independent Behavior Inventory" (p. 18) for a hospital-based program. Bolding and Llorens (1991) also evaluated the effects of a "habilitative hospital admission" (p. 796) for the multidisciplinary teaching of ADL's. Evaluation measures included goal setting abilities, ADL performance, and the Piers-Harris Children's Self-Concept Scale. Analysis of the program confirmed

that, "hospital admission can be an effective means of increasing independence and decreasing frequency of physical care by parents" (Bolding and Llorens, 1991, p. 796). What these hospital-based programs and other camps have in common, is the variety of activities planned by the multidisciplinary health care team to meet emotional and independence requirements. Programs with the focus on peer interaction are most beneficial for the adolescent with spina bifida to help meet their socialization needs.

In summary, medical literature related to exercise and children with myelomeningocele was generally more qualitative/descriptive or descriptive/anecdotal, than quantitative research. There was little focus specifically on adolescent populations and the development of self-esteem for individuals with spina bifida. Current research remains difficult to replicate, and an exhaustive literature search of many disciplines was performed to obtain the studies presented here. Studies that did focus on adolescents with spina bifida suggested a possible link between increased independence in ADL's, having a positive effect on socialization and self-esteem. These studies supported the need for nursing intervention and further research on the benefits of socialization, education and recreation to improve self-esteem and ADL's in adolescents with spina bifida.

Conceptual Framework

Dorothea Orem's conceptual framework of nursing, also known as the "self-care deficit theory of nursing" (Orem, 1991, p. 73) was a natural choice for the conceptual framework for this study. The underlying hypothesis of the study was,

that adolescents who learn to independently perform their activities of daily living (ADL's) will have a higher self-concept. Orem states this is the essence of nursing.

Orem (1991) refers to three types of self-care requisites necessary to perform self-care: universal, developmental, and health-deviation.

1) Universal-There are eight basic universal requisites for all humans. For the purposes of this study, only elimination, activity and rest equilibrium, solitude and social interaction balance, and the promotion of normal functioning within social groups will be addressed.

2) Developmental-This requisite is concerned with promoting stages of development and care associated with adverse conditions that can affect development. This study focused on the pubertal stage of adolescent development.

3) Health-Deviation-This requisite results from disturbed bodily function requiring medical treatment and addresses disabilities, like spina bifida.

The six central concepts of Orem's conceptual framework are discussed in Orem (1991) and Fawcett (1989), and contributed in understanding the conceptual framework of this study.

1) Self-care is the care that an individual can perform without assistance from others, and is performed in relation to the three self-care requisites (universal, developmental, and health-deviation) described above. Self-care is "a goal oriented activity that is learned" (Fawcett, 1989, p. 211). A self-care agent is the "provider of self-care" (Orem, 1991, p. 117). Orem values the individuals' abilities to care for

themselves, and recognizes that nursing can assist clients to look at themselves as self-care agents.

2) Self-care agency is defined by Orem as the "capability to take action directed toward care of self" (Fawcett, 1989, p. 214). Agency means action in this definition.

3) Therapeutic self-care demand refers to a "prescription for the self-care measures to be performed in order to meet identified sets of self-care requisites-- universal, developmental, and health-deviation (Orem, 1991, p. 316). Fawcett (1989) simply states therapeutic self-care demand as the "self-care actions that are needed to meet the self-care requisites" (p. 214). Orem expounds that in some situations, nursing could improve in the ways that individuals are assisted in meeting their therapeutic self-care demands.

4) Self-care deficit exists when "self-care agency is not sufficient to meet the therapeutic self-care demand" (Fawcett, 1989, p. 214). A nurse/patient relationship may develop when a self-care deficit is present.

5) Nursing agency according to Orem (1983), refers to the "essential quality of a person that is enabling for nursing practice" (p. 214). Fawcett (1989) explains that "the goal of nursing agency is to help people meet their own therapeutic self-care demands" and that nursing agency refers to "the ability to nurse" (p. 217).

6) Nursing system is described by Orem (1983) as "when the named relationships among persons and among their characterizing qualities are brought about and maintained for some duration of time" (p. 215). Of the three types of

systems of nursing intervention described by Orem (1983) wholly compensatory, partly compensatory, and supportive-educative, only the supportive-educative intervention was applied to the conceptual framework of this study. In the supportive-educative role, nurses provided guidance in self-care deficits (actual and potential) as the client moved toward independence.

Orem's "universal self-care requisites" (1991, p. 126) were applied to the dependent variables of socialization and goal setting in this study. The promotion of normalization (promoting a realistic self-concept) is important in assisting adolescents with self-care now and for the future.

Orem's "developmental self-care requisites" (Orem, 1991, p. 130) deal with social adaptation and status-associated problems that can adversely affect human development, and more specifically explains the dependent variable of self-esteem in this study. Peer-acceptance and sexuality for disabled adolescents are important issues at this pubertal period of development.

Orem's "health-deviation self-care requisites" (Orem, 1991, p. 134), particularly habilitative measures to help compensate for disabilities, are applicable to the dependent variable of independence in ADL's for this study. Modifying self-concept in accepting a particular state of health and "learning to live with the effects of pathologic conditions" (Orem, 1991, p. 134) are most relevant to the purposes and goals of this intervention.

The theory of self-care as described by Orem, serves as a guide to nurses in assessment, planning, implementation, and evaluation of therapeutic self-care demands

for adolescents with physical disabilities. "Continuing self-care is essential for life, health, and personal well-being" (Orem, 1991, p. 143). The variables used in this study are framed within the structure of Orem's self-care deficit theory of nursing. The three dependent variables in the study are: 1) knowledge of socialization and future goals, 2) self-esteem, and 3) independence in ADL's. They are related to Orem's three self-care requisites respectively: 1) universal, 2) developmental, and 3) health-deviation.

The independent variables of education, recreation, socialization, and ADL's overlap with the dependent variables. The independent variables are difficult to measure since they are not mutually exclusive in weekly activities (education classes, hikes, videos, morning and evening ADL's, exercise classes, zoo safari, group discussions, vocational/college information classes, mall trip, life skills classes, computer training, grooming skills, dating tips, swimming, dancing, recreation training, boat trip and party, see Camp SPIRIT-Schedule in Appendix A). After one week of intervention, this population was exposed to some concentrated combination of these activities in the form of classes, outings, and other experiences provided by the nursing system. Since the same population was used in pre-camp, post-camp, and follow-up observations, the separate measurements of the independent variables are just as important.

The universal self-care requisites were addressed through: bowel/bladder programs (elimination); scheduled times for activities and sleep (activity and rest equilibrium); group activities to neutralize social isolation (solitude and social

interaction balance); and new recreation/socialization opportunities (promotion of normal functioning within social groups).

The developmental (pubertal stage) self-care requisites were confronted by classes in money management, vocational rehabilitation, coping skills, adaptive driving, transitioning, guided imagery, student services, computers, grooming, dating/sexuality, and interview/career skills. Activities such as the movie about developmental issues adolescents face, and the meeting with an adult role model should provide guidance for adolescents. Socialization opportunities are provided to increase self-esteem and gain experience with male and female peers. Orem's developmental self-care requisites were interpreted as "the bringing about and maintenance of living conditions that support life processes and promote the processes of development, that is, human progress toward higher levels of the organization of human structures and toward maturation during...the developmental stages of childhood, including adolescence and entry into adulthood," (Fawcett, 1989, p. 213). Orem's developmental self-care requisites were translated as "the provision of care either to prevent the occurrence of deleterious effects of conditions that can affect human development or to mitigate or overcome these effects from conditions" (Fawcett, 1989, p. 213), such as educational and social deprivation, loss of health and friends/family, and other abrupt changes.

The health-deviation self-care requisites were addressed in several ways. Therapy was provided (as necessary) to teach independence skills and adolescents received rewards for completing morning/evening ADL's. Educational classes in

preventing further disability by increasing recreational activities, performing ADL's independently, coping with spina bifida, and to some extent all other activities, should assist adolescents in improving their self-care agency. Clearly all of the activities to which the subjects in this research were exposed are directed at the self-care requisites as Orem has defined them.

Orem distinguished two actions by the terms "self-care agency" and "dependent-care agency," (Fawcett, 1989, p. 214). Since the camp concerned affected individuals and not their parents, this research clearly dealt with self-care agency, the adolescent participating in self-care as a self-care agent.

Orem would agree that adolescents whose self-care agency is not adequate to meet their own therapeutic self-care demands can benefit from nursing agency. "Nurse-patient relationships are established, then, when an actual or potential self-care deficit is evident" (Fawcett, 1989, p. 217). The treatment focused on the supportive-educative type of nursing system previously described by Orem.

Operational Definitions

To clarify terminology related to this research, the following operational definitions of concepts are provided.

1. Activities of Daily Living (ADL's)-These are activities to be performed on a daily basis and include: getting up in the morning, toileting, grooming, dressing, transfers (from bed, to wheelchair, to toilet), making the bed, setting out clothes, bathing, and getting ready for bed at night.
2. Adolescent-Refers to young adult between the ages of 13-19 years old.

3. Educational Activities-These are educational classes directed by professionals in: schooling, recreation options, bowel and bladder programs, money management, vocational rehabilitation, coping skills, nutrition class, adaptive driving, transition training, identification of architectural barriers, guided imagery, college student services, computer training, dating and sexuality classes, interview skills and career folders.
4. Hospital-based Camp-An inpatient hospital setting (therapeutic environment) in which trained health professionals provide specific activities on a 24 hour basis on: social, recreational, and educational topics. Subjects will sleep in hospital rooms, though other experiences do not necessarily occur inside the hospital.
5. Myelomeningocele-Congenital defect involving the spinal cord that may result in neurological deficits involving the: extremities, bowel, and bladder functions.
Myelomeningocele is the most severe form of spina bifida. The term spina bifida is used interchangeably with myelomeningocele in the text.
6. Recreation-In this study, recreation refers to regular physical activity, exercise, or sport.
7. Self-Esteem/Self-Concept-This is the opinion that the individual has about oneself. Self-esteem/self-concept are used concurrently in this study. This is a frequent problem in adolescents with myelomeningocele.
8. Socialization-This term refers to mostly social or recreational interactions that adolescents' have with peers.

Chapter III

Methods

This chapter will address the research hypothesis, pilot study, design, subjects, instrumentation and procedures used in this investigation. The purposes of this study were to demonstrate specific outcomes of a treatment program designed to help adolescents with myelomeningocele: 1) to increase knowledge of socialization, and future goals; 2) to improve self-esteem; and 3) to improve independence in activities of daily living (ADL's) using the therapeutic intervention of a hospital-based camp.

Research Hypothesis

The problem in Orem's terms is that a self-care deficit exists in this population of adolescents with spina bifida and that the nursing agency (nursing) can demonstrate in a supportive-educative intervention how to help adolescents meet their therapeutic self-care demand.

The research hypothesis for this study was: an intensive/directed in-hospital experience utilizing selected therapeutic interventions for adolescents with spina bifida would result in: 1) an increase in their knowledge of socialization and assistance in future goal setting; 2) improvement of their self-esteem; and 3) improvement of their independence in activities of daily living (ADL's). The self-care deficits before and after the intervention, were measured indirectly by the: 1) Socialization and Goals Questionnaire (SGQ); 2) Piers-Harris Children's Self-Concept Scale (PHCSCS); and 3) Functional Independence Measure (FIM).

Pilot Study

A pilot study of the Piers-Harris Children's Self-Concept Scale (PHCSCS) and some of the activities of daily living procedures (ADL's), was performed at Shriners Hospital in Greenville, South Carolina. This hospital had previously implemented a similar hospital-based camp for children with myelomeningocele ("Camp Eagle's Wing"). Significant differences between Camp Eagle's Wing and Camp SPIRIT were: 1) the camp was two weeks long; 2) a main purpose at Camp Eagle's Wing was for subjects to learn self-intermittent catheterization; 3) there were only five females at this camp; 4) subjects ages were less than 10 years old; and 5) there were no control groups. This pilot study served the following purposes: 1) to gain experience in implementing a hospital-based camp in teaching children with myelomeningocele ADL's; 2) to work with the Director of Myelodysplasia Services/ Camp Coordinator in another hospital; and 3) to pilot test the PHCSCS for use with the present study.

PHCSCS was the instrument selected to measure self-esteem over time. The PHCSCS was given to the Camp Eagle's Wing group pre- and post-hospitalization. This information helped the researcher establish feasibility of the PHCSCS on adolescents with spina bifida.

Children are still developing self-esteem, but results should be stable by seven to eight years of age, according to the theory underlying this instrument. The PHCSCS manual recommends ignoring changes in scores on test-retest if less than ten points. This means that of all total points, only one of the children in the pilot study

had a significant increase in their total self-esteem score. The first group mean score (observation one, on day one of camp) was 46.8 and the second group mean score (observation two, on the last day of camp) was 47.6, not significant as changes in group means on a retest consistently go up in a positive direction up to 5 points (even if no intervention occurred). Results of the PHCSCS were analyzed for the pre-and post intervention only.

The fact that no improvement in self-esteem could be demonstrated in the pilot study was explained by the following reasons. Camp Eagle's Wing had an emphasis on performing ADL's which enabled children to concentrate on their handicaps. The emphasis was not on improving self-esteem as there was no psychological intervention or counseling specifically in this area. Interventions only affected certain cluster scales and did not promote significant changes in total self-concept scores. Also, the intervention may not have been powerful or long enough to elicit anticipated changes in self-esteem. While the PHCSCS appears to be a reliable instrument, it is not appropriate for showing improved self-esteem in a test-retest manner following a brief intervention like this particular hospital-based camp.

The pilot study demonstrated the effectiveness of a hospital-based camp that was organized by a clinical nurse specialist. Children did show dramatic improvement in becoming independent in self-intermittent catheterization and self-care at Camp Eagle's Wing.

Lessons learned from the Camp Eagle's Wing pilot study were: 1) it is desirable to have a control group to compare results with the experimental group;

2) there should be some measurable way to evaluate increased knowledge of self, recreation, socialization, and future goals (for older children); 3) the PHCSCS should be given at a later time, perhaps a month following the intervention, as self-esteem is difficult to measure and results do not always show up short-term; 4) there should be a quantitative way to measure improvement in independence in ADL's; and 5) a qualified alternate volunteer list should be made along with alternate activities, in planning the camp. As a consequence of the pilot, this investigator devised the Socialization and Goals Questionnaire, added a third follow-up observation period (one month after the treatment), and located the Functional Independence Measure instrument to evaluate ADL's.

Design

This Camp SPIRIT study utilized a combination of quasiexperimental, equivalent control-group, and interrupted time series designs. The quasiexperimental method was chosen since the participants and controls were not randomly selected for treatment and the study "does manipulate the experimental condition and incorporates various types of control to enhance the internal validity of the findings" (Woods and Catanzaro, 1988, p. 178). The internal validity is assured by the control group in this analysis. This study was an equivalent control-group design as the control and the experimental groups were drawn from the same populations. In contrast, Woods and Catanzaro (1988) differentiated equivalent control-group design from "nonequivalent control-group design" as a "design in which the groups are naturally occurring collectives and thus are not allocated randomly to the treatment and control groups at

the same point in time" (p. 562). The interrupted time series design as described by Woods and Catanzaro (1988) is applicable to this study as it "involves collection of data over an extended period of time during which an intervention is interspersed" (p. 179). An illustration of this longitudinal study design is displayed below with "O" representing observations and the "X" representing the treatment. The diagram shows subjects being measured at one interval at the start of the intervention (O1=Observation 1) and two additional intervals following the intervention (O2=Observation 2, and O3=Observation 3). The control group is shown below, by intervals only (O1=Observation 1, O2=Observation 2, and O3=Observation 3).

Experimental:	O1	X	O2	O3

Control:	O1		O2	O3

Subjects

There were sixteen subjects for this study, eight were in the experimental group and eight were in the control group. Criteria for selection of the experimental subjects were: 1) equal numbers of males and females; 2) ages between 13 and 19 years old with a self-care deficit (myelomeningocele); 3) subjects volunteering to spend one week in the hospital-based treatment program; 4) school achievement level above seventh grade; 5) adolescents requiring no acute medical care; 6) level of paralysis that does not prohibit the subject's participation in planned activities; and 7) a patient of Shriners Hospital system.

Criteria for selection of the eight control subjects were the same as for the eight experimental subjects except that control subjects were not required to be a part

of the hospital treatment. Instead, controls were contacted by telephone and the investigator read and recorded responses to the three measurements (SGQ, PHCSCS, and FIM) at three observation times comparable to the experimental group. To respect the needs of the control group, they were contacted by telephone for easy access and minimal intrusion, so as not to inflict undue hardship on this group that would not be receiving the treatment. This was an asset in that the two groups did not have contact with each other so cross-contamination of results did not occur.

Human Subjects

This study was approved by the Human Subjects Committees at Shriners Hospital for Crippled Children and Oregon Health Sciences University. Confidentiality of subject data was maintained by giving each subject a number and separating subject names from responses and by locking data in a file located in the principal investigator's private office. Consent forms were signed by parents and children (see Appendix B).

Potential negative effects from this intervention were heightened awareness of self-care deficits. A professional staff member was with the adolescents at all times to detect negative consequences of the study. If the health professional identified any concerns, proper referrals would have been made. Debriefing was scheduled at the end of the study and could occur at any time during and after the treatment. The subject could withdrawal from the program at any time or for any reason.

Instrumentation

Three instruments used in the study were given at three different points in time (pre-treatment, post-treatment, and one month follow-up). These instruments were: 1) the Socialization and Goals Questionnaire (SGQ); 2) the Piers-Harris Children's Self-Concept Scale (PHCSCS); and 3) the Functional Independence Measure (FIM). They were chosen to measure the concepts that Orem described as self-care requisites, and are described below along with a Pre-Camp Questionnaire designed to evaluate potential concerns of the subjects prior to camp. Since it is difficult to measure or show significant improvement in self-esteem using the PHCSCS alone, different measurement instruments to assess the effectiveness of the camp in areas other than self-esteem, such as a specifically devised questionnaire and a type of ADL tool, appeared to meet these criteria.

The first instrument employed was the Socialization and Goals Questionnaire (SGQ) (see Appendix E), and was designed by the investigator. No other single instrument was available to measure the following variables: knowledge of socialization; recreation; and future goals. Peer review determined face validity. More research is required to establish reliability and validity estimates of the tool. The SGQ was administered at three points in time; the first and last day of treatment and on follow-up at one month. The SGQ was also used to evaluate the adolescent's expectations for camp and to help determine the degree of satisfaction experienced. For statistical purposes, only questions one through eleven were coded for both the experimental and control groups. Positive comments, (correct responses or

identification of goals) were given a code of "1" and were expected to increase following the intervention. Negative comments (incorrect responses) were given a code of "3" and were expected to decrease following the intervention. Where the subject was uncertain of a response or could not decide, a code of "2" was given. Uncertain responses were also expected to decrease following the intervention. Evaluation responses were studied qualitatively, so no codes were given. The control group responses were not expected to change significantly as there was no treatment provided.

The second instrument used measured the dependent variable of self-esteem and was the Piers-Harris Children's Self-Concept Scale (PHCSCS) (see Appendix F). The manual for the PHCSCS (1991) indicated that this tool has reliability coefficients ranging from 0.42 to 0.96 and internal consistency estimated from 0.88 to 0.93. The PHCSCS has proven to be valid in a wide range of studies involving children from 8 to 18 years old. In addition to raw/total scores, another level of interpretation is made available through six cluster scale (subscale) scores. According to the PHCSCS manual (1991), the assumption is that self-concept has different dimensions, including: 1) behavior; 2) intellectual and school status; 3) physical appearance and attributes; 4) anxiety; 5) popularity; and 6) happiness and satisfaction (p. 38). The PHCSCS was completed by the subjects the first and last day of the treatment and on follow-up at one month. Self-concept scores were expected to improve following the intervention. Higher total scores equaled higher self-concept. It was learned from the PHCSCS manual that low scores are felt to reflect negative self-

attitudes. Scoring the clusters was done according to specifications in the Piers-Harris children's self-concept scale: Revised manual 1984. The control group scores were not expected to change significantly, demonstrating the effectiveness of the treatment to the experimental subjects. According to the Piers-Harris children's self-concept scale: Revised manual 1984, changes in self-concept occur over time, but not rapidly or in response to isolated experiences or interventions. Permission to use this tool was obtained from the publishers and distributors of the tool, Western Psychological Services.

The third instrument used measured the variable of independence in performing activities of daily living (ADL's), and was the Functional Independence Measure (FIM) (see Appendix G). The Guide to the Uniform Data Set (1991, p. 4) describes the FIM and its use with a "seven-level scale which represents major gradations in independent and dependent behavior." There are 18 items to score with a maximum of 7 and minimum of 1 possible. The FIM measures actual behavior and was designed to be used by any trained discipline. Data was coded after admission, before discharge, and on follow-up. Due to length of the study, times were adjusted accordingly. The Guide states that the "FIM was found to have face validity and to be reliable" (1991, p. 4), although no actual statistics were provided. The FIM was the only measure of ADL's found that could be applied to adolescents with self-care deficits in a camp setting. Permission to use the FIM was obtained by purchasing a copy of the Guide for use of the Uniform Data Set for Medical Rehabilitation

including the Functional Independence Measure, 1991, from the Uniform Data System for Medical Rehabilitation at the State University of New York.

Another instrument used for the initial assessment of the experimental group of adolescents was the Pre-camp Questionnaire. The Pre-camp Questionnaire surveyed potential concerns of subjects prior to the treatment (see Appendix C). Concerns evaluated included activities of daily living (ADL's), time spent away from home, special supplies and equipment, medication, recreation program, areas parents and adolescents felt were important to concentrate on, and special interest items, e.g., latex allergies. This questionnaire was helpful for staff to adequately prepare for special needs prior to the adolescent's arrival at the hospital.

Procedures

The procedures used in the treatment to measure variables are described in this section. The study was based at Shriners Hospital in Portland, Oregon which serves a large number of patients with spina bifida. An interdisciplinary team consisting of physicians, nurses, physical/occupational therapists, social workers, and child life specialists were responsible for choosing adolescents to participate in this study. Telephone calls were made by the investigator to selected families describing the objectives for the experimental group (Camp SPIRIT). At that time, questions were answered and initial commitment from the families was obtained. The Pre-camp Questionnaire was reviewed to evaluate potential concerns of subjects prior to the treatment and to have initial information to give to hospital staff to prepare adequately for the adolescent's admission to the hospital.

Following approval from Shriners Hospital for Crippled Children and Oregon Health Sciences University Human Subjects Committees, a seven day hospital-based camp took place in the fall of 1992 (see Appendix H). The week long treatment focused on independence and consisted of: socialization/recreation experiences; information on education/vocation (future goals); activities designed to improve self-esteem; and improve function in activities of daily living (ADL's), for the adolescents with spina bifida. A pre-camp letter with helpful information (see Appendix C) was sent for the purpose: 1) to educate parents regarding the objectives of the program; 2) to orient families on how to prepare their adolescents for the experience; and 3) to send a preliminary camp schedule for the week. On the morning of the first day of the treatment, a consent was signed by parents/guardians for adolescent's participation in research. A release form was also obtained, "protecting the institution from liability, and giving permission" (Dorman, 1989, p. 515) for the adolescent to be treated by supervising medical staff in emergency situations. Photography consents were also signed for photographs to be used for research and publicity purposes. Shriners Hospital for Crippled Children is a non-profit organization and provides hospitalization and treatment free of charge. For the cost of this intervention (minus hospitalization) refer to Appendix I. On the first day of camp, the adolescents completed the Socialization and Goals Questionnaire (SGQ) and the Piers-Harris Children's Self-Concept Scale (PHCSCS). The Functional Independence Measure (FIM) was completed by the nurse with assistance from occupational therapists, within 24 hours of admission to the hospital.

For the week-long treatment to the experimental subjects, they were checked into the hospital by 9:00 a.m. Sunday and were released by 5:00 p.m. on the following Sunday. Two four-bed patient rooms were set aside on the inpatient unit, one for four males and the other for four females. The nurse researcher reviewed the weekly routine and goals with all subjects individually. It was significant that each day contained some activities in the following areas: pre-arranged exercise activity, ADL component, peer interaction experience, education and future oriented class (vocational/college review, sexuality instruction, or stress management). Refer to Appendix A for a complete list of daily activities.

The nurse investigator supervised the treatment program and hospital staff, across hospital shifts, and helped to carry out scheduled activities for the day. An outside volunteer assisted in out-of-hospital activities and served as a chaperon. There were outside consultants that gave classes in the areas of psychology, family therapy, grooming, adaptive driving, and college and vocational opportunities. Physicians were on call as per hospital routine for medical questions or emergencies. Additional volunteers were recruited for select programs, such as outdoor sports and social activities. Attributes of volunteers that were useful included: an adult with spina bifida to act as a role model; off-duty nurses/therapists; nonhandicapped peers; nursing students; and therapy/child life students from nearby universities.

Subjects were responsible for ADL's: getting up in the morning, toileting, grooming, dressing, transfers (from bed, to wheelchair, to toilet), making the bed, setting out clothes, bathing, and getting ready for bed at night, personal laundry, and

keeping their rooms orderly. Special emphasis was on bowel/bladder program assistance as necessary. Adolescents received increased exposure to recreational, educational, and social opportunities available in the community. Classes were taught by qualified personnel on personal hygiene, diet, overcoming architectural barriers, social/dating skills and sexuality and career planning. Oregon has many institutions of higher education with "special facilities for the handicapped" which were explored (Ayrault, 1971, p. 222).

A looseleaf notebook was provided for all subjects to organize as well as keep records of activities. The notebooks had pockets and a "Camp SPIRIT Schedule." Four tabs identified sections titled: "Daily Schedules;" "Speaker Notes;" "ADL's;" and "Journal." The purpose of the notebook was that it provided information while undergoing treatment, as well as to serve as a record and reference for use after the camp.

A variety of seasonal recreational/sports options were strongly encouraged or used during treatment. Inherent in all parts of the treatment (Camp SPIRIT) was an underlying motivational component (behavioral modification). According to behavioral modification theory, Sherman et al. (1985), suggested using tokens as awards for activities that were successfully completed. Tokens could later be redeemed for small amounts of money or special privileges. At Camp SPIRIT, these tokens were called "SPIRIT Bucks" (green paper rectangles with special stickers in the middle). For each activity of daily living completed, a subject could earn a "quarter buck." In the notebook section titled "ADL's" (Appendix D), daily morning

and evening activities and bowel function could be logged. Examples of ADL's that could earn "bucks" were: setting alarm/getting up on time; making the bed; bladder program (cathing/pad); dressing; bowel program; washing; setting out clothes; and writing in the journal. Some subjects eventually earned up to two and a half bucks a day illustrating the power of positive reinforcement. These were redeemed for prizes on the last day of camp at the family party. Recreation could eventually become a reward as well, by providing an impetus for peer interaction and increased self-esteem. When an activity was rewarded and thus reinforced, it was much more likely to be repeated (Myers, Cerone, & Olson, 1981). For information on setting up a hospital-based camp and to review daily activities of Camp SPIRIT, see Appendix H.

Chapter IV

Results and Discussion

The purposes of this study were to demonstrate specific outcomes of a program designed to help adolescents with myelomeningocele: 1) to increase knowledge of socialization, and future goals; 2) to improve self-esteem; and 3) improve independence in activities of daily living (ADL's). The intervention was designed to test the hypothesis that a hospital-based camp would accomplish these purposes. The results of the investigation of 16 adolescents with spina bifida supported this hypothesis.

Statistical analysis for the study was used to examine the differences between the experimental and control subjects on the three measurements and at three different observation times, before and after the intervention and at follow-up. Analysis of variance (ANOVA) was a statistical measure of the significance of the changes in mean values for the experimental and control group scores between observation points, 01, 02, and 03. The p value was significant at the .05 level. Consultation was sought from the Office of Research Development and Utilization at the Oregon Health Sciences University regarding this analysis. Each variable investigated in this study will also be analyzed by using Orem's self-care deficit theory of nursing.

Socialization and Goal Setting

The first component of the hypothesis was that the treatment would improve the socialization and goal setting responses of adolescents with spina bifida. This variable was measured using the Socialization and Goals Questionnaire (SGQ). In the

experimental and control groups between observations 01, 02, and 03, ANOVA was used to analyze count data for the positive, negative, and uncertain responses on the questionnaire to determine if group differences held up over time. In Tables 1-4, means and standard deviation are noted on the left side. The group heading is a measure of statistical difference between control and experimental groups. The time heading refers to the change of all 16 subjects together over three times, as one group. The interaction heading refers to group and time together which relates to whether the experimental group changes over time in a different way than the control group. The interaction column is the most significant finding for the purposes of this study.

In Table 1, SGQ positive responses, there was a significant change for the group over time as a result of the treatment with $p=.0017$. There was also a significant difference between groups over time as a result of the intervention. The test of interaction was significant with $p=.0014$. The experimental group's positive responses changed dramatically and the control group's responses did not. In Figure 1, the SGQ graph illustrates the increase in positive responses for the experimental group, while the control group showed no increased responses over time.

Table 1

Socialization and Goals Questionnaire Positive Responses
Means (Standard Deviations) and Tests of Significance

	Pre-Camp	Post-Camp	Follow Up	p-Value for Tests		
				Group	Time	Interaction
Control	08.88	09.00	08.75	.1296	*.0017	*.0014
	(2.17)	(1.85)	(1.75)			
Experi.	08.88	10.50	10.63			
	(1.25)	(0.76)	(0.52)			

Note. N=16

*p significant at .05 level

Socialization and Goals Questionnaire
(mean positive responses over 3 time intervals)

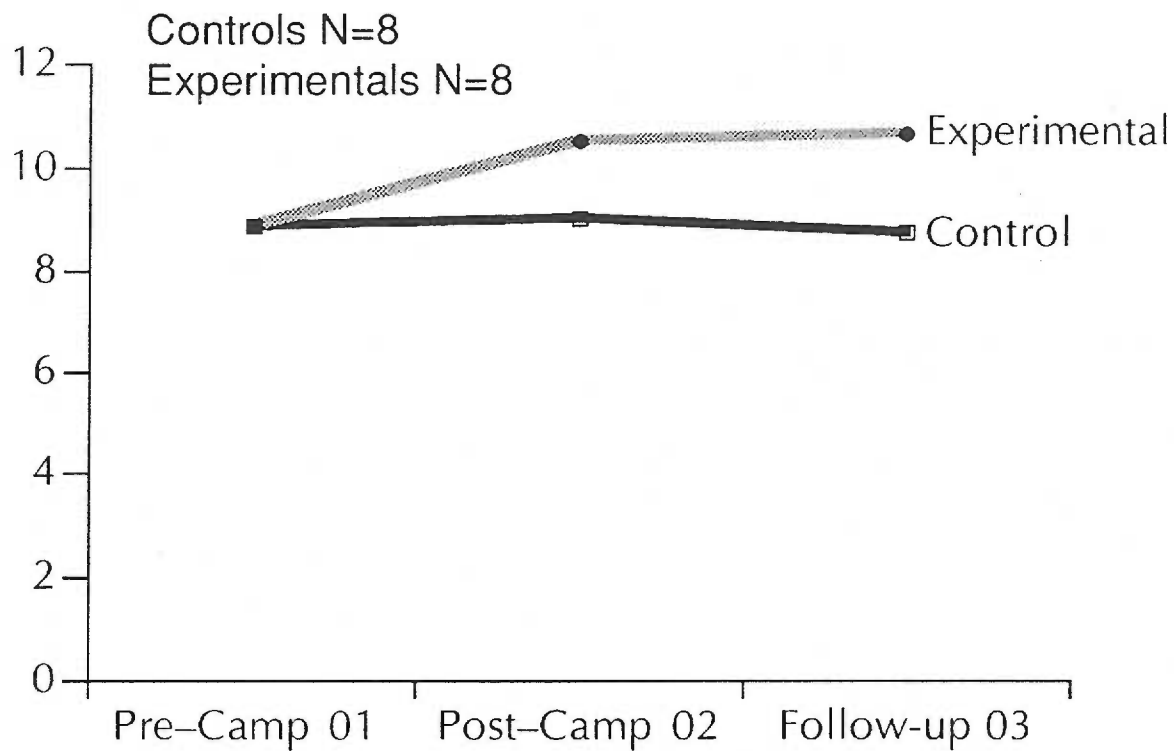


Figure 1. Socialization and Goals Questionnaire
(mean positive responses over 3 time intervals).

In Table 2, SGQ Negative Responses, there was a significant change, $p = .0076$, under group as the control and experimental groups differed in negative responses. There were no significant changes for all 16 subjects together over the three time intervals, as seen under the time heading. There were no significant differences between groups over time as a result of the intervention, as seen in the interaction column. Under the follow-up column, there was a dramatic decrease in negative responses in the experimental group, which was expected.

Table 2

Socialization and Goals Questionnaire Negative Responses
Means (Standard Deviations) and Tests of Significance

	Pre-Camp	Post-Camp	Follow Up	p-Value for Tests		
				Group	Time	Interaction
Control	1.00	1.00	1.00	*.0076	.8567	.8567
	(1.31)	(0.76)	(1.07)			
Experi.	0.25	0.25	0.00			
	(0.46)	(0.46)	(0.00)			

Note. N=16

*p significant at .05 level

In Table 3, SGQ undecided responses, the two groups were similar in undecided responses. There was a significant change for the control and experimental groups over time at $p=.0039$. The test of interaction gave a significant $p=.0047$, meaning that there was a significant difference between groups in undecided responses as a result of the intervention.

Table 3

Socialization and Goals Questionnaire Undecided Responses
Means (Standard Deviations) and Tests of Significance

				p-Value for Tests		
	Pre-Camp	Post-Camp	Follow Up	Group	Time	Interaction
Control	1.13	1.00	1.25	.5963	*.0039	*.0047
	(1.36)	(1.51)	(1.75)			
Experi.	1.88	0.25	0.38			
	(1.13)	(0.46)	(0.52)			

Note. N=16

*p significant at .05 level

It was interesting to explore whether results would differ from post-camp to follow-up, when they did not differ between pre-camp, post-camp, and follow-up. In Table 4, SGQ positive results are displayed for post-camp and follow-up interventions only. There was a significant difference between groups with $p=.0199$. It is not surprising that there were no significant changes seen in the interaction column, as changes seen in the interval from pre-camp to post-camp (in Table 1) account for all of the changes. The interaction column (in Table 4) shows no further changes from post-camp to follow-up, which is consistent with prolonged retention of treatment information on socialization and goals.

Table 4

Socialization and Goals Questionnaire Positive Responses
Means (Standard Deviations) and Tests of Significance

	Post-Camp	Follow Up	p-Value for Tests		
			Group	Time	Interaction
Control	09.00	08.75	*.0199	.7758	.3984
	(1.85)	(1.75)			
Experi.	10.50	10.63			
	(0.76)	(0.52)			

Note. N=16

*p significant at .05 level

The adolescents appeared to gain in cohesion (doing things as a group) during the week-long treatment and were able to verbalize or list on the SGQ, an increased amount of socialization and recreational opportunities for adolescents with myelomeningocele. Where the experimental group was undecided on the SGQ before the treatment, they could now verbalize their goals. This meant that they learned how to express themselves in this area as a result of the treatment. There were no internal conflicts between individuals in the experimental group, possibly due to the homogenous group and understanding each others needs (peer support). The experimental group exchanged addresses and called each other at least one month after the treatment. They retained information as shown by negative responses converting to positive responses on the SGQ between observations. The hypothesis was that positive responses would increase following the treatment and this was supported. Controls did not change significantly from pre-camp to follow-up responses and there was no group cohesion, both of which were predicted.

The literature stated that health professionals should work with children to help normalize social experiences of children developing with spina bifida, in order to decrease social isolation and associated sequelae during and beyond adolescence. The study's findings supported those in the literature in that adolescents were able to identify social/recreational activities appropriate for them, and they acted on this information by getting together for a dance weeks after the intervention. Adolescents also were able to identify appropriate occupations and set goals after high school graduation, which is a normal activity for this age group.

According to Orem, the treatment assisted the self-care agency in meeting the universal self-care requisite related to social interaction and normal functioning within social groups. Normalization was promoted by the nursing agent (nurse) by encouraging the self-care agent (adolescent) to pursue social/recreational opportunities for peer interaction, meeting the developmental self-care requisite. Nursing agency assisted the self-care agent in meeting the therapeutic self-care demand. As parents are unable to meet all social and vocational needs, nurses can improve self-care in the supportive-educative role described in this treatment.

The SGQ showed that the treatment was successful in answering questions for adolescents regarding socialization/recreation and future goal setting. Subjects that listed goals on the pre-camp SGQ, listed more detailed/realistic goals post-camp. On the section of the SGQ which was not coded and submitted to quantitative analysis, regarding camp expectations, most subjects wanted to know about being more independent, having fun, and meeting new people. On the post-camp observation, all subjects felt the camp met their expectations. The favorite parts were "driving," "all week," "new friends," and "fun." Recommended changes were "nothing," "food," "no school," "getting up early," "less exercise," and "some boring speakers." Negative responses were mostly voiced by one subject. For controls, the SGQ provided information as to where teaching was needed. Self-care deficits identified for individuals in the control group will be met in upcoming clinic visits by nurses in the supportive-educative role.

Self-Esteem

The second component of the hypothesis was that the treatment would increase the self-esteem of adolescents with spina bifida. This variable was measured by the Piers-Harris Children's Self-Concept Scale (PHCSCS). In the experimental and control groups between observations 01, 02, and 03, ANOVA was used to analyze PHCSCS total scores and cluster scores to determine if group differences held up over time. In Tables 5-18, means and standard deviation are again noted on the left side. The group heading is a measure of statistical difference between control and experimental groups. The time heading refers to the change of all 16 subjects together over three times, as one group. The interaction heading refers to group and time together which relates to whether the experimental group changes over time in a different way than the control group. The interaction column is the most significant finding for the purposes of this study.

In Table 5, PHCSCS total scores, the time was significant with $p=.0330$, meaning that responses for all 16 subjects changed over time. For total scores, there was no significant difference between groups over time as a result of the treatment. Differences between groups over time were more evident in cluster scores which will be illustrated in PHCSCS cluster tables, which follow the PHCSCS total scores tables.

Table 5

Piers-Harris Children's Self-Concept Scale-Total Scores
Means (Standard Deviations) and Tests of Significance

				p-Value for Tests		
	Pre-Camp	Post-Camp	Follow Up	Group	Time	Interaction
Control	54.50	57.63	57.63	.8425	*.0330	.4358
	(19.94)	(21.51)	(21.51)			
Experi.	54.00	55.13	55.13			
	(15.55)	(14.65)	(14.65)			

Note. N=16

*p significant at .05 level

In Table 6 PHCSCS Behavior cluster scores showed significance for time only with $p = .0074$, meaning that responses for all 16 subjects changed over time. There were no significant differences between groups as a result of the treatment.

Table 6

Piers-Harris Children's Self-Concept Scale-Behavior Cluster Means (Standard Deviations) and Tests of Significance

				p-Value for Tests		
	Pre-Camp	Post-Camp	Follow Up	Group	Time	Interaction
Control	12.75	12.88	13.25	.7940	*.0074	.0914
	(4.86)	(4.61)	(3.92)			
Experi.	12.38	13.00	14.88			
	(2.67)	(3.02)	(1.13)			

Note. N=16

*p significant at .05 level

In Table 7, PHCSCS intellectual/school status cluster scores were significant for time with $p=.0458$ meaning that all 16 subjects changed over time. The test of interaction with $p=.0116$, showed a significant difference between groups over time as a result of the treatment. This could be interpreted that for the experimental group under intellectual/school status, the nursing role was educative and learning at camp was a positive experience for adolescents. There was no support or education given to the control group, therefore no significant changes occurred.

Table 7

Piers-Harris Children's Self-Concept Scale-Intellectual/School Status Cluster Means (Standard Deviations) and Tests of Significance

	Pre-Camp	Post-Camp	Follow Up	p-Value for Tests		
				Group	Time	Interaction
Control	11.88	12.88	11.88	.7955	*.0458	*.0116
	(3.91)	(4.16)	(4.58)			
Experi.	10.63	11.25	13.38			
	(3.78)	(3.11)	(1.92)			

Note. N=16

*p significant at .05 level

In Table 8 PHCSCS Physical Appearance/Attributes cluster scores showed significance for time only with $p = .0005$, meaning that responses for all 16 subjects changed over time. There were no significant differences between groups as a result of the treatment. There was only one grooming class for females which apparently was not effective to change this cluster score.

Table 8
Piers-Harris Children's Self-Concept Scale Physical Appearance/Attributes Cluster Means (Standard Deviations) and Tests of Significance

				p-Value for Tests		
	Pre-Camp	Post-Camp	Follow Up	Group	Time	Interaction
Control	9.88	10.50	11.00	.8442	*.0005	.2277
	(3.36)	(3.96)	(3.42)			
Experi.	9.00	10.00	11.50			
	(3.30)	(2.14)	(1.41)			

Note. N=16

*p significant at .05 level

In Table 9, PHCSCS Anxiety cluster scores were significant for time with $p=.0461$ meaning that all 16 subjects changed over time. The test of interaction with $p=.0175$ showed a significant difference between groups over time as a result of the treatment. For this Anxiety cluster, this could be interpreted that experimental subjects felt less anxious. Possibly the coping classes and the supportive role of the nurse was demonstrated here. There was no support or education given to the control group, therefore no significant changes occurred.

Table 9

Piers-Harris Children's Self-Concept Scale-Anxiety Cluster
Means (Standard Deviations) and Tests of Significance

	Pre-Camp	Post-Camp	Follow Up	p-Value for Tests		
				Group	Time	Interaction
Control	7.63	9.25	8.13	.6822	*.0461	*.0175
	(5.21)	(5.04)	(5.38)			
Experi.	8.63	8.75	10.50			
	(4.47)	(4.50)	(3.38)			

Note. N=16

*p significant at .05 level

In Table 10 PHCSCS Popularity cluster scores showed significance for time only with $p=.0139$, meaning that responses for all 16 subjects changed over time. There were no significant differences between groups as a result of the treatment.

Table 10

Piers-Harris Children's Self-Concept Scale-Popularity Cluster
Means (Standard Deviations) and Tests of Significance

				p-Value for Tests		
	Pre-Camp	Post-Camp	Follow Up	Group	Time	Interaction
Control	7.25	8.00	8.00	.4297	*.0139	.0772
	(3.33)	(4.00)	(3.70)			
Experi.	8.50	8.25	10.13			
	(2.45)	(2.71)	(1.96)			

Note. N=16

*p significant at .05 level

In Table 11 PHCSCS Happiness/Satisfaction cluster scores showed significance for time only with $p=.0310$, meaning that responses for all 16 subjects changed over time. There were no significant differences between groups as a result of the treatment.

Table 11

Piers-Harris Children's Self-Concept Scale-Happiness/Satisfaction Cluster Means (Standard Deviations) and Tests of Significance

	Pre-Camp	Post-Camp	Follow Up	p-Value for Tests		
				Group	Time	Interaction
Control	8.00	8.50	8.38	.9505	*.0310	.0974
	(2.98)	(3.46)	(3.46)			
Experi.	7.88	8.00	9.25			
	(2.59)	(2.14)	(0.89)			

Note. N=16

*p significant at .05 level

Basically, the statistical results of the PHCSCS were not significant for pre-camp, post-camp, and follow-up, except for the intellectual/school status and anxiety clusters. The pilot study did not demonstrate significant results for the PHCSCS measurement either, even though observations were only available for pre-camp and post-camp. Realizing that it takes time to show improvement in self-esteem (greater than one week), the question the investigator set out to answer was, could improvement in self-esteem be demonstrated in one month follow-up after the

treatment. Tables 12-18 demonstrated results of the ANOVA between the post-camp and the one month follow-up observations for the PHCSCS.

In Table 12, PHCSCS total scores for post-camp and follow-up were significant for time with $p=.0244$ meaning that all 16 subjects changed over time. The test of interaction with $p=.0145$ showed a significant difference between groups over time as a result of the treatment. The findings illustrated that it may take time to show improvement in self-esteem. For future reference, a comparison of results at a six month follow-up observation to evaluate total self-esteem scores over time could prove interesting.

Table 12

Piers-Harris Children's Self-Concept Scale-Total Scores
Means (Standard Deviations) and Tests of Significance

	Post-Camp	Follow Up	p-Value for Tests		
			Group	Time	Interaction
Control	57.63	57.13	.7565	*.0244	*.0145
	(21.51)	(20.97)			
Experi.	55.13	65.00			
	(14.65)	(09.68)			

Note. N=16

*p significant at .05 level

In Table 13, PHSCS Behavior cluster scores for post-camp and follow-up showed significance for time only with $p=.0552$, meaning that responses for all 16 subjects changed over time. There were no significant differences between groups as a result of the treatment.

Table 13

Piers-Harris Children's Self-Concept Scale-Behavior Cluster Means (Standard Deviations) and Tests of Significance

	Post-Camp	Follow Up	p-Value for Tests		
			Group	Time	Interaction
Control	12.88	13.25	.5994	*.0552	.1848
	(4.61)	(3.92)			
Experi.	13.00	14.88			
	(3.02)	(1.13)			

Note. N=16

*p significant at .05 level

In Table 14, PHCSCS Intellectual/School Status cluster scores for post-camp and follow-up were significant for the test of interaction with $p=.0127$, which again showed a significant difference between groups over time as a result of the treatment. Significant results could have implications for the adolescents in their public school situation. Possibly doing well in the treatment setting, may improve self-esteem outside the treatment setting as well.

Table 14

Piers-Harris Children's Self-Concept Scale-Intellectual/School Status Cluster Means (Standard Deviations) and Tests of Significance

	Post-Camp	Follow Up	p-Value for Tests		
			Group	Time	Interaction
Control	12.88	11.88	.9714	.3208	*.0127
	(4.16)	(4.58)			
Experi.	11.25	13.38			
	(3.11)	(1.92)			

Note. N=16

*p significant at .05 level

In Table 15, PHCSCS Physical Appearance/Attributes cluster scores for post-camp and follow-up showed significance for time only with $p = .0109$, meaning that responses for all 16 subjects changed over time. There were no significant differences between groups as a result of the treatment. The lack of significant results again may indicate that the treatment (grooming) was not strong enough to bring about improvement in this area.

Table 15

Piers-Harris Children's Self-Concept Scale Physical Appearance/Attributes Cluster Means (Standard Deviations) and Tests of Significance

			p-Value for Tests		
	Post-Camp	Follow Up	Group	Time	Interaction
Control	10.50	11.00	1.0000	*.0109	.1644
	(3.96)	(3.42)			
Experi.	10.00	11.50			
	(2.14)	(1.41)			

Note. N=16

*p significant at .05 level

In Table 16, PHCSCS Anxiety cluster scores for post-camp and follow-up were significant for the test of interaction with $p=.0038$, which again showed a significant difference between groups over time as a result of the treatment. Anxiety reduction in the treatment may have long lasting benefits (up to one month) resulting in improved self-concept for the experimental group in this area.

Table 16

Piers-Harris Children's Self-Concept Scale-Anxiety Cluster
Means (Standard Deviations) and Tests of Significance

	Post-Camp	Follow Up	p-Value for Tests		
			Group	Time	Interaction
Control	09.25	08.13	.6873	.4628	*.0038
	(5.04)	(5.38)			
Experi.	8.75	10.50			
	(4.50)	(3.38)			

Note. N=16

*p significant at .05 level

In Table 17, PHCSCS Popularity cluster scores for post-camp and follow-up were significant for time with $p = .0283$ meaning that all 16 subjects changed over time. The test of interaction with $p = .0283$ showed a significant difference between groups over time as a result of the treatment. This cluster was not significant when comparing pre-camp, post-camp, and follow-up observations together. Adolescents may have experienced peer-support and improved perception of popularity, due to telephone calls from new friends acquired during the treatment.

Table 17

Piers-Harris Children's Self-Concept Scale-Popularity Cluster
Means (Standard Deviations) and Tests of Significance

	Post-Camp	Follow Up	p-Value for Tests		
			Group	Time	Interaction
Control	08.00	08.00	.4571	*.0283	*.0283
	(4.00)	(3.70)			
Experi.	08.25	10.13			
	(2.71)	(1.96)			

Note. N=16

*p significant at .05 level

In Table 18, PHCSCS Happiness/Satisfaction cluster scores for post-camp and follow-up were significant for the test of interaction with $p=.0473$, which showed a significant difference between groups over time as a result of the treatment. This cluster was not significant during the comparison of pre-camp, post-camp, and follow-up observations together. Adolescents in the experimental group appeared happier and are apparently more satisfied, as shown in the follow-up observation.

Table 18

Piers-Harris Children's Self-Concept Scale-Happiness/Satisfaction Cluster Means (Standard Deviations) and Tests of Significance

			p-Value for Tests		
	Post-Camp	Follow Up	Group	Time	Interaction
Control	08.50	08.38	.8888	.0969	*.0473
	(3.46)	(3.46)			
Experi.	08.00	09.25			
	(2.14)	(0.89)			

Note. N=16

*p significant at .05 level

These results demonstrated the importance of a follow-up observation for self-esteem changes of at least one month following the end of treatment. The total scores, and the addition of two clusters, illustrate that nursing in the supportive/educative role can improve certain levels of self-concept for adolescents over time through a hospital-based treatment program.

Furthermore, a qualitative analysis of results is helpful when it is difficult to determine from statistical information alone, how useful an approach was to a specific client. LeFort (1993) found that, "there is general agreement that tests of statistical significance do not provide information about the clinical significance or practical importance of research results" (p. 57). In a small group, it is relevant to look at individual subjects when evaluating the importance of an intervention, so that individual improvement over time is not overlooked.

For example, in individual #3, a pre-test total score was 19 out of 80 positive responses on the PHCSCS. At the follow-up observation, the total score was 50 out of 80 positive responses.

Individual #7 possessed the greatest number of self-care deficits and had a total score on the PHCSCS which actually declined immediately post-camp. As in the pilot study, lower post-camp scores could be related to the focus on deficits, that is concentration on disabilities. In the follow-up observation, the total score was 73 positive responses out of 80, which indicates that some self-care requisites might have been reached, leading to improvement in self-concept.

Self-concept has many facets that may take an extended period of time to become evident. The increase in some of the cluster scores within the PHCSCS illustrated that treatment was effective in some areas, and that further or different treatment was needed in other areas. The PHCSCS showed striking gains in strengths in some individuals as demonstrated by upward trends in selected clusters. This improvement was not seen in control subjects over time.

The themes from the literature were that the self-esteem crisis is more profound in this population of adolescents with handicaps, due to the dearth of appropriate role models. This has important implications, as it has been found that an increasing number of individuals with myelomeningocele are expected to live to adulthood. Hopefully, there will be a corresponding increase in the amount of successful role models like the one described in the treatment. Adolescents described in the literature and in this study felt left out as they participated in few activities outside the home. Friends were fewer as adolescents matured. This appeared to have a negative effect on self-esteem. The subjects participated in few sports, which can also decrease self-esteem for many reasons. Exercise/recreation are thought to provide psychological enhancement, which possibly was shown in the experimental group, by increased self-concept scores.

In light of Orem's self-care theory, the nursing agent (nurse) in the supportive/educative role can assist the self-care agent (adolescent) to meet the therapeutic self-care demands of both developmental and universal self-care requisites. The PHCSCS clusters related to school status and anxiety and finally, popularity and happiness, did improve over time, due to the therapeutic demands being directly met by the nursing agency and indirectly met through increased socialization and recreation. The PHCSCS measurement is easy to administer and interpret using the corresponding manual. However, it is only one way to measure self-concept in this population.

Independence in Activities of Daily Living (ADL's)

The third component of the hypothesis was, that the treatment would increase independence in ADL's of adolescents with spina bifida. This variable was measured by the Functional Independence Measure (FIM). In the experimental and control groups between observations 01, 02, and 03, ANOVA was used to analyze FIM total scores to determine if group differences held up over time. In Tables 19-20, means and standard deviation remain on the left side. The group heading is a measure of statistical difference between control and experimental groups. The time heading refers to the change of all 16 subjects together over three times, as one group. The interaction heading refers to group and time together which relates to whether the experimental group changes over time in a different way than the control group. The interaction column is the most significant finding for the purposes of this study.

In Table 19, FIM total scores, there was no significant difference between groups over time as a result of the treatment. This can be explained as there were generally high levels of independent function for both the control and experimental groups.

Table 19

Functional Independence Measure-Total Scores
Means (Standard Deviations) and Tests of Significance

				p-Value for Tests		
	Pre-Camp	Post-Camp	Follow Up	Group	Time	Interaction
Control	115.63	115.63	115.63	.8820	.2117	.2117
	(12.79)	(12.79)	(12.79)			
Experi.	115.75	116.50	117.00			
	(08.46)	(07.35)	(06.72)			

Note. N=16

*p significant at .05 level

In Table 20, FIM total scores, there was no significant difference in the interaction from post-camp to follow-up for the group, related to high levels of independence in ADL's functioning.

Table 20

Functional Independence Measure-Total Scores
Means (Standard Deviations) and Tests of Significance

	Post-Camp	Follow Up	p-Value for Tests		
			Group	Time	Interaction
Control	115.63	115.63	.8305	.3343	.3343
	(12.79)	(12.79)			
Experi.	116.50	117.00			
	(7.35)	(6.72)			

Note. N=16

*p significant at .05 level

The FIM was adequate to measure the subject's level of independence in ADL's, although a more sensitive instrument might have yielded more significant results. This instrument would be useful for a population with higher self-care deficits as well. On an individual level, the experimental group had three subjects achieve a slightly higher score on the FIM and two individuals gained one point. One experimental subject gained four points immediately after the intervention and four more points at follow-up. This did not demonstrate statistical significance for the group, but it was significant for that individual. Even the act of putting on one's own

pants without assistance is significant for a given individual and the family. If self-care deficit improves, even by one point, this has clinical significance which can be more meaningful to the individual and the family than statistical significance. The treatment, therefore, demonstrated clinical significance for several individuals. In general, the FIM identified common problems for this population centering around sphincter control (bowel/bladder) and locomotion (support with stairs).

In evaluation of ADL's it was helpful for the investigator to have assistance from occupational therapists to validate findings. Investigators and clinicians must use caution in scoring an individual lower in the hospital than they would normally be scored at home. The subject may have a lower bed or bathtub adaptations at home, which improve independence in transfers there but which are not available in the hospital. For the purposes of this treatment, the nurse should assess the total function of the individual and score at the highest level the individual can achieve, whether this is at home or in the hospital setting.

The theme from the literature was that achieving independence was more difficult for handicapped adolescents. Using Orem's perspective, the concept of independence is difficult, due to the self-care requisite of health-deviation. In the supportive/educative role, the nurse agent (nurse) should make the client more of a self-care agent than a receiver of care, that is in a dependent role. The important goal is to develop a lifestyle compatible with the effects of the health-deviation, which can be assisted by the nursing agent through education and guidance. Orem concurs that clinical significance can be more important than group significance, as

demonstrated by the FIM in this study. Recommendations from the literature reinforced that more research is needed on hospital-based camps with multidisciplines working together to help the client to develop the skills needed for independence. In Orem's terms, therapeutic self-care demands can be identified by the nursing agency to meet self-care requisites.

Chapter V

Summary and Conclusions

This study explored the benefits of a hospital-based camp for promoting independence in adolescents with spina bifida. The purposes of this study were to demonstrate specific outcomes of a program designed to help adolescents with myelomeningocele: 1) to increase knowledge of socialization, and future goals; 2) to improve self-esteem; and 3) improve independence in activities of daily living (ADL's). The intervention was designed to test the hypothesis that a hospital-based camp would accomplish these purposes. The results of the investigation of 16 adolescents with spina bifida supported this hypothesis.

This study used a quasiexperimental, equivalent control-group, interrupted time series design. The sample consisted of 16 subjects, eight experimental and eight control group subjects, between 13 and 19 years old, with spina bifida. The experimental subjects volunteered to spend one week at Shriners Hospital in the treatment program (see Appendix H), the controls were contacted by telephone. Three instruments: 1) Socialization and Goals Questionnaire (SGQ); 2) Piers-Harris Children's Self-Concept Scale (PHCSCS); and 3) Functional Independence Measure (FIM), were given over three interrupted time intervals and analyzed by analysis of variance pre-camp, post-camp, and follow-up. The level of significance used was $p=.05$. The research hypothesis was supported in that socialization and goals can be significantly improved for individuals and group, by a hospital-based camp as shown by the SGQ. Self-Concept was difficult to measure as it changes over longer periods

of time and there are many variables involved in self-esteem. The PHCSCS demonstrated that total self-esteem scores for individuals and group can improve, seen in the one month follow-up in areas of: intellectual/school status, anxiety, popularity, and happiness/satisfaction. The FIM was an accurate measure of activities of daily living. The experimental group had relatively high independence function for their disability, so did not dramatically improve in ADL's as a group. Individually, the FIM was able to show clinical improvement in three subjects.

This study demonstrated that clinical significance was more meaningful to individuals than statistical significance. Nurses are in a unique position to improve socialization and goals, self-esteem, and independence in adolescents with spina bifida. A variety of instruments should be explored to record results of interventions over time, as all benefits may not be evident immediately following the treatment.

The therapeutic intervention of the hospital-based camp had a positive outcome. The hypothesis was supported according to Orem's theory, as the nursing agency can assist the self-care agent to meet therapeutic self-care demands, necessary to achieve the self-care requisites of: 1) universal self-care (socialization and goals), normalization in peer interactions; 2) developmental self-care (self-esteem), sexuality and identity; and 3) health-deviation self-care (independence in ADL's), prevention of further deviation from function. This study supported Orem's contention that a self-care deficit existed in this population with spina bifida, when self-care agency was not sufficient to meet the therapeutic self-care demand.

The findings from the treatment supported those in the existing literature that adolescents with spina bifida do lead sedentary lifestyles, and that needs for socialization with peers are unmet. Lower scores on self-esteem in the pre-camp period of time may be related to this identity crisis. Exercise may lead to increased peer-interaction with possible long-term psychological enhancement. A follow-up study at six months could illustrate long-term application of the treatment to increase socialization, improve self-esteem, and improve independence in ADL's. Support for the use of measurements to study self-esteem, goal setting, and independence in a camp situation is found in the literature. This study demonstrated that these measurements can easily be given in a hospital-based camp and that multidisciplines are helpful in decreasing self-care deficits. Changes do come slowly, particularly in self-esteem, so long-term follow-up is recommended whenever feasible. More research is needed on the applicability of these measurements and on the ability of the nursing agency to help adolescents with spina bifida to become more independent through a supportive/educative approach.

Limitations

One limitation of this study included the age range and developmental levels of the participants. Adolescents were 13 to 19 years old with a mean age of 16 years. In the control group, the youngest adolescent was in seventh grade and the oldest was a freshman in college. In the experimental group, the youngest adolescent was in seventh grade and the oldest was a senior in high school. A recommendation for future studies is to group participants by school level.

Another limitation was the small sample size and inability to do a random selection of subjects due to availability of adolescents with myelomeningocele who met the criteria for participation. There may have been some variation in response to direct contact with the experimental group and indirect (telephone) contact with the control group and the instruments used for the treatment.

The final limitation was the brief length of time the study was conducted. Perhaps a longer camp would yield more significant results in the areas of self-esteem and ADL's.

Implications

The clinical implications of the findings are apparent in the need to assess all adolescent's knowledge of self related to their diagnosis, opportunities for socialization, setting mutual goals for the future, recreation and exercise routines, support and coping mechanisms, and independence in ADL's. Further study could examine factors related to the increase in independence in ADL's which might also result in increased self-esteem. This study implied that a hospital-based camp was an effective means of learning about oneself and establishing education/career goals. If there are no community supports outside the family to assist adolescents (with physical challenges) to overcome self-care deficits, nurses should consider the possibility of a hospital-based camp to provide support and education. Many benefits are difficult to measure with just one instrument, but perhaps the most positive finding is the socialization that occurs during and after the intervention. This benefit

is difficult to measure, but it is possibly one of the most satisfying results for the adolescent.

Orem's theory can also be applied to preventive health care. The emphasis on self-care agency and the recognition of the person's ability to care for self, could lead to more efficient use of health care services by decreasing the amount of time the client spends using these services. This is an important issue in cost containment. Increasing financial independence of adolescents transitioning into adulthood through education of vocational goals would be a positive outcome in meeting self-care requisites.

This treatment applied Orem's theory, in demonstrating that increasing independence of the self-care agent (adolescent) can lead to individual improvement in socialization, self-esteem, and ADL's. This study supported Orem's findings and is useful in clinical practice. In the educative role, nursing educators and managers can work with students and staff nurses to let them know that by increasing self-care requisites, the client can become more independent. This could change nurses' views regarding patients coming to the hospital for treatment, that is the nurse could perceive adolescents with myelomeningocele coming to the hospital for health promotion instead.

Recommendations

Recommendations for further study may benefit future hospital-based camps. A larger sample size is recommended to increase generalizability of results. Measurements should be further explored and refined and more than one instrument

should be used for measuring improvement after treatment in hospital-based camps. New instruments such as the Socialization and Goals Questionnaire should be clinically tested on this population, for validity to measure knowledge of socialization, and ability to set future goals. Participants could be grouped by school level rather than age. In the population of children with disabilities, age is not the most accurate measure of development. The observation time should be expanded to at least six months or longer to measure long-term implications of the treatment. Controls should be educated and supported in identified self-care deficit areas. Camps should be attempted for children of all ages and with many different types of diagnoses. It appears this is an important time to bring this age group together to transition into adulthood, especially for adolescents with myelomeningocele.

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Appendix A

Camp SPIRIT Schedule

CAMP SPIRIT-SCHEDULE

Time	Sun.(10/4)	Mon.(10/5)	Tues.(10/6)	Weds.(10/7)	Thur.(10/8)	Fri.(10/9)	Sat.(10/10)	Sun.(10/11)
7:00A-8:00A		Wake Up & ADL's Breakfast	Wake Up & ADL's Breakfast	Wake Up & ADL's Breakfast	Wake Up & ADL's Breakfast	Wake Up & ADL's Breakfast	7:30 Wake Up	7:30 Wake Up
8:00A-8:30A		Breakfast	Breakfast	Breakfast	Breakfast	Breakfast	ADL's	ADL's
8:30A-9:00A		Warm-up	Warm-up	Warm up	Warm up	Warm up	Breakfast	Breakfast
9:00A-9:30A	Check-in Unpack	Exercise Class	Exercise Class	Exercise Class	Exercise Class	Exercise Class	Richard Simmons	W/C Exercises
9:30A-10:00A	Orientation -Consents	School	School	School	School	Dating Tips	Exercise Tape	Bible Read or Free Time
10:00A-11:00A	Goals PiersHarris	School	School	School	School	Myelo Sexuality	W/C Fashions	Goals PiersHarris
11:00A-11:30A	ADL's	School	School	School	School	Sexuality Q & A	Practice for Party	ADL's
11:30A-12:00P	Lunch	ADL's	ADL's	ADL's	ADL's	Sexuality Q & A	ADL's & Lunch	Lunch
12:00P-12:30P	Depart Tryon Park	Lunch	Lunch	Lunch	Lunch	ADL's	Leave for Boat Trip	D/C Planning
12:30P-1:00P	Arrive Tryon Park	School	School	School	School	Lunch	To Boat	Pack
1:00P-2:00P	Hike	School	School	School	School	Party Practice Swim Gear	Sternwheeler	Practice for Party
2:00P-3:00P	Hike Return	Leave for Zoo	Money Managemt	Coping Skills	Guided Imagry	Interview Skills 2:30	Sternwheeler	Party Set Up
3:00P-4:00P	Travel/leis. Un-Game	Video Safari	Vocational Rehab.	Nutrition Class	PSU Student Services	Career Folders & To Swim	Sternwheeler	Party
4:00P-5:00P	Sports Options	Video Safari	Vocational Rehab.	Adaptive Driving	Computer Class	Swimming	Return from boat	D/C & Return Home
5:00P-6:00P	ADL's & Dinner	ADL's & Dinner	ADL's & Dinner	Transitions & Dinner	Computer Class	ADL's & Dinner	ADL's & Dinner	
6:00P-7:00P	Plan Teen Dinner & Movie	Bowel & Bladder Programs	To Wash.SQ Mall	ADL's & ID Arch. Barriers	Teen Dinner	Dress & Prepare/ Dancing	Movies TBA	
7:00P-8:00P	Movie "Gaby"	Adult with Myelo	Malling	Laundry & Call Home	Grooming Makeovers	Dancing	Movies TBA	
8:00P-9:00P	Movie PM Routine	Group & PM Routine	Return PM Routine	Group & PM Routine	Grooming & PM Routine	Dancing & PM Routine	Group & PM Routine	
9:00P-10:00P	ADL's & Bed	ADL's & Bed	ADL's & Bed	ADL's & Bed	ADL's & Bed	ADL's & Bed	ADL's & Bed	

AM ADL's: Get up,Cath,Dress

PM ADL's:Cath,Bowels,Wash,Set out clothes,Journal, Set Alarm

Appendix B

Informed Consent to Participate in Research Project

SHRINERS HOSPITALS FOR CRIPPLED CHILDREN
PORTLAND UNIT

INFORMED CONSENT TO PARTICIPATE IN RESEARCH PROJECT

Participant _____ Human Studies Committee
Approval Date August 7, 1992
Investigator Susan Cooper Labhard, BSN, RN (503)241-5090

Title of project, study or investigational drug: Camp SPIRIT
S: Socialization/Self-Esteem; P: Programs in vocational goals; I: Independence; R: Recreation; I: Improvement; T: Teamwork); A Hospital-based program for Promoting Independence in Adolescents with Spina Bifida.

Before agreeing to (your, your child's, your ward's) participation in this therapeutic camp, it is important that you read and understand the following explanation of the proposed procedures. It describes the purpose, procedures, possible benefits, risks, discomforts, and precautions of the therapeutic intervention. It also describes alternative procedures available and the right to withdraw from the program at any time. It is important to understand that no guarantee or assurance can be made as to the results. It is also understood that refusal to participate in this study will not influence standard treatment for (your, your child's, your ward's) medical care. Discussions regarding hospitalization apply only to the hospitalized group.

PURPOSE:

1. I agree to participation of _____ (myself, my child, my ward) in a study being conducted by Susan Cooper Labhard, RN and/or certain of her assistants. I understand that the study involves research and that the objective and purpose of the research is as follows: By admitting adolescents to the hospital for socialization with peers, education and recreation activities this experience will promote independence in activities of daily living (ADL's), and increased self-esteem, for adolescents with spina bifida.
2. The duration of (my, my child's, my ward's) participation in the study will be for: One week (Sunday-Sunday)

PROCECURES:

3. The procedures to be followed are: Orientation program. Check into hospital for week experience consisting of daily physical activities, ADL's, peer interactions and future oriented classes. Pre ADL/Self-esteem tests on first day, and post ADL/Self-esteem tests on the last day, and one month after the program.

All procedures will be routine.

BENEFITS:

4. There are no assurances as to any benefits, since the purpose of this study is to investigate the effectiveness of this week-long experience. I understand that the benefits to (me, my child, my ward) or to others which might be received from this research are:

Independence in activities of daily living for adolescent and increased self-esteem.

RISKS:

5. There are no reasonably foreseeable risks or discomforts to (me, my child, my ward) as a result of participating in this research study.

ALTERNATIVE PROCEDURES:

6. The following alternative procedures or courses of treatment are available that might be advantageous to (me, my child, my ward): Child can return home at any point in the program.

CONFIDENTIALITY:

7. I understand that (my, my child's, my ward's) participation in this study and my medical records will be kept confidential in accordance with applicable state and federal laws and that no information identifying (me, my child, my ward) will be released without my permission. However, a statistical report of this research project, which may include slides or photographs that do not identify (me, my child, my ward), may be disclosed in a scientific paper.

CONTACT FOR QUESTIONS:

8. I have had the opportunity to ask Susan Cooper Labhard, RN questions about the research project. I understand that I am to contact Susan Cooper Labhard, RN, at (503)241-5090 for answers to pertinent questions about research, (my, my child's, my ward's) rights as a research subject, and in the event of an adverse reaction or a research related injury to (me, my child, my ward's). I understand that I am to receive no payment for (my, my child's, my ward's) participation in this study. I further understand that in the event of an injury or adverse reaction resulting from (my, my child's, my ward's) participation in this research, no compensation, financial or otherwise, is offered by Shriners Hospitals of Crippled Children, Portland Unit. However, I have not waived my legal rights by signing this form. I also understand that Shriners Hospitals for Crippled Children, Portland Unit, can only provide emergency medical treatment in the event that a physical injury is sustained as a result of this research study.

VOLUNTARY PARTICIPATION/WITHDRAWAL:

- 9. Participation in this research study is voluntary and refusal to participate will involve no penalty or loss of benefits to which (I, my child, my ward) would otherwise be entitled. I further understand that I may withdraw my consent and discontinue participation in this study at any time without penalty or loss of benefits to which (I, my child, my ward) would otherwise be entitled. I further understand that refusal to participate or withdrawal from the study will not influence (my, my child's, my ward's) usual and normal treatment at Shriners Hospitals for Crippled Children, Portland Unit.
- 10. There are no consequences for withdrawing (me, my child, my ward) from the Camp SPIRIT Program. I only need to notify Ms. Labhard in person, in writing at Shriners Hospital for Crippled Children, Portland Unit, or by phone (503)241-5090.
- 11. Significant findings developed during the course of this research, which may relate to my willingness to continue participation, will be provided to me.
- 12. There will be 8 subjects involved in this study. Hospitalized and control subjects will be chosen by a multidisciplinary team consisting of myelodysplasia nurses, physical and occupational therapists, social services and child life.
- 13. I have read the above and have had all questions fully answered to my satisfaction. I understand and hereby consent to (my, my child's, my ward's) participation in this research project and to the performance of the outlined procedures upon (myself, my child, my ward). I have been given a copy of this Informed Consent form.

Signature of Witness

Signature of Parent or Legal Guardian

Signature of Parent or Legal Guardian

Date

Signature of Subject

(Signature of both parents should be obtained where possible and signature of patient should be requested if 14 years of age or over.)

Using language that is understandable and appropriate, I have discussed this project and the items listed above with the subject and/or his authorized representative.

Date

Signature of Supervising Physician

Date

Signature of Project Director or his/her Representative

Appendix C

Introductory Letter, Hospital Information
and Pre-Camp Questionnaire


Shriners Hospital
FOR CRIPPLED CHILDREN
Portland Unit

September 21, 1992

Dear _____ and Family:

We are excited that you have made the decision to participate in Camp SPIRIT from October 4-11, 1992. Camp SPIRIT is: S=Socialization/Self-Esteem; P=Programs in vocational goals; I=Independence; R=Recreation; I=Improvement; T=Teamwork!

Activities are planned to enhance peer relationships and to provide information that teens need to know. A professional staff from Shriners Hospital and the community are committed to this program and desire to bring you the best experience possible.

Enclosed, please find the following items that will be helpful in planning your trip:

- 1) Camp SPIRIT-Schedule: Daily activities listed. You will receive a final schedule in your booklet October 4th.
- 2) Portland Public Schools form: Give this to your teacher to plan assignments October 5-8.
- 3) Important to Know form: Contains a checklist of items to bring to camp.

Plan to check-in to 3rd floor and meet your roommates on Sunday, (10/4), between 9:00-10:00 a.m. Consent forms will be signed at that time. An opportunity to call home will be Wednesday (10/7) between 7:00-8:00 p.m. Parent/Teen party is Sunday (10/11) at 3:00 p.m., followed by discharge and return home. Please direct any questions to Susan Labhard, RN (503) 241-5090 or 1-800-221-5970. I look forward to seeing you soon!

SCHEDULE FOR FAMILIES

CAMP SPIRIT-SCHEDULE

Time	Sun.(10/4)	Mon.(10/5)	Tues.(10/6)	Weds.(10/7)	Thur.(10/8)	Fri.(10/9)	Sat.(10/10)	Sun.(10/11)
7:00A-8:00A		Wake Up & ADL's	Wake Up & ADL's	Wake Up & ADL's	Wake Up & ADL's	Wake Up & ADL's	7:30 Wake Up	7:30 Wake Up
8:00A-8:30A		Breakfast	Breakfast	Breakfast	Breakfast	Breakfast	ADL's	ADL's
8:30A-9:00A		Warm-up	Warm-up	Warm up	Warm up	Warm up	Breakfast	Breakfast
9:00A-9:30A	Check-in Unpack	Exercise Class	Exercise Class	Exercise Class	Exercise Class	Exercise Class	Richard Simmons	W/C Exercises
9:30A-10:00A	Orientation -Consents	School	School	School	School	Dating Tips	Exercise Tape	Bible Read or Free Time
10:00A-11:00A	Goals PiersHarris	School	School	School	School	Myelo Sexuality	W/C Fashions	Goals PiersHarris
11:00A-11:30A	ADL's	School	School	School	School	Sexuality Q & A	Practice for Party	ADL's
11:30A-12:00P	Lunch	ADL's	ADL's	ADL's	ADL's	Sexuality Q & A	ADL's & Lunch	Lunch
12:00P-12:30P	Depart Tryon Park	Lunch	Lunch	Lunch	Lunch	ADL's	Leave for Boat Trip	D/C Planning
12:30P-1:00P	Arrive Tryon Park	School	School	School	School	Lunch	To Boat	Pack
1:00P-2:00P	Hike	School	School	School	School	Party Practice Swim Gear	Sternwheeler	Practice for Party
2:00P-3:00P	Hike Return	Leave for Zoo	Money Managment	Coping Skills	Guided Imagry	Interview Skills 2:30	Sternwheeler	Party Set Up
3:00P-4:00P	Travel/leis. Un-Game	Video Safari	Vocational Rehab.	Nutrition Class	PSU Student Services	Career Folders & To Swim	Sternwheeler	Party
4:00P-5:00P	Sports Options	Video Safari	Vocational Rehab.	Adaptive Driving	Computer Class	Swimming	Return from boat	D/C & Return Home
5:00P-6:00P	ADL's & Dinner	ADL's & Dinner	ADL's & Dinner	Transitions & Dinner	Computer Class	ADL's & Dinner	ADL's & Dinner	
6:00P-7:00P	Plan Teen Dinner & Movie	Bowel & Bladder Programs	To Wash.SQ Mall	ADL's & ID Arch. Barriers	Teen Dinner	Dress & Prepare/ Dancing	Movies TBA	
7:00P-8:00P	Movie "Gaby"	Adult with Myelo	Malling	Laundry & Call Home	Grooming Makeovers	Dancing	Movies TBA	
8:00P-9:00P	Movie PM Routine	Group & PM Routine	Return PM Routine	Group & PM Routine	Grooming & PM Routine	Dancing & PM Routine	Group & PM Routine	
9:00P-10:00P	ADL's & Bed	ADL's & Bed	ADL's & Bed	ADL's & Bed	ADL's & Bed	ADL's & Bed	ADL's & Bed	

AM ADL's: Get up, Cath, Dress

PM ADL's: Cath, Bowels, Wash, Set out clothes, Journal, Set Alarm

IMPORTANT TO KNOW

1. Surgery and Treatment consent form must be signed by the patient's legal guardian. Proof of guardianship is necessary.
2. If your child has any signs of illness or infection, or has been exposed to any communicable disease such as: chicken pox, measles, mumps, etc., please notify us before you come to the hospital. We also need to know if your child has any dental problems - infected teeth, etc.
3. Sometimes additional tests such as special x-rays are required upon admission, prior to surgery. If these tests are done at another facility, but ordered by us, we would like to have your insurance information available for these places to bill. Shriners will pay the portion your insurance does not cover. You will not be asked to pay any of these charges. Please bring any insurance information, including welfare with you to the hospital.

CHECKLIST OF THINGS TO BRING TO THE HOSPITAL

1. MEDICAL HISTORY INFORMATION, DOCTORS NAMES AND ADDRESSES, IMMUNIZATION RECORDS
2. INSURANCE INFORMATION AND POLICY NUMBER
3. ANY PRESENT MEDICATIONS AND DIRECTIONS
4. PERSONAL CARE ITEMS
5. SWIM SUIT, OLD SHORTS, COAT OR JACKET
6. SUPPLY OF EASY CARE CLOTHING, SHOES - INCLUDE NIGHTWEAR (MARK WITH NAME) YOU MAY DO LAUNDRY AT THE HOSPITAL IF YOU WISH
7. FAVORITE TOY OR HOBBY SUITABLE FOR HOSPITAL
8. SCHOOL WORK AND READING MATERIAL

IF YOUR CHILD USES ANY OF THE FOLLOWING, PLEASE BRING THEM

1. ONE DAY SUPPLY: ILEO BAG, SPECIAL CATHETER, OR MEDICAL EQUIPMENT
2. SPLINTS, BRACES, PROSTHESES
3. STANDING FRAME, WHEELCHAIR, OR WALKER.
4. EYEGLASSES

EXTRAS WOULD INCLUDE: STAMPS, MONEY FOR PAY PHONE, RADIO OR TAPE PLAYER

*PERSONAL SPENDING MONEY (APROXIMATELY \$20.00)

PLEASE MARK ALL PERSONAL BELONGINGS WITH PATIENT'S NAME

To successfully implement the Shriners Hospital policy of quality care for children and their families, the following list of guidelines and responsibilities have been developed.

VISITING HOURS
Parents or Guardians - - - 24 hours
Brothers and Sisters - - - 7:00 am - 8:00 pm
Other Visitors - - - - - 12:00 pm - 8:00 pm

- * After 8:00 pm, parents/guardians will follow Rooming-In Guidelines
- * Between 10:00 pm & 7:00 am, visitors are limited to one Rooming In parent or guardian
- * All children, visiting on the unit **MUST** be supervised by parents **AT ALL TIMES**.

CAFETERIA HOURS
Continental Breakfast - - - 6:00 am - 10:00 am
Lunch - - - - - 11:00 am - 1:30 pm
Dinner - - - - - 5:00 pm - 6:00 pm

Shriners has implemented a **NO SMOKING** policy throughout the hospital. **Smoking areas are not provided**, within the hospital, for employees, parents or patients.

ROOMING - IN GUIDELINES

As space permits, one parent/guardian per patient may stay overnight in the greenroom or patient's room. Fold out beds are provided in both of these areas. Rooms with 2 patient beds have one fold out bed and can accommodate only one parent in the room. Rooms with 4 patient beds have space for only 2 parents (1 parent/child) in the room. Parents are encouraged to discuss among themselves who will sleep in the patient's room and who will sleep in the greenroom.

Rooming in priority or first choice should be given to any parent whose child has just returned from surgery. To insure privacy and prevent embarrassment to our teenage patients, Rooming-In parents need to be of the same sex as the patients in the room

SAFETY GUIDELINES

- * Each patient will sleep in his/her own bed/crib, **not in the parent's** bed.
- * Each parent will sleep in his/her own bed, **not in the child's** bed.
- * During sleep time, keep side rails raised on the bed/crib.

If a sibling wishes to stay overnight, instead of the parent, he/she must be over 18 years of age. Siblings under 18, including nursing infants, **MAY NOT** stay overnight.

WE DO NOT ALLOW SLEEPING IN A CAR/VAN/CAMPER/TRUCK THAT IS PARKED OVERNIGHT IN OUR PARKING STRUCTURE.

If you need assistance with obtaining overnight sleeping arrangements, outside the hospital, please contact Social Services or the Nursing Supervisor.

PATIENT BED TIME
Lights out - TV turned off
Patients under 6 years of age - - - - 8:00 pm
Patients 7 years - 12 years of age - 8:30 pm
Patients over 13 years of age - - - 10:00 pm
Rooming-in parent/guardian - - - - - 10:00 pm - - 7:00 am
Parents wishing to Room-In must be here before - - - 10:00 pm

Parents who wish to watch TV, read, socialize etc, after patient bed time, may do so in the parent lounge.

BEFORE 7:00 am

All Rooming-in parents are responsible for:

- * Restoring their sleep area to its original condition in preparation for day use.
- * Folding up their own bed and removing their own sheets and blankets.

USE OF SHOWERS

Rooming-In parents are welcomed to use the shower facilities:

- * Before 7:00 am
- * After 10:00 am (check with your child's nurse for the best time)
- * Late evening (after patients are settled for the night)

PRE-CAMP QUESTIONNAIRE

ACTIVITIES OF DAILY LIVING	NO HELP	SM HELP	LG HELP	FREQ.
Brush Teeth				
Brush Hair				
Dress				
Transfer				
Bathe				
Wash Face/Hands				
Check Skin				
Do Bladder/SIC Program				
Do Bowel Program				
Make Bed				
Clean room				
Make meal hot/cold				
Recreation Program				

1) Has the camper ever spent the night away from non-relative (other than hospitalization)?

2) Special supplies or equipment needed for camp experience?

3) Will the camper be on medication during the week?

4) What area do you feel is most important to concentrate on?

5) Special interest items:

NAME: _____ DOB: _____ #: _____

Appendix D

Morning (AM) and Evening (PM)
Activities of Daily Living (ADL's)
and Bowel Tracking Sheet

Appendix E

Socialization and Goals Questionnaire

(SOCIALIZATION AND GOALS QUESTIONNAIRE)

CAMP SPIRIT

PRELIMINARY QUESTIONNAIRE

1. Do teens with spina bifida have as much need for exercise as teens without spina bifida? circle YES or NO
2. Do you expect to go to college? circle YES or NO
3. Do you plan to date? circle YES or NO
4. Can teens with spina bifida go dancing? circle YES or NO
5. Does spina bifida exclude teens from participating in sports? Circle YES or NO
6. Can teens with spina bifida participate in group social activities? Circle YES or NO
7. Can a female with spina bifida get pregnant? Circle YES or NO
8. Can a male with spina bifida father a child? Circle YES or NO
9. Please list your goals after graduation.
10. Please list your five year goals.
11. How do you expect to support yourself?
12. What do you expect from this experience?

NAME:

DATE:

(SOCIALIZATION AND GOALS QUESTIONNAIRE)

CAMP SPIRIT

EXIT QUESTIONNAIRE

1. Do teens with spina bifida have as much need for exercise as teens without spina bifida? circle YES or NO
2. Do you expect to go to college? circle YES or NO
3. Do you plan to date? circle YES or NO
4. Can teens with spina bifida go dancing? circle YES or NO
5. Does spina bifida exclude teens from participating in sports? Circle YES or NO
6. Can teens with spina bifida participate in group social activities? Circle YES or NO
7. Can a female with spina bifida get pregnant? Circle YES or NO
8. Can a male with spina bifida father a child? Circle YES or NO
9. Please list your goals after graduation.
10. Please list your five year goals.
11. How do you expect to support yourself?
12. Did this experience meet your expectations?
13. What was the best part of Camp SPIRIT?
14. What parts of Camp SPIRIT would you change?

NAME:

DATE:

(SOCIALIZATION AND GOALS QUESTIONNAIRE)

CAMP SPIRIT

FOLLOW-UP QUESTIONNAIRE

1. Do teens with spina bifida have as much need for exercise as teens without spina bifida? circle YES or NO
2. Do you expect to go to college? circle YES or NO
3. Do you plan to date? circle YES or NO
4. Can teens with spina bifida go dancing? circle YES or NO
5. Does spina bifida exclude teens from participating in sports? Circle YES or NO
6. Can teens with spina bifida participate in group social activities? Circle YES or NO
7. Can a female with spina bifida get pregnant? Circle YES or NO
8. Can a male with spina bifida father a child? Circle YES or NO
9. Please list your goals after graduation.
10. Please list your five year goals.
11. How do you expect to support yourself?

NAME:

DATE:

Appendix F

Piers-Harris Children's Self-Concept Scale
and Authorization Letter

WPS TEST REPORT™ Piers-Harris Children's Self-Concept Scale

Western Psychological Services • 12031 Wilshire Boulevard • Los Angeles, California 90025

DIRECTIONS:

First fill in all identification information requested below, including name, school, date, sex, race (optional), grade, age, and student identification number. For grade, age, and student ID number, write the numbers in the boxes above the circles and then darken the circles that match. If you haven't been assigned a student ID number, ask your teacher or examiner.

Then read each of the statements on the front and back of this form. If a statement describes you, fill in the **Y** circle for Yes. If a statement does *not* describe you, fill in the **N** circle for No.

Try to answer all the statements, but do not fill in both the **Y** and **N** circles for the same statement. When you choose an answer,

make dark, heavy marks that cover the whole circle.

Example: 1. My classmates make fun of me. YES NO

If this statement describes you, fill in the **Y** circle.

If this statement does not describe you, fill in the **N** circle.

Use only a black-leaded pencil; do *not* use ink or felt-tipped pens. Make no stray marks on this answer sheet. If you make a mistake, erase your first mark completely and fill in the circle you want to choose.

Name: _____
 School: _____
 Date: _____

GRADE	
0	0
1	1
2	2
3	3
4	4
5	5
6	6
7	7
8	8
9	9

AGE	
0	0
1	1
2	2
3	3
4	4
5	5
6	6
7	7
8	8
9	9

STUDENT ID NUMBER									
0	0	0	0	0	0	0	0	0	0
1	1	1	1	1	1	1	1	1	1
2	2	2	2	2	2	2	2	2	2
3	3	3	3	3	3	3	3	3	3
4	4	4	4	4	4	4	4	4	4
5	5	5	5	5	5	5	5	5	5
6	6	6	6	6	6	6	6	6	6
7	7	7	7	7	7	7	7	7	7
8	8	8	8	8	8	8	8	8	8
9	9	9	9	9	9	9	9	9	9

SEX	RACE (Optional)			
Male	American Indian	Asian	Black	
Female	Hispanic	White	Other	

	YES	NO		YES	NO
1. My classmates make fun of me.	<input checked="" type="radio"/>	<input type="radio"/>	16. I have good ideas.	<input checked="" type="radio"/>	<input type="radio"/>
2. I am a happy person.	<input checked="" type="radio"/>	<input type="radio"/>	17. I am an important member of my family.	<input type="radio"/>	<input type="radio"/>
3. It is hard for me to make friends.	<input type="radio"/>	<input type="radio"/>	18. I usually want my own way.	<input checked="" type="radio"/>	<input type="radio"/>
4. I am often sad.	<input checked="" type="radio"/>	<input type="radio"/>	19. I am good at making things with my hands.	<input type="radio"/>	<input type="radio"/>
5. I am smart.	<input type="radio"/>	<input type="radio"/>	20. I give up easily.	<input type="radio"/>	<input type="radio"/>
6. I am shy.	<input checked="" type="radio"/>	<input type="radio"/>	21. I am good in my school work.	<input type="radio"/>	<input type="radio"/>
7. I get nervous when the teacher calls on me.	<input type="radio"/>	<input type="radio"/>	22. I do many bad things.	<input checked="" type="radio"/>	<input type="radio"/>
8. My looks bother me.	<input checked="" type="radio"/>	<input type="radio"/>	23. I can draw well.	<input type="radio"/>	<input type="radio"/>
9. When I grow up, I will be an important person.	<input type="radio"/>	<input type="radio"/>	24. I am good in music.	<input type="radio"/>	<input type="radio"/>
10. I get worried when we have tests in school.	<input checked="" type="radio"/>	<input type="radio"/>	25. I behave badly at home.	<input type="radio"/>	<input type="radio"/>
11. I am unpopular.	<input type="radio"/>	<input type="radio"/>	26. I am slow in finishing my school work.	<input checked="" type="radio"/>	<input type="radio"/>
12. I am well behaved in school.	<input checked="" type="radio"/>	<input type="radio"/>	27. I am an important member of my class.	<input type="radio"/>	<input type="radio"/>
13. It is usually my fault when something goes wrong.	<input type="radio"/>	<input type="radio"/>	28. I am nervous.	<input type="radio"/>	<input type="radio"/>
14. I cause trouble to my family.	<input checked="" type="radio"/>	<input type="radio"/>	29. I have pretty eyes.	<input type="radio"/>	<input type="radio"/>
15. I am strong.	<input type="radio"/>	<input type="radio"/>			

CONTINUE ON BACK

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 Wilshire Boulevard, Los Angeles, California 90025."

IMPORTANT: Examiner must enter
 number on Transmittal Form
 in submitting for scoring.

	YES	NO		YES	NO
30. I can give a good report in front of the class.	<input type="radio"/>	<input type="radio"/>	56. I get into a lot of fights.	<input type="radio"/>	<input type="radio"/>
31. In school I am a dreamer.	<input type="radio"/>	<input type="radio"/>	57. I am popular with boys.	<input type="radio"/>	<input type="radio"/>
32. I pick on my brother(s) and sister(s).	<input type="radio"/>	<input type="radio"/>	58. People pick on me.	<input type="radio"/>	<input type="radio"/>
33. My friends like my ideas.	<input type="radio"/>	<input type="radio"/>	59. My family is disappointed in me.	<input type="radio"/>	<input type="radio"/>
34. I often get into trouble.	<input type="radio"/>	<input type="radio"/>	60. I have a pleasant face.	<input type="radio"/>	<input type="radio"/>
35. I am obedient at home.	<input type="radio"/>	<input type="radio"/>	61. When I try to make something everything seems to go wrong.	<input type="radio"/>	<input type="radio"/>
36. I am lucky.	<input type="radio"/>	<input type="radio"/>	62. I am picked on at home.	<input type="radio"/>	<input type="radio"/>
37. I worry a lot.	<input type="radio"/>	<input type="radio"/>	63. I am a leader in games and sports.	<input type="radio"/>	<input type="radio"/>
38. My parents expect too much of me.	<input type="radio"/>	<input type="radio"/>	64. I am clumsy.	<input type="radio"/>	<input type="radio"/>
39. I like being the way I am.	<input type="radio"/>	<input type="radio"/>	65. In games and sports, I watch instead of play.	<input type="radio"/>	<input type="radio"/>
40. I feel left out of things.	<input type="radio"/>	<input type="radio"/>	66. I forget what I learn.	<input type="radio"/>	<input type="radio"/>
41. I have nice hair.	<input type="radio"/>	<input type="radio"/>	67. I am easy to get along with.	<input type="radio"/>	<input type="radio"/>
42. I often volunteer in school.	<input type="radio"/>	<input type="radio"/>	68. I lose my temper easily.	<input type="radio"/>	<input type="radio"/>
43. I wish I were different.	<input type="radio"/>	<input type="radio"/>	69. I am popular with girls.	<input type="radio"/>	<input type="radio"/>
44. I sleep well at night.	<input type="radio"/>	<input type="radio"/>	70. I am a good reader.	<input type="radio"/>	<input type="radio"/>
45. I hate school.	<input type="radio"/>	<input type="radio"/>	71. I would rather work alone than with a group.	<input type="radio"/>	<input type="radio"/>
46. I am among the last to be chosen for games.	<input type="radio"/>	<input type="radio"/>	72. I like my brother(sister).	<input type="radio"/>	<input type="radio"/>
47. I am sick a lot.	<input type="radio"/>	<input type="radio"/>	73. I have a good figure.	<input type="radio"/>	<input type="radio"/>
48. I am often mean to other people.	<input type="radio"/>	<input type="radio"/>	74. I am often afraid.	<input type="radio"/>	<input type="radio"/>
49. My classmates in school think I have good ideas.	<input type="radio"/>	<input type="radio"/>	75. I am always dropping or breaking things.	<input type="radio"/>	<input type="radio"/>
50. I am unhappy.	<input type="radio"/>	<input type="radio"/>	76. I can be trusted.	<input type="radio"/>	<input type="radio"/>
51. I have many friends.	<input type="radio"/>	<input type="radio"/>	77. I am different from other people.	<input type="radio"/>	<input type="radio"/>
52. I am cheerful.	<input type="radio"/>	<input type="radio"/>	78. I think bad thoughts.	<input type="radio"/>	<input type="radio"/>
53. I am dumb about most things.	<input type="radio"/>	<input type="radio"/>	79. I cry easily.	<input type="radio"/>	<input type="radio"/>
54. I am good-looking.	<input type="radio"/>	<input type="radio"/>	80. I am a good person.	<input type="radio"/>	<input type="radio"/>
55. I have lots of pep.	<input type="radio"/>	<input type="radio"/>			

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May 18, 1993

Susan Labhard
c/o Shriner's Hospital
Outpatient Clinic

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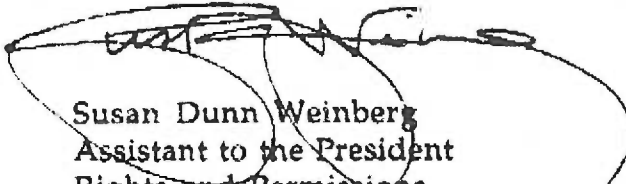
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SDW:se

Appendix G

Functional Independence Measure

UNIFORM DATA SYSTEM FOR MEDICAL REHABILITATION REHABILITATION FOLLOWUP CODING SHEET

1. Rehab Facility Code

2. Patient Number

3. Admission Date
 MONTH DAY YEAR

4. Discharge Date
 MONTH DAY YEAR

19. Other Diagnoses: (since discharge) ICD Code for new impairments, co-morbidity, and complications

1	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
2	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
3	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
4	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

5	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
6	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
7	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

ICD9Code

13. Living Arrangement

a. Setting FOLLOWUP
 01- Home 02-Board and Care 03-Transitional Living
 04- Intermediate Care 05-Skilled Nursing
 06-Acute Unit-your own facility
 07 - Acute Unit-Another facility 08-Chronic Hospital
 09-Rehab Facility 10-Other 11-Died

b. Living with FOLLOWUP
 1-Alone 2-Family/Relatives 3-Friends
 4-Attendant 5-Other

14. Vocational Status

a. Category FOLLOWUP
 1-Employed 2-Sheltered 3-Student 4-Homemaker
 5-Not working 6-Retired-age 7-Retired-disability

b. Effort FOLLOWUP
 1-Full-time 2-Part-time 3-Adjusted workload

15. Followup

a. Date MONTH DAY YEAR

b. Information source
 1-Patient 2-Family 3-Other

c. Method
 1-In person 2-Telephone 3-Mail

d. Health Maintenance primary secondary
 1- Own care 2-Unpaid helper
 3-Paid attendant 4-Paid professional

e. Therapy
 1- None 2-Outpatient Therapy
 3- Home Based Paid Therapy 4- Both 2 & 3
 5-Inpatient Hospital

22. Functional Independence Measure (FIM)

LEVELS	7 Complete Independence (Timely, Safety)	NO HELPER
	6 Modified Independence (Device)	
	Modified Dependence	HELPER
	5 Supervision	
	4 Minimal Assist (Subject = 75%+)	
	3 Moderate Assist (Subject = 50%+)	
	Complete Dependence	
2 Maximal Assist (Subject = 25%+)		
1 Total Assist (Subject = 0%+)		

<u>Self Care</u>		FOLLOWUP
A. Eating		<input type="text"/>
B. Grooming		<input type="text"/>
C. Bathing		<input type="text"/>
D. Dressing-Upper Body		<input type="text"/>
E. Dressing-Lower Body		<input type="text"/>
F. Toileting		<input type="text"/>
<u>Sphincter Control</u>		
G. Bladder Management		<input type="text"/>
H. Bowel Management		<input type="text"/>
<u>Mobility</u>		
Transfer:		
I. Bed, Chair, Wheelchair		<input type="text"/>
J. Toilet		<input type="text"/>
K. Tub, Shower		<input type="text"/>
<u>Locomotion</u>		
L. Walk/wheel Chair	wc	<input type="text"/>
M. Stairs		<input type="text"/>
<u>Communication</u>		
N. Comprehension	av	<input type="text"/>
O. Expression	vn	<input type="text"/>
<u>Social Cognition</u>		
P. Social Interaction		<input type="text"/>
Q. Problem Solving		<input type="text"/>
R. Memory		<input type="text"/>
Total FIM		<input type="text"/>

NOTE: Leave no blanks; enter 1 if patient not testable due to risk.

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UNIFORM DATA SYSTEM FOR MEDICAL REHABILITATION INPATIENT CODING SHEET

COMPLETE
BOTH SIDES

SIDE 2

Patient Number _____/_____/_____

15. Followup: Use separate Followup Coding Sheet

16. Impairment Group (complete on discharge) .

Put condition requiring admission to rehabilitation here, using Impairment Group Codes listed at the bottom of page 1. Be as specific as possible.

17. Date of Onset (of impairment) MONTH DAY YEAR

18. Principal Diagnosis (complete on discharge) ICD 9 Code
Use ICD code related to Impairment Group here.

19. Other Diagnoses (complete on discharge) ICD Code for other impairments, etiology, co-morbidity, and complications

1	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	
2	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	
3	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	
4	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	
		5	<input type="text"/>	<input type="text"/>	<input type="text"/>	
		6	<input type="text"/>	<input type="text"/>	<input type="text"/>	
		7	<input type="text"/>	<input type="text"/>	<input type="text"/>	

20. Payment Source (complete on Discharge)

a. Primary
b. Secondary

- 01-Blue Cross 02-Medicare 03-Medicaid/Welfare
- 04-Commercial Insurance 05-HMO 06-Worker's Comp.
- 07-Crippled Child. Serv. 08-Regional Ctr. Devel. Disab.
- 09-State Voc. Rehab. 10-Private Pay 11-Employee Courtesy
- 12-Free 13-Champus 14-Other 15-None

21. Charges (Rehab only) (Dollars only)

a. Total Rehab. Hospital \$
b. Include Physician? 1-Yes 2-No

22. Functional Independence Measure (FIM)

L E V E L S	7	Complete Independence (Timely, Safely)	NO
	6	Modified Independence (Device)	HELPER
		Modified Dependence	
	5	Supervision	
	4	Minimal Assist (Subject = 75%+)	
	3	Moderate Assist (Subject = 50%+)	HELPER
		Complete Dependence	
	2	Maximal Assist (Subject = 25%+)	
	1	Total Assist (Subject = 0%+)	

	ADMIT	DISCH
<u>Self Care</u>		
A. Eating	<input type="text"/>	<input type="text"/>
B. Grooming	<input type="text"/>	<input type="text"/>
C. Bathing	<input type="text"/>	<input type="text"/>
D. Dressing-Upper Body	<input type="text"/>	<input type="text"/>
E. Dressing-Lower Body	<input type="text"/>	<input type="text"/>
F. Toileting	<input type="text"/>	<input type="text"/>
<u>Sphincter Control</u>		
G. Bladder Management	<input type="text"/>	<input type="text"/>
H. Bowel Management	<input type="text"/>	<input type="text"/>
<u>Mobility</u>		
Transfer:		
I. Bed, Chair, Wheelchair	<input type="text"/>	<input type="text"/>
J. Toilet	<input type="text"/>	<input type="text"/>
K. Tub, Shower	<input type="text"/>	<input type="text"/>
<u>Locomotion</u>		
L. Walk/wheel Chair	<input type="text"/>	<input type="text"/>
M. Stairs	<input type="text"/>	<input type="text"/>
<u>Communication</u>		
N. Comprehension	<input type="text"/>	<input type="text"/>
O. Expression	<input type="text"/>	<input type="text"/>
<u>Social Cognition</u>		
P. Social Interaction	<input type="text"/>	<input type="text"/>
Q. Problem Solving	<input type="text"/>	<input type="text"/>
R. Memory	<input type="text"/>	<input type="text"/>
Total FIM	<input type="text"/>	<input type="text"/>

NOTE: Leave no blanks; enter 1 if patient not testable due to risk.

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Appendix H

Setting up a Hospital-based Camp and Outline of Camp SPIRIT

Setting up a Hospital-based Camp

The Decision

Experience with this population and literature review illustrated the problems that adolescents with physical challenges face, and the lack of support mechanisms for adolescents to deal with socialization and independence issues. When planning any camp, it is important to keep both the developmental milestones of the participants in mind as well as ultimate goals of the experience. List activities to be accomplished and form a schedule with speakers and assistants. This can take two weeks to two months, depending on the experience of the nurse and the availability of personnel and facilities.

The Location

The location is important not only for financial considerations, but medical and availability concerns. A summer camp in the mountains was offered for use this past fall. While the location would be spectacular, toileting facilities could be a challenge. The purpose of the camp was more than socialization and recreation. The location of the camp in the mountains would prohibit many speakers from making long drives from the city. Also, should there be medical emergencies, isolation would be a factor. By staying at the hospital the campers had a clean place to stay with easy access to food and bathroom facilities. Physicians and other supportive professionals were readily available for short time periods, without having to commit a day out of a busy schedule. Supervision by the night nursing shift allowed the nurse researcher a good rest. There was also access to activities for adolescents that only a big city could provide.

Initial disadvantages to having an inpatient hospital-based camp were based on the thought that adolescents volunteered to be admitted to the hospital. Though this did not defer anyone from signing up, it may be a factor for some. Advantages and disadvantages were discussed with the group, and it was mutually decided that for a week, the hospital would be more convenient and would not prevent them from participating again in the future. It is important to isolate this kind of group as much as possible from other children being admitted to the hospital for other reasons.

The Consents

A proposal must be written for research or grant purposes. Any research must be approved by the Human Subjects Committee of the facility. An outline of the camp's activities and time frames is helpful. Written approval should also be granted from the hospital Administrator, Chief of Medical Staff, and the Director of Patient Care Services. It is also necessary for parents or guardians to sign a consent for the adolescent's admission to the hospital and a consent for emergency treatment as well as for photography purposes.

The Participants

Campers should be close to the same developmental age and ability. A multi-disciplinary team is helpful in choosing the participants that would most benefit from the experience. Naturally, the number of staff required, depends on the abilities and needs of the campers. If a lot of teaching in bowel/bladder programs and self-care skills are required, one RN for every two patients is recommended. For eight adolescents that were fairly independent, one nurse counselor working a 12 hour shift with assistance from one other nurse in the morning and two occupational therapists

would be adequate. For future camps, it would be helpful to have a nurse available for an eight hour shift beginning in the morning.

Camp SPIRIT

A daily outline of Camp SPIRIT was provided to enable future investigators a personal appraisal of the camp.

Sunday. Campers and parents checked in at approximately 9:00 a.m. and adolescents were assigned to a bed in either the four bed girls room or the four bed boys room. Once consents were signed, parents departed and the SGQ and the PHCSCS were completed. Campers unpacked, did activities of daily living (ADL's) and had lunch. The first recreation experience was a wheelchair hike, in a local park. For outings, it worked well to have an adult volunteer or staff member for every two campers. While eight campers could fit in two wheelchair-lift vans, one large van with a truck to carry wheelchairs was preferred by the adolescents. Two adults trained in safe body mechanics are required to lift each adolescent into the van. After returning to the hospital-based camp, a sports options video was shown followed by discussion of sports that people with physical challenges could participate in. After dinner, a movie ("Gaby, A True Story") was shown about an adolescent with physical disabilities going to college and dating. There was popcorn and socialization during the movie. PM ADL's are described in the schedule. Upkeep of the notebook and the reward system were explained to campers and daily schedules distributed.

Monday. Campers were required to set the alarm and perform A.M. ADL's as described on the schedule. Occupational therapy began assessing independence in ADL's. The nurse then met with the therapists and completed the FIM. Suggestions in dressing were offered. Physical therapy had planned a.m. exercises. While this was not a favorite activity for all of the campers, each adolescent was required to do

some a.m. stretching and weight lifting activity. The object was to prove that one could have a busy day and still allow time to build up muscles and exercise to keep weight down. As this camp was in the fall, campers were required to bring their school assignments for hospital school from 9:30 a.m. to 2:00 p.m. This did prohibit additional activities on the schedule. It may have also had an unmeasurable effect on self-esteem of the group. The group would have enjoyed a summer camp so that school would not be a factor. That afternoon, we went to the local zoo for a video safari. This socialization experience was to give the campers a public speaking opportunity and future benefit. The adolescents were to describe themselves or an animal in front of the video camera. Each camper was to speak and would receive a copy of the video to take home. Usually talkative, the adolescents had difficulty in front of the camera. In the future, it might be helpful to have this activity later in the week when participants knew each other better and could speak more at ease. A picnic dinner followed. That evening an adult with spina bifida spoke to the campers as a role model. Of the ten of us, it was an unusual feeling to be the only one in the room without spina bifida. The speaker had made a success of her life both personally and professionally. She was also an active skier. The adolescents could relate to her stories and the time passed quickly. A brief group meeting was held to touch base prior to bed ADL's and distribution of the "SPIRIT Bucks" for tasks completed. Each camper was given the next day's schedule for the notebooks.

Tuesday. After school, a class was taught in money management. Then a Vocational Rehabilitation Counselor assessed individual interests and provided the campers with suggestions for realistic vocations and how to prepare for them. After

dinner, we loaded into the van for the mall. Two vans were planned for most outings, however, the adolescents requested to ride in the same van after the first trip. Eight campers were assisted into the van, while the wheelchairs were brought along in a truck. The campers had bonded and had no desire for separation, even for a brief trip. The mall was a socialization and learning experience. The goal was for the campers to find a T-shirt with the word "SPIRIT" on it using clues provided by the volunteers. Even the administrator joined in on this one! Some of the campers were getting in to the idea of the notebook and the "SPIRIT Buck" reward system. Under the ADL's section was a bowel tracking sheet. It was important that campers keep track of stools to avoid constipation and this was one way to remember. For every bowel program, the camper received a "quarter buck." One of the males stated, "I've never gotten paid for going to the bathroom before. You mean if I have another bowel movement, I get another buck?" It got to be a game, seeing who could collect the most bucks in one day for logging their ADL's. It was also a way for the nurse to keep track of everyone's programs. Stickers could be used for younger children.

Wednesday. After school, a psychologist from the university came to discuss "coping skills" with the campers. Questions were answered about what to do if you were left out of a group and what to do when you felt alone. In another room of the hospital, a nutrition class was provided by the dietitian. Campers learned about high-fiber foods and good choices of low calorie foods and liquids for a healthy lifestyle. Due to decreased mobility, it is very easy for adolescents to become overweight. Material was presented in an age appropriate manner with many visual aids. Another method of independence that is on the mind of most adolescents is

driving. An Adaptive Driving class was taught, complete with a van with hand controls. Transportation options were discussed with the adolescents. Outpatient nurses then held a Transitions into Adulthood class to prepare the adolescents for taking responsibility for their own care as independent consumers. As this was the middle of a busy week, no outside activities were planned so that the campers could catch up on laundry and call home. It was learned during the pilot study that calls to home could be disruptive to campers. Often there were tears and feelings of homesickness for the young girls in the pilot. It was prearranged that the adolescents at Camp SPIRIT would only be allowed to use the telephone on this evening, and it turned out to be an arrangement that worked well, for campers and parents. The group then started in the parking garage and worked it's way up to all the floors, identifying architectural barriers. The adolescents really got into rights of the disabled and felt that they were doing a community service. Suggestions were to be typed by the nurse and forwarded to administration.

Thursday. Everyone is in to the routine. The adolescents are following the schedule and arrive at required activities on time. After school, the child life specialist taught everyone to relax with "Guided Imagery." A Portland State University representative from Handicapped Student Services then described college options to the campers and many career choices were suggested. A computer class was then taught by rehabilitation in conjunction with Oregon Health Sciences University. Campers were paired based on abilities and after two hours, everyone was able to produce their own fancy stationery. Campers had previously chosen the menu for adolescent dinner and assembled their own meal. In the future, it would be

a nice option to actually go to the grocery store and pick out the items and prepare the entire meal. Grooming makeovers and photos followed. The females got their hair styled by an outside consultant and makeup was applied. The males all received massages. Each evening there was time allotted for "group," so the adolescents had time to talk things out in a controlled yet relaxed setting. During reward time which was around bedtime (which got later and later as the week progressed) it was an opportunity for the nurse to visit with each individual to assess mental state and give positive reinforcement. While visiting with one of the quieter males one evening, the question of "how are things going?" was answered by "I'm sad." This was a surprise as things seemed to be going well for this adolescent. When questioned why he was sad, the male replied, "because I have to go home Sunday."

Friday. As a result of a holiday, there was no school, only morning ADL's and exercises. An informal group was held to discuss dating tips. During the week there was a box that had a heart on it, wrapped in a attractive manner, with a hole cut in the top. This was for the adolescents to place questions regarding their sexuality. The box was hidden in the female and male rooms throughout the week for this day. A family counselor came over from the university and separated the females and males to meet with each group individually. Intimate questions were asked and answered and each adolescent was given a practical book on sexuality for future reference. The group was then joined for further discussion. After lunch, discussion about the weekend upcoming party was followed by a career counselor to discuss interview skills. Campers received a job guide and helpful information on how to use past experience to write a resume. Adolescents learned that there were options to

college and vocational school. Each camper learned how to assemble their own career folder. Swimming at the Easter Seals heated pool followed. It was interesting to note that two of the campers had not been swimming before. Everyone got in the water and had such a nice time that we stayed an additional hour. As there is frequently decreased sensation below the defect, the concrete inside the pool can be a hazard to the adolescent with spina bifida, so socks/tights were encouraged to protect the skin. The campers that could swim, assisted those that could not. It was nice to see such compassion among adolescents. After dinner, it was time to dress up and prepare for dancing "downtown" at an under 21 club that did not serve alcohol. There was one chaperon per adolescent and everyone seemed to have a great time dancing to the music with their non-disabled peers. Many of the campers had never been taken dancing before and it was very exciting. Some of the male adolescents at the club asked the female campers to dance. It was very touching to watch the females being spun around in their wheelchairs, something that could not be planned.

Saturday. After sleeping in, and a brief exercise routine and group, the campers left for a boat ride on the Columbia River. Some campers had another first--their first time out on a boat on the river. The weather was wonderful and the crew got involved in helping the campers to feel most welcome. A trip to Saturday Market (a Portland shopping tradition) followed. The group decided they wanted their own party for the last night together. Pizza was ordered and instead of a movie everyone talked and listened to music. As it was a beautiful warm autumn evening, with a full moon, we decided to take a "moonlight roll." Everyone got in a wheelchair, even the nurse, and the nine of us rolled up a hill to a pavilion near the

university. We looked over Portland's twinkling lights and had the "group." Many topics were discussed about the week's experience and life in general. It was an interesting feeling being confined to a wheelchair, and the obstacles it presented. The best part was feeling like a member of the group. The adolescents were complimented on how well they looked out for each other and how patient they were with their fellow campers. It was a tearful and warm experience and everyone squeezed their eyes shut so the night would never be forgotten.

Sunday. After the morning routine, another exercise/recreation video was shown. Campers were given paper and asked to write one nice thing about each camper on the paper and then give it to the person. Each camper would then be able to have a paper with at least eight positive traits listed. The nurse started the paper and the adolescents acted shy at first, but all complied and then insisted on doing a paper for the nurse. The SGQ was given, followed by the PHCSCS. The FIM was completed the next day after consultation with the therapists. Campers then packed and prepared for the farewell party with their families. Pictures of the week-long experience had been taken and slides, along with the zoo video, were shown to everyone. "SPIRIT Bucks" were redeemed for prizes and each camper was given a special award and a hospital sweatshirt. After debriefing with parents, campers were discharged to home. Adolescents remained in touch by phone and even arranged a mini-reunion for a "Teen Halloween" dance, held at the hospital later that month. Follow-up was arranged to complete the SGQ, PHCSCS, and FIM by telephone in one month.

Appendix I
Cost of the Intervention

Cost of the Intervention

<u>Item</u>	<u>Cost</u>
<u>Piers-Harris Children's Self-Concept Scale</u>	\$ 95.00
<u>Functional Independence Measure</u>	\$ 140.00
PHSCS Computer Answer Sheets/Test Reports	\$ 209.44
PHSCS Computer Answer Sheets/Test Reports	\$ 130.90
Easter Seals Pool Rental	\$ 30.00
Sternwheeler Cruise	\$ 131.40
Film/Development and Videos	\$ 60.00
Monogrammed SPIRIT T-Shirts for Adolescents	\$ 132.00
Pizza for Farewell Party	\$ 21.00
Family Therapist	\$ 50.00
Video Rental: Gaby-A True Story	\$ 3.00
Van Parking for Sternwheeler and Dance	\$ 15.00
Notebooks/Paper/Pens/Xeroxing	\$ 30.00
Prizes/Miscellaneous were donated	\$ 0.00
Totals	\$1,047.74