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with able-bodied adolescents**

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San Jose State University, 1993

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WAYS OF COPING:
ADOLESCENTS WITH SPINAL CORD INJURY
COMPARED WITH ABLE-BODIED ADOLESCENTS

A Thesis
Presented to
The Faculty of the Department of Occupational Therapy
San Jose State University

In Partial Fulfillment
of the Requirements for the Degree
Master of Science

By
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May, 1993

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ABSTRACT

WAYS OF COPING: ADOLESCENTS WITH SPINAL CORD INJURY COMPARED WITH ABLE-BODIED ADOLESCENTS

by Becky A. Gardner

This thesis examines the sequelae of the ways in which adolescents cope with spinal cord injuries, as compared to the coping of their able-bodied peers. The Ways of Coping questionnaire (Lazarus & Folkman, 1988), sent to the 20 subjects of this pilot study, quantifies the descriptive data, allowing for matched t-test analysis. Eight coping strategies are delineated on this questionnaire. Data indicated that each subject used all eight strategies, and used seven of eight of them with similar frequency. Statistical significance was found in the use of the positive reappraisal coping strategy.

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CHAPTER 1

INTRODUCTION

Purpose

Adolescence is a time of change and growth, which requires a great deal of coping. The purposes of this study were to determine how adolescents cope with the onset and sequelae of spinal cord injury, and if adolescents with spinal cord injury cope significantly differently than those without injury.

Statement of the Problem

Currently, there are 10,000 new cases of spinal cord injury (SCI) each year (Richmond & Metcalf, 1986). Thirty percent of these injuries occurred in persons 15 to 24 years of age in the United States (Bracken, Freeman, & Hellenbrand, 1981). Of those with paraplegia from spinal cord injury, 27% occurred between the ages of 15 and 20, and 62% of people with quadriplegia from spinal cord injury were under 25 years of age at onset (Bracken, Freeman, & Hellenbrand,

1981). These data indicate that there are thousands of adolescents with spinal cord injuries. These adolescents must adjust to and cope with their vastly changed bodies and life tasks. Many do so successfully.

Pennington and Sharrott (1985) have stated,

Occupational therapy is required to address coping skills in adolescents by virtue of the view of the human that the profession endorses. Occupational therapy adheres to the perspective that the human exists as a biological, psychological, and social being and that all therapeutic intervention must be designed with each of these aspects in mind.

(p. 13)

Information on how adolescents cope with spinal cord injury is the necessary first step to determining effective ways of coping and eventually determining how OTs can facilitate these effective ways of coping. This study focused solely on how adolescents cope (both able-bodied and spinal cord injured), as successful coping cannot be systematically determined until the ways of coping have been identified. If it can be learned how these successful adolescents cope,

occupational therapists (OTs) may be able to more easily facilitate the adjustment of clients within this age group, and thus become more effective.

This study is unique in that it appears to be the first of its kind. Dewis (1989) stated:

No studies could be found that specifically addressed the issue of age of onset (i.e. late adolescence to young adulthood) as a major factor in adjustment to the disability [spinal cord injury], or that examined the impact of spinal cord injury from the viewpoint of the young person involved. (p.390)

This study attempted to address these issues by examining specifically adolescent adjustment, and coping with SCI from the adolescent viewpoint.

Objectives

This research was designed to meet the following objectives:

1. To identify the range and distribution of coping processes typically used by adolescents.
2. To identify any differences between able-bodied adolescents and those with spinal cord injuries with

respect to the range and distribution of coping processes.

3. To determine whether there was significant difference found between the two study groups.
4. To generate data which can be used by occupational therapists to increase their understanding of coping strategies used by adolescents, specifically the individual with spinal cord injury.
5. To generate data which can be used by researchers to begin to determine which coping strategies are effective, and eventually to determine how occupational therapists can facilitate this process.

Questions

The research questions to be answered in this study were:

1. What are the range and distribution of coping strategies used by study adolescents?
2. Will adolescents with spinal cord injury report a similar range and distribution of coping strategies compared to able-bodied adolescents?
3. Is there a significant difference in the use of coping strategies by the two study groups?

Definitions

Conceptual definitions

Accepting responsibility - "Acknowledges one's own role in the problem with a concomitant theme of trying to put things right" (Folkman & Lazarus, 1988, p. 8).

Adjustment - "A change made to improve condition or function" (Thomas, 1985). In this context, a change made by the adolescent to improve his/her mental condition with regard to stressors brought on within adolescence.

Adolescent - A person between childhood and adulthood, completing the developmental tasks of adolescence (such as identity, body image, separation, peer relations, occupational development).

Confrontive coping - "Describes aggressive efforts to alter the situation and suggests some degree of hostility and risk-taking" (Folkman & Lazarus, 1988, p. 8).

Coping - "Cognitive and behavioral efforts to master, reduce, or tolerate the internal and/or external

demands that are created by the stressful transaction" (Folkman & Lazarus, 1980).

Distancing - "Describes cognitive efforts to detach oneself and to minimize the significance of the situation" (Folkman & Lazarus, 1988, p. 8).

Emotion-focused coping - One of two types of coping, in which the person attempts to reduce or regulate stressful emotions (Folkman & Lazarus, 1980). Includes distancing, self-controlling, escape-avoidance, and positive reappraisal coping scales (Folkman, Lazarus, Pimley, & Novacek, 1987).

Escape-avoidance - "Describes wishful thinking and behavioral efforts to escape or avoid the problem" (Folkman & Lazarus, 1988, p. 8).

Planful problem solving - "Describes deliberate problem-focused efforts to alter the situation, coupled with an analytic approach to solving the problem" (Folkman & Lazarus, 1988, p. 8).

Positive reappraisal - "Describes efforts to create positive meaning by focusing on personal growth. It also has a religious dimension" (Folkman & Lazarus, 1988, p. 8).

Problem-focused coping - One of two types of coping, in which the person manages or alters the person-environment relationship that is the source of the stress (Folkman & Lazarus, 1980). Includes confrontive coping, seeking social support, accepting responsibility, and planful problem solving coping scales (Folkman et al., 1987).

Seeking social support - "Describes efforts to seek informational support, tangible support, and emotional support" (Folkman & Lazarus, 1988, p. 8).

Self-controlling - "Describes efforts to regulate one's feelings and actions" (Folkman & Lazarus, 1988, p. 8).

Operational definitions

Able-bodied - A person without spinal cord injury.

Adolescent - Any person over the age of 13 and under the age of 20. Measured in this study by self-report and medical records.

Coping - Cognitive and behavioral efforts to master, reduce, or tolerate demands of a stressful transaction, measured by the Folkman and Lazarus Ways of Coping Questionnaire (1988). Specifically, this instrument assesses eight coping scales: Confrontive coping,

distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, planful problem solving, and positive reappraisal.

Coping strategies - The specific coping technique employed to cope with a given stressor.

SCI - spinal cord injury.

Spinal cord injury - A lesion to the spinal cord, complete or incomplete, as documented in medical records.

Assumptions

Assumptions within this study were:

1. The sample of adolescents with spinal cord injury who participated in this study were representative of at least West Coast, English-speaking adolescents with spinal cord injury.
2. Subjects answered all questions completely and honestly.
3. Adolescents with spinal cord injury must cope with both the disability and the "normal" developmental dilemmas.

Limitations

Limitations of this study were:

1. Small sample size which resulted from difficulty locating and identifying adolescents with a spinal cord injury and a very low response rate from the adolescents with spinal cord injuries who were contacted.
2. The sample was limited to subjects who agreed to participate. This self-selection may have biased the sample.
3. The sample was exclusively English-speaking. Adolescents from different cultures may use different coping processes.
4. The sample was from a geographically limited area (Oregon and California), and therefore may not be generalizable.
5. The sample was limited to only those subjects who would consent to the study. This may have biased the sample since those who were not confident in their coping processes may not have agreed to take part in the study.
6. The information gathered is subject to a lack of reliability secondary to misinterpretation of the questions on the questionnaire.

Significance of the Study

This study has yielded results regarding the coping strategies of the adolescent who has sustained spinal cord injury as well as the able-bodied adolescent. As it is a goal of occupational therapy to treat holistically, occupational therapists should foster coping through the choice of activities, and through the therapeutic relationship with the client. However, this may be overlooked as occupational therapists may not have sufficient information regarding the needs of the client to foster coping skills. To be effective facilitators of the coping process, occupational therapists must know how adolescents, including those with spinal cord injury, cope.

No studies were found that dealt with this problem, thus this may be the first research of its kind. It has been reported in previous literature (Dewis, 1989) that there is no research which specifically addresses spinal cord injury with onset in adolescence and the disability's impact on adjustment in these persons' lives. This study was designed to address this lack of information.

By describing how these adolescents coped, this study lays the groundwork for further research in the area. These findings, regarding how adolescents cope, can later be used to study the effectiveness of certain coping strategies, and eventually to determine how occupational therapists can facilitate effective coping processes.

By knowing how adolescents cope (both in general and specifically in the spinal cord injured population), therapists will have better understanding to guide the treatment of the psychosocial aspects of physical disability, and thus the whole person.

CHAPTER 2

REVIEW OF THE LITERATURE

This review will bring together literature from four major areas. Specifically, this chapter will include: an overview of coping, coping as a developmental task during adolescence, coping with spinal cord injury by adolescents and in general, and finally the developmental occupational therapy frame of reference used in this study.

Coping

Folkman and Lazarus (1980) defined coping as "cognitive and behavioral efforts to master, reduce, or tolerate the internal and/or external demands that are created by the stressful transaction" (p. 220). Folkman (1984) noted that an important feature of this definition is that coping is defined independently of its outcome. Therefore, a person can cope with a situation, and have it result either positively or negatively. This concept is substantiated with research by Frank, Umlauf, Wonderlich, Askanazi, Buckelew, & Elliot (1987) who found (via a cluster-analytic approach) that the more coping attempts that

were made, and coping mechanisms used, the less effective was overall adjustment to spinal cord injury.

Folkman and Lazarus (1980) described a widely accepted model of coping which differentiated between two types of coping, emotion-focused and problem-focused. The problem-focused category referred to coping processes which include cognitive problem-solving, used to manage the problem or its source. The emotion-focused category referred to cognitive and behavioral efforts to manage and/or decrease emotional distress (Folkman & Lazarus, 1980). This dual process model was revised in 1985 to replace the original two coping scales with eight, which more accurately reflect the authors' enhanced understanding of coping. Integrating this new approach with their previous framework, Folkman, Lazarus, Pimley, and Novacek (1987) organized the eight coping scales into problem and emotion-focused categories. Confrontive coping, seeking social support, accepting responsibility, and planful problem solving were assigned to the problem-focused coping category, while distancing, self-controlling, escape-avoidance, and positive reappraisal were described as emotion-focused. Therefore, since the prior dichotomy continues to be relevant, and as

most of the coping research which employs Lazarus' frameworks use the old format, they will be included in this literature review. However, the revised eight-scale model was used as the framework for examining coping strategies reported in this thesis.

Folkman and Lazarus (1980) introduced Lazarus' "Ways of Coping" questionnaire, which is widely used in coping research, in a longitudinal study of coping in a middle-aged community sample. It was found that coping strategies varied widely for the same individuals when presented with different situations. These initial findings were substantiated in subsequent research with additional populations (Folkman, Lazarus, Gruen, & DeLongis, 1986). It was also found that personality characteristics alone had little to do with the selected coping patterns. Finally, the stereotyped differences in coping processes between men and women were tested and were not supported. Men were not found to be more problem-focused nor women found to be more emotion-focused. This was further substantiated by Blanchard-Fields and Irion (1988).

Folkman (1984), using Lazarus' theoretical framework in the development of a theory on control, stress and coping, noted that "Emotion-focused coping

... can be used to alter the meaning of a situation and thereby enhance the individual's sense of control over his or her distress (cf. Averill, 1973; Silver & Wortman, 1980a)" (p. 844). She further substantiates this by citing Rothbaum et al. (1982) who make the same observation but term it "secondary control." In a study of middle-aged married couples regarding coping and health, Folkman et al. (1986) found problem-focused coping to be strongly influenced by the situational context.

McCrae (1982) conducted a study on age differences in coping, with subjects aged 21 to 91 years of age. By evaluating the stressfulness of the subjects' life events and their answers on a coping questionnaire (including Lazarus' initial questionnaire), it was determined that younger adults rely more upon hostile reactions and escapist fantasy (emotion-focused coping) regardless of the type of stress. This has particular significance for adolescents' response to SCI.

A conflicting study by Folkman, Lazarus, Pimley, and Novacek (1987), however, compared coping processes of younger (approximate mean age of 40) and older (mean age of 68) age groups. It was determined that the younger group used more active, problem-focused coping

processes and they perceived their stressful encounters to be changeable, while the older group used more passive, emotion-focused coping processes and perceived stressful situations as unchangeable. Folkman et al. (1987) interpreted these findings as supporting a developmental interpretation of coping in that subjects' age made a difference in their coping strategies across diverse contexts; however, perceived controllability confounds these findings.

This perceived controllability or changeability in a given stressful situation was addressed in an article by Folkman, Lazarus, Dunkel-Schetter, DeLongis, and Gruen (1986). It was found that in situations in which changeability was perceived to be high, subjects used more confrontive coping, planful problem solving, and positive reappraisal which is more problem-focused coping and less escape-avoidance (emotion-focused) coping when compared to situations perceived to be low in changeability. Within this same study, it was found that subjects used more variable coping processes such as confrontive coping, escape-avoidance, and self-control when their self-esteem was at stake. This has direct implications for an adult sample of persons with spinal cord injuries.

In a review of literature on coping behavior, Panzarine (1985) described the major factors which affected coping processes. These are: 1) stressor characteristics - acute, chronic-intermittant, chronic, and event sequence; 2) environmental resources - economic, educational, other sociocultural, and social network available; and 3) personal characteristics - psychological preparation, degree of fatalism and inflexibility, sense of perceived or actual control, and problem-solving abilities. She stressed that researchers of coping need to consider the multidimensionality of coping, the changes that occur in coping over time and contexts, and the salient variables which affect the coping process (noted above).

There are many other frameworks for examining and interpreting how populations cope, including frameworks by Baum, Singer, and Baum (1981); Coelho, Adams, and Hamburg (1974); Jalowiec and Powers (1981); Moos and Billings (1982); and Pearlin and Schooler (1978). However, Lazarus' framework was considered to be most relevant as it specifically addressed the ways in which people cope and the multidimensionality of coping, and is widely accepted in the field of coping research.

In summary, coping is an attempt to deal with stress. According to the Lazarus definition, the outcome need not necessarily be successful for coping to have occurred. Coping is a highly complex process which is related to personal and situational factors in tandem, but not specifically to any of these factors alone. The different ways of coping may be used by the same individual when confronted with different stressful circumstances and may be influenced by that individual's developmental stage.

Coping as an Adolescent Developmental Task

Adolescents face many challenges and dilemmas while performing their developmental life roles. Typically, the adolescent must cope with changes in many realms at once, making satisfactory coping more difficult. These events are supported by research from Simmons, Burgeson, Carlton-Ford, and Blyth, (1987) who proposed that synchronous timing of life transitions during early adolescence jeopardizes the adolescent's ability to cope. They studied adolescents who were transferring from grade schools to junior high schools, looking at other life stressors for each individual as well. The findings supported their hypothesis:

females exhibited lower self-esteem with an increasing number of life changes, and both males and females displayed decreases in grade point averages and in participation in extracurricular activities with increasing transitions. They further substantiate evidence (Werner & Smith, 1982) that boys react more negatively than girls to stressors as children, but this trend reverses in adolescence. In conclusion, Simmons et al. (1987) note that:

children appear less able to cope if at the same time they are uncomfortable with their bodies because of physical changes, with family because of changes in family constellation, ... and with peers because of the emergence of opposite-sex relationships and the disruption of prior peer networks. (p. 1231-1232)

Goldberg (1981) notes, "Adolescence presents a series of developmental tasks that are mastered with difficulty by the able-bodied youth" (p. 66). Due to a number of physical and psychological factors, this difficult time is often met with volatile reactions by all adolescents. Anger and hostile reactions are common coping techniques of the able-bodied, as well as the spinal cord injured adolescent, due to their

developmental stage (McCrae, 1982; Rutledge and Dick, 1983).

This is also illustrated when developmental coping was compared between adolescents and adults. It was found that adolescents are highly consistent in their coping strategies, as they used emotion-focused coping for both perceived controllable and non-controllable situations. This is opposed to adults who used problem-focused coping for controllable situations, and emotion-focused coping for non-controllable situations (Blanchard-Fields & Irion, 1988; Folkman, Lazarus, Pimley & Novacek, 1987). They also found that the typically stressful events with which adolescents in this sample must cope, were mostly school and family related. Finally, they reported that age alone was not a good indicator of coping, but that social and cognitive maturity should be examined.

More research needs to be done on the specifics regarding adolescent coping. The available research demonstrates that "normal" adolescent coping strategies are centered around the emotionally charged issues of physical changes, school, and family and peer role changes. This may imply that adolescents would more likely react with the emotion-focused coping

strategies, since perceived controllability was ruled out which implies support for developmental theories about adolescent coping.

Coping with Spinal Cord Injury

Coping with spinal cord injury is an enormous and complex task which may have as many methods as there are persons with spinal cord injury. To illustrate the importance of this subject, many authors have cited indicators of long-term maladjustment such as: suicide, which is now the third largest killer of persons with SCI (Geisler, Jousse, Wynne-Jones, & Breithaupt, 1983); self neglect (Macleod, 1988); divorce; and a higher incidence of drug abuse (Bedbrook, Beer, & McLaren, 1985).

Many studies on coping with spinal cord injury attempt to correlate the many aspects of the person and the condition with their attempts at coping. Despite many studies which have found the level of SCI to be a significant factor (i.e., Koehler, 1989), and many which do not find it significant to coping (i.e., Green, Pratt, & Grigsby, 1984), level of injury was found to have no impact on coping in a study using a

analysis approach and Lazarus' Ways of Coping questionnaire (Frank et al., 1987).

Other factors which are disputed as they relate to coping include time since injury, age, self-concept, and personality factors and intelligence. Koehler's findings (1989) counter Shadish, Hichman, & Arrick's findings (1981) in which time since injury was a significant factor in the choice of coping strategies. Frank et al. (1987) determined that age was a significant factor in coping atrategy employed in their study sample, whereas Green et al. (1984) had not found a significant difference due to age. Koehler (1989) found self-concept to be significantly correlated with successful coping, whereas Green et al. (1984) found the opposite in their sample. Koehler (1989) and Mueller (1962) agreed in their studies, that specific personality factors significantly impacted coping strategies, which is the opposite of Folkman and Lazarus' findings (1980). Katz, Gordon, Iverson, and Myer (1978) determined through studying histories of patients, that intelligence was not a significant factor in coping with paraplegia.

Gunther (1977) and Orfirer (1970) have general theories regarding coping with SCI. Gunther (1977)

proposed a "Regression Hypothesis" which stated that patients regress to developmentally earlier and simpler thought processes. This hypothesis was formed from the results of a psychoanalytic study of 400 patients, half of whom had a spinal cord injury.

Orfirer (1970) purported that the disabled may have more difficulty adjusting to their disability and dealing with their grief than persons who are trying to cope with the death of loved ones. Other authors support this claim (Friedman-Campbell & Hart, 1984; Tucker, 1980; Werner-Beland, 1980). Simple stage theories of grieving for physical disabilities have been challenged by Shadish, Hickman, & Arrick (1981), who studied emotional distress of SCI as a function of time, and by Frank et al. (1987) who found individual cognitive processes to be most important, using a cluster analytic approach. Buckelew, Frank, Elliot, Chaney, & Hewett (1991) found that "contrary to stage theory, age and time since injury were not related to locus of control or psychological distress measures" (p. 129).

Tucker (1980) further described the difficulty in coping with disabilities is related to the lack of social norms for coping with loss of physical

functioning, as well the scarcity of people who can relate to the patient with SCI. She further noted that as persons with SCI are forced to become more physically dependent, they must become more mentally/emotionally independent as there are so few people who can serve as role models and/or help them with integration.

There are two distinct views on depression in persons with SCI in the literature. The more traditional view is reflected in the older literature (Siller, 1969) and it states that depression is a necessary step in coping with spinal cord injury; if depression is not exhibited, something inappropriate is taking place. The new finding is that the absence of depression in coping with SCI is correlated with good adjustment (Bartol, 1978; Cook, 1976). Hohmann's study (1966) helps to explain the new finding: much of the depression seen in SCI patients is a learned reaction to fulfill expectations of staff, and to prevail upon them to carry out tasks that the patients can no longer accomplish themselves implying that true depression is often really absent. Of most importance, Craig, Hancock, Dickson, Martin, and Chang (1990) note that

"It seems that in most cases of spinal injury, clinical depression resolves over time" (p. 421).

Related to the research on depression is research on denial, which is also conflicting. Again, the earlier viewpoint assumes that denial is harmful to the patient and his/her adjustment (Hughes, 1980; Jahoda, 1958; Valliant, 1977). Lazarus (1983) changed his viewpoint regarding denial, stating that it is no longer a primitive, unsuccessful defense, but instead, denial has a protective value for people in crisis. This viewpoint has been substantiated by further research (Frank et al., 1987; Richards, 1986; Taylor, 1983), who have re-termed denial as "illusions" when used in a positive manner. Taylor (1983) has stated, "Illusion may be essential for adequate coping" (p. 1171).

Coping with Spinal Cord Injury - Adolescents

Examining the research on adolescent adjustment to SCI reveals that there are many similarities, as well as many differences, between generic and adolescent coping.

A highly debated issue in the literature is whether or not age is a significant factor in coping with spinal cord injuries. It was found in two studies that age is not a significant factor in adjusting to SCI, with samples consisting of both adolescents and adults (Richards, 1986; Rintala & Willems, 1987). This viewpoint is supported by literature on psychologic inoculation, which illustrates that previous attempts to cope with mild stress increases one's ability to cope with subsequently greater stress. It presumes all adolescents to have been faced with some form of stress before spinal cord injury (McAlister, Perry, & Maccoby, 1979; Zeltzer, Kellerman, Ellenberg, Dash, & Rigler, 1980).

Blanchard-Fields & Irion (1988) found in normal developmental coping that adolescents consistently used emotion-focused coping while adults used both forms. Further, another set of literature found that age, specifically adolescence and young adulthood, was correlated with difficulty in coping with SCI (Hallin, 1968; Kemp & Vash, 1971; Kerr & Thompson, 1972; Ludwig & Adams, 1968). Dewis (1989) and Grossenbacher (1985) reported that difficulty in coping is due more to being in an earlier psychosocial stage, and that adolescents

simply lack the life experiences necessary to know how to begin coping with SCI.

Furthermore, Frank et al. (1988) found that "younger" patients, less than 27 years of age, reported more negative effects as a result of their SCI than did "older" patients, those over 27 years of age. They concluded that "from a psychological perspective, patient age connotes different developmental processes, tasks or resources that could influence the adjustment process. Evidence available to date suggests age is often an important mitigating variable in adjustment to catastrophic illness or injury" (p. 128).

Most of the more recent literature, however, has found that youth is correlated with adjustment to SCI. Krause and Crewe (1991) noted that "research suggests that age is negatively correlated with adjustment after spinal cord injury, particularly age at onset of injury. Youth therefore, may be an important resource in adjusting to a disability" p. 92. They concluded by noting, "It can easily be deduced that the younger the age at injury, the greater the opportunity to adjust to the disability" (p. 98). Lundqvist, Siosteen, Blomstrand, Lind, and Sullivan (1991) found that youth was associated with high quality of life scores which

was not so with older persons with SCI. Finally, Craig et al. (1990) completed a literature review which critically examined the methodologies of the articles and concluded that, "despite these problems, some consistent findings have emerged. For instance, younger patients adjust better to spinal cord injury than older persons (Woodrich & Patterson, 1983; Smith-Hanen, 1976)" (p. 422).

Level of injury and sex of patient were found not to be significantly correlated with adolescent coping with SCI (Richards, 1986). Another similarity found in the generic versus adolescent coping literature was further support of the positive aspects of denial as related to adolescents (Grossenbacher, 1985; Rutledge & Dick, 1983; Zeltzer et al., 1980).

The major differences between adolescent and generic coping with spinal cord injury are regarding the difficulty that adolescents with spinal cord injury have with developmental tasks after their injury. Goldberg (1981) maintained that although all developmental tasks are much more difficult; achieving separation, body image, independence, sexual identity, educational and vocational development are the most difficult tasks for the disabled adolescent to master.

Grossenbacher (1985) lists adolescent developmental tasks severely impacted by spinal cord injury consisted of: identity, body image, sexual identity, peer relations, and occupational choice.

Rutledge and Dick (1983) separated the different reactions of early, middle, and older adolescents. Early adolescents' biggest issue is separation from parents. As separation is made more difficult and complex with spinal cord injury, many in early adolescence find it easier to regress and not separate. Those in middle adolescence will often react with anger to spinal cord injury as they have most likely just resolved the issue of separation and they must deal with it all over again. Finally, older adolescents are less labile in their reactions; which is further supported by Nicholson (1980). Richards (1986) states that adolescent spinal cord injury patients experience emotional distress but that it dissipates one year after injury. In terms of depression, these adolescents remain statistically no different from the rest of the population. Dewis (1989) summed up the difficulties experienced by adolescents by stating that normalcy in all realms of life is a key concern of the adolescent with spinal cord injury.

Following research, using self-report methods, and literature review, Dewis (1989) concluded that adolescent coping with spinal cord injury typically occurs with consciously chosen strategies by the adolescents. The more common strategies included: preventing and/or camouflaging bowel/bladder accidents when in public or with friends; covering up body with clothes (this is seen as a rejection by the patient that the handicap is his/her total identity); minimizing unattractiveness of appliances with personal touches; and severing prior peer relationships when the peer could not deal with the friend's spinal cord injury.

In conclusion, while there is some knowledge of how adolescents cope with some "normal" or major life stressors, including spinal cord injury, there is a need for further research that gathers data to view the range and distribution of coping strategies used by adolescents with spinal cord injury when compared with able-bodied adolescents. It has been argued that adolescents are in a unique situation; they are faced with many developmental challenges at once, with little previous experience regarding how to cope with the new demands. It has been suggested that they respond with

emotion-focused forms of coping due to the nature of the stressors; however, this needs to be studied further.

The Developmental Frame of Reference

In describing an occupational therapy developmental frame of reference Llorens (1970, 1976, 1991) stated that occupational therapy needs to concentrate on the physical, social, and psychological aspects of human life tasks and relationships, while examining both longitudinal and horizontal development. This examination of developmental life tasks is completed by evaluating individual functioning and its integration with social, psychological, and physical components.

Some of the premises upon which Llorens (1970, 1976, 1991) based this frame of reference, that are particularly relevant to this study, include: 1) growth and development occur in a fixed sequence, extending through late adulthood; 2) physical trauma can interrupt the growth and development process; 3) this interruption will cause a gap in the developmental cycle, leading to a lack of coping and adaptive behavior necessary for change; 4) occupational therapy,

through the application of purposeful activities, can provide the developmental links necessary to close the gap between needs and expectations, and abilities (Llorens, 1970, 1976, 1991). Within Llorens' frame of reference, the occupational therapist is, therefore, viewed as the change agent who facilitates growth and development.

As occupational therapists need to concentrate on the social and psychological aspects as well as the physical, according to this frame of reference, promotion of coping strategies is needed at all ages. Adolescence is a time of many dilemmas, requiring optimal coping skills. This fact, added to the recognition that normal development in an adolescent who has spinal cord injury is impaired with a physical disability, demonstrates a need for research to determine ways in which occupational therapists assist the development of coping processes in disabled adolescents.

Summary

Coping is a highly complex process which has been shown to be related to multiple personal and situational factors. An individual may employ

different coping strategies for different stressors, and this decision is influenced by the individual's developmental stage. Adolescent coping has been shown to be more emotion-focused, but this may be at least partially due to the issues they are coping with.

In dealing with spinal cord injury, there are few social norms and few personal role models to guide the individual, making the task more difficult than coping with other life-altering issues. This difficulty is compounded for adolescents, as they must also cope with normal adolescent issues. Depression is no longer considered a necessary step in coping with SCI, and denial is now viewed as a healthy part of the coping process. By using the developmental frame of reference, the occupational therapist can act as change agent to facilitate this coping process.

CHAPTER 3

DESIGN AND METHODOLOGY

The purposes of this study was to determine: 1) how adolescents cope with the onset and sequelae of SCI, 2) if adolescents with spinal cord injuries coped similarly or differently from able-bodied adolescents, and 3) whether there was a significant difference in the coping. Therefore, the questions answered were: 1) What are the range and distribution of coping strategies used by study adolescents? and 2) Will adolescents with spinal cord injuries report similar range and distribution of coping strategies as compared with able-bodied adolescents? 3) Is there a significant difference in the use of coping strategies by the two study groups? Survey research was used to gather data.

Survey Instrument

The survey instrument used was the Ways of Coping questionnaire (Folkman & Lazarus, 1988). This questionnaire, distributed by Consulting Psychologists' Press, is on a computer form and consists of 66 Likert-scale type questions. It is composed of eight coping scales. These are: 1) Confrontive coping, 2)

Distancing, 3) Self-controlling, 4) Seeking social support, 5) Accepting responsibility, 6) Escape-avoidance, 7) Planful problem solving, and 8) Positive reappraisal. For definitions of the eight scales, please refer to the definitions section in Chapter One. The questionnaire was originally composed of only two scales: emotion-focused and problem-focused coping. However, as these "failed to reflect the richness and complexity of human coping processes" (Folkman & Lazarus, 1988, p. 5), they have been replaced by the eight scales. See appendix C for a sample questionnaire form.

Subject Selection

Subjects with spinal cord injuries, in this study, were at least one year post injury because research has shown that the majority of adjustment has taken place by this time; subjects are generally stable and not statistically different from the rest of the population (Green et al., 1984; Richards, 1986). Therefore, the use of coping strategies is essentially complete at that time, so that subjects are able to explain which coping methods were employed, as required by the Ways of Coping questionnaire. Subjects with spinal cord injury were obtained through Santa Clara Valley Medical

Center, Santa Clara, California; California's Independent Living Centers (ILCs), throughout California; Emanuel Hospital's Rehabilitation Center, Portland, Oregon; and Good Samaritan's Rehabilitation Institute of Oregon, Portland, Oregon, via lists of past patients'/clients' names. According to Lundqvist et al. (1991), "Patient's ratings of their physical and mental functioning are important because they often do not correlate with the opinions of ... the medical staff. Techniques for measuring health status put forward in recent years support this means of assessment" (p. 78).

Collection Techniques

Approval was first sought from each facility, then lists of past patients were obtained, with the exception of California's ILCs. The ILCs sent a listing of each center, secondary to wanting clients to remain completely anonymous. A packet of five questionnaires was sent to each center, to the attention of each coordinator, who was asked to distribute them to residents who fit the study criteria.

Approximately 230 questionnaires were sent (with consent forms and return postage-paid envelopes) to persons with spinal cord injury who fit the study criteria. Once questionnaires were obtained from subjects with spinal cord injury, fifteen questionnaires were sent to able-bodied adolescents who stated they would participate in this study and who met the criteria. This group was a sample of adolescents from referrals from known individuals in the community, who identified adolescents with similar characteristics of the spinal cord injured group.

Statistical Techniques

Analysis of variance, specifically a series of matched t-tests, was used to analyze the data. Subjects from the two groups were matched in terms of the demographic variables of gender and approximate age. All subjects were adolescents of varying ages when they were coping with their stressor. The mean age of the group with spinal cord injury was 30 at the time of reporting their past coping methods, but the mean years of their spinal cord injury was 17. The mean age of the able-bodied group was 17. The variables analyzed were the eight coping scales

outlined in the Ways of Coping literature (Folkman & Lazarus, 1988).

CHAPTER 4

DATA AND RESULTS

Data for this study were collected by survey questionnaire. Although the information obtained is descriptive in nature, the questionnaire quantifies the information via Likert-type scales. Two hundred-thirty questionnaires were mailed to persons with spinal cord injuries, either directly or via coordinators at California's Independent Living Centers. Ten were returned completed. Fifteen questionnaires were then mailed to able-bodied adolescents who agreed to participate in the study, and who were grossly matched to the sample with spinal cord injury. Ten were returned completed. Given the size of the return, the data were analyzed and considered as pilot data. Completed survey forms were returned to Consulting Psychologists' Press and scored via computer. A print-out of the means and standard deviations for reported use of each scale was returned to this researcher.

Demographic Data

The sample with spinal cord injury ranged in age from 15 to 19 (mean age 17) at the time of their injuries. At the time of reporting, they ranged in age from 19 to 45 (mean age 30). The able-bodied sample, at the time of reporting, ranged in age from 13 to 19 (mean age 17).

Each group consisted of six males and four females. All subjects were originally from Oregon or California, but some had since left the state to attend college. All subjects spoke English as their primary language. Subjects were matched for statistical analysis, as shown in Table 1.

Questionnaire Data

Each respondent reported using all eight strategies, and both groups reported using them with similar frequency. Both groups used self-controlling, seeking social support, planful problem solving, and positive reappraisal coping scales with more frequency. See Table 2 for numerical data.

Table 1

Demographic Matching of Subjects

Adolescents with SCI				Able-bodied Adolescents	
ID #	Report Age	Age at Injury	Gender	Age	ID Letter
1	34	17	M	17	A
2	45	17	F	18	B
3	21	15	M	13	C
4	23	19	M	18	D
5	24	19	M	17	E
6	21	18	M	18	F
7	31	19	M	15	G
8	19	15	F	15	H
9	35	19	F	19	I
10	36	19	F	19	J

Table 2

Reported Number and Distribution of Coping Scales
by Sample Adolescents*

Scale	Adolescents with SCI (N=10)			Able-Bodied Adolescents (N=10)		
	Number of Scales	Mean	Std. Dev.	Number of Scales	Mean	Std. Dev.
Distancing	8	7.1	3.7	8	6.4	4.0
Seek. soc. sup.	8	8.1	3.0	8	9.2	4.0
Escape-avoid.	8	7.8	4.7	8	7.9	4.2
Pos. reappraisal	8	10.7	4.2	8	8.0	4.4
Confrontive	8	6.7	2.6	8	6.8	3.2
Self-control.	8	9.9	4.2	8	8.4	3.8
Accept. respon.	8	3.7	3.5	8	4.3	3.4
Plan. prob. sol.	8	8.8	2.2	8	7.4	3.9

*Since all coping scales were used by all subjects,
there was no range of scales, therefore, data are
reported as a number.

Scoring and Analysis

Frequency distribution for use of each coping strategy was determined for each scale for the two groups, and reported as means and standard deviations. Paired t-tests were then calculated to test for significant differences between the two groups.

Results

Question 1: What are the range and distribution of coping strategies typically used by study adolescents?

All eight coping scales were used by both groups, therefore no range can be reported. The distribution of coping strategies for the two groups yielded similar distributions. Adolescents with spinal cord injury reported the largest mean use of the Positive reappraisal scale (10.7), while able-bodied adolescents reported the largest mean use of the Seeking social support scale (9.2). On the whole, able-bodied adolescents responded with greater standard deviations, than did their peers with SCI. Therefore, while all eight scales were used, able-bodied adolescents had more varied responses. See Table 2 for numerical results.

Question 2: Will adolescents with spinal cord injuries report similar range and distribution of coping strategies as compared to able-bodied adolescents?

Upon comparison, the two sample groups reported the same number of coping methods with no range. The frequency distributions were similar. The sample with spinal cord injury reported the most frequent use of Positive reappraisal strategy, with Self-controlling and Planful problem solving ranking two and three, respectively. While the able-bodied sample reported using Seeking social support most frequently, with Self-controlling and Positive reappraisal strategies ranking two and three, respectively. See table 3 for complete rankings of the coping strategies by the sample groups.

Question 3: Is there a significant difference in the use of coping strategies by the two study groups?

To reach significance with $p < .05$, t must have been larger than the critical value of 2.365. One significant difference was found ($p < .05$), for the reported use of Positive reappraisal. (See Table 4). Adolescents with SCI used Positive reappraisal

Table 3

Rankings of Most Commonly Used Coping Scale
by Sample Adolescents

Ways of Coping Scale		
Rank	Adolescents with SCI	Able-Bodied Adolescents
1	Positive reappraisal	Seeking social support
2	Self-controlling	Self-controlling
3	Planful Problem solving	Positive reappraisal
4	Seeking social support	Escape-avoidance
5	Escape-avoidance	Planful problem solving
6	Distancing	Confrontive coping
7	Confrontive coping	Distancing
8	Accepting responsibility	Accepting responsibility

Note. Rank of 1 indicates the greatest frequency of use for each group.

significantly more frequently than did their able-bodied peers.

No significant difference was found between the two groups for the following coping scales: 1) Confrontive coping, 2) Distancing, 3) Self-controlling, 4) Seeking social support, 5) Accepting responsibility, 6) Escape-avoidance, and 7) Planful problem solving. For *t* values for each scale, see Table 4.

Therefore, all adolescents in this study reportedly used (with roughly the same frequency) the coping strategies of hostility, detachment, self-control, seeking advice, acknowledgement, avoidance, and problem-solving.

Table 4

Comparison of Distribution of Coping Processes
via Matched t-tests

Coping Scale	<u>t</u>	Standard Deviation
Confrontive coping	-1.38	3.44
Distancing	.42	5.29
Self-controlling	1.10	4.29
Seeking social support	- .73	4.74
Accepting responsibility	- .42	4.50
Escape-avoidance	- .06	5.32
Planful problem solving	1.25	3.53
Positive reappraisal	3.29*	5.29

* $p < .05$

CHAPTER 5

DISCUSSION, RECOMMENDATIONS, AND SUMMARY

Discussion

Question 1: What are the range and distribution of coping strategies used by study adolescents?

The adolescents in this study reported using all eight coping scales, therefore, no range can be reported. It has been found, for this adolescent sample, that coping strategies are used similarly by the two groups.

The literature review revealed no studies which had previously compared able-bodied subjects to subjects with spinal cord injury. In related literature, wherein the two groups were examined separately, multiple coping strategies were employed, similar to the findings in this thesis.

In terms of distribution, the literature reported that adolescents consistently used more of the emotion-focused coping strategies: Distancing, Escape-avoidance, Positive reappraisal, and Self-controlling (Blanchard-Fields and Irion, 1988; Folkman, Lazarus, Pimley, and Novacek, 1987). In this study,

adolescents of both groups tended to use slightly more of the emotion-focused coping strategies. The mean reported use of emotion-focused coping strategies by the groups with spinal cord injury was 8.9. Mean use of emotion-focused strategies was 7.7 for the able-bodied group. Means for reported used of problem-focused coping strategies were 6.8 for the group with spinal cord injury, and 9.9 for the able-bodied group.

Question 2: Will adolescents with spinal cord injury report similar range and distribution of coping strategies as compared to able-bodied adolescents?

Both groups used all eight scales, therefore no ranges can be reported. The frequency distribution of coping strategies was similar for both groups. Of note, however, is the fact that both groups varied widely within each scale (denoted by the large standard deviations, shown in Table 2). This implies that coping within these groups of adolescents is quite individualistic; although every adolescent used each coping strategy.

Adolescents with SCI, it appears, follow Llorens' developmental frame of reference, in that they may have had an interruption of their developmental cycle which

leads to a lack of coping necessary for change within their first year post-injury. However, coping strategies can be used to facilitate continued growth and development. This theme was verified by findings in the literature in which adolescents with spinal cord injury coped with greater difficulty, and slower pace, with developmental issues (Dewis, 1989; Goldberg, 1981; Grossenbacher, 1985; Rutledge and Dick, 1983). The literature reported that after their adjustment period, adolescents with SCI coped very similarly to able-bodied adolescents. In this study, adolescents with SCI reportedly used more Positive reappraisal significantly more frequently than did their able-bodied peers. This finding could be related to rehabilitation, in which small gains are consistently pointed out to the patient and positively praised. Many successive small gains could be seen by the patient as at least part of the "personal growth," which is then the focus for promoting further coping.

Question 3: Is there a significant difference in the use of coping scales by the two study groups?

Despite the large standard deviations, which make statistical differences less likely, there was one

significant difference found: adolescents with SCI use more Positive reappraisal than their able-bodied peers.

Positive reappraisal, as defined by Folkman & Lazarus (1988), "describes efforts to create positive meaning by focusing on personal growth. It also has a religious dimension" (p. 8). It appears, due to the nature of spinal cord injury, that Positive reappraisal would logically be the most used adaptive coping method of the eight strategies, as one could not alter or avoid the spinal cord injury (at least not for any length of time). Therefore, coping using this strategy may be the more effective technique for coping with spinal cord injury.

Recommendations and Implications

As a pilot study, the findings of this research suggest expansion to larger study would be useful to determine the validity of these findings, as well as to discover whether a larger sample would yield other significant differences. Lacking personal contacts in the field of spinal cord injury, this investigator found it difficult to obtain responses from the group with spinal cord injury greater than one year post-

injury. Therefore, it is recommended that multiple investigators, who have experience within the spinal cord injury field, conduct collaborative research. Further, such factors as geographic location or culture may be areas to examine as well.

Implications for Occupational Therapy

If the results of this pilot study with its small sample size are subsequently found to be valid, occupational therapists, as well as families, could act as "change agents" to facilitate growth and development by supporting adolescents with spinal cord injury in their efforts to cope, by emphasizing the Positive reappraisal strategy. This appears to be a natural role for occupational therapy, as personal adaptations, and training of new techniques lead to new skills which then become the "positive" aspect when the adolescent reappraises changes that have occurred since spinal cord injury. Grossenbacher (1985) stated well the value of occupational therapy in facilitating coping via positive reappraisal: "The occupational therapist, because of concern for the activities of living that ultimately bring the greatest personal satisfaction to the [adolescent] patient, has the unique potential to

provide the most caring, functional and individualized rehabilitation program to the injured adolescent" (p.90).

Summary

In this study data were collected about the coping strategies used by adolescents with and without spinal cord injury. Questionnaires and consent forms were sent to persons with and without spinal cord injury who ranged in age from 13 to 19 at the time of using the coping strategies. Twenty questionnaires were used (ten from each group). A series of matched t-tests were calculated to determine differences between the two groups. The data indicated that the two groups coped similarly; employing seven of the eight coping scales with comparable frequency (although varying widely within each scale). Positive reappraisal, however, was used significantly more by adolescents with spinal cord injury.

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APPENDIX A:
COVER LETTERS

- 1 - FOR SPINAL CORD INJURED SUBJECTS
- 2 - FOR ABLE-BODIED SUBJECTS

Dear _____ :

I need your help in conducting a study of the ways in which adolescents cope with major life events. I have obtained your name from The Rehabilitation Institute of Oregon (RIO) or Emmanuel Rehabilitation Center (ERC) as being one of the adolescent spinal cord injured patients who has graduated from their program. The results of this study should increase our understanding of how adolescents cope, which can be later used to improve the quality of occupational therapy care.

You should be clear that your participation in this study is voluntary, and that non-participation will not affect your relations with San Jose State University, RIO or ERC. Also, any information that could be identified with you will remain anonymous and could only be disclosed with your permission.

Would you please spend about 30 minutes and complete the enclosed consent form and questionnaire? If you prefer, your lettered answers can be written on the sheet provided instead of on the computerized answer form. Participants aged 18 and over should fill out the consent form for themselves, and participants 17 and younger need to use the consent form for minors, filled out by the parent.

As I wish to compare the ways in which adolescents with spinal cord injuries cope to the ways in which adolescents without spinal cord injuries cope, I am also asking that you supply the names, phone numbers, and addresses of two friends without spinal cord injuries. They need to be your age and from the same school. I will contact at least one of them and ask them to fill out the same questionnaire.

Please complete the consent form, the questionnaire, and the information on two friends, and return them in the envelope provided.

If you have any questions about this study, I would be happy to talk with you. Please call me at 524-5136. I hope that you can find the time to participate in this study, to help us better understand what adolescents go through and to improve the quality of Occupational Therapy care.

Sincerely,

Becky Gardner, OTR/L

Graduate Student, Occupational Therapy

Dear _____ and parent:

I need your help in conducting a study of the ways in which adolescents cope with major life events. The study compares the ways adolescents with spinal cord injury cope to the ways adolescents without spinal cord injury cope. The results of this study should better our understanding of adolescent coping, which can be used to improve the quality of occupational therapy treatment when working with this age range.

You should be clear that your participation in this study is voluntary, and that non-participation will not affect your relationship with San Jose State University, Valley Medical Center, Shriner's, Emanuel Rehabilitation Center, or the Rehabilitation Institute of Oregon. Also, all information that could be identified with you will remain anonymous and could only be disclosed with your permission.

Would you please spend about 30 minutes and complete the enclosed consent form and questionnaire?

Participants aged 18 and over should fill out the consent form for themselves, and participants 17 and younger need to use the consent form for minors, filled out by the parent.

Please complete the consent form and the questionnaire, and return them in the envelope provided by April 15, 1992.

If you have any questions about this study, I would be happy to talk with you. Please call me at 524-5136. I hope that you can find the time to participate in this study, to help us better understand what adolescents go through and to improve the quality of Occupational Therapy care.

Sincerely,

Becky Gardner, OTR/L
Graduate Student,
Occupational Therapy

APPENDIX B:
INFORMED CONSENT FORMS

- 1 - FOR ADOLESCENTS OVER 18
- 2 - FOR ADOLESCENTS UNDER 18 (CONSENT FOR MINORS)

College of Applied Sciences and Arts • Department of Occupational Therapy
One Washington Square • San José, California 95192-0059
Main Office: 408/924-3070 • Fieldwork Office: 408/924-3078 • FAX: 408/924-3088

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AGREEMENT TO PARTICIPATE IN RESEARCH

SAN JOSE STATE UNIVERSITY

RESPONSIBLE INVESTIGATOR: Becky Gardner

TYPE OF PROTOCOL: Descriptive survey of adolescent
coping skills

I have been asked to participate in a research study that is investigating the ways in which adolescents cope with stress. The results of this study should further our understanding of how adolescents, both spinal cord injured and able-bodied, cope with the major stressor of their lives.

I understand that:

1) As a participant with spinal cord injury I will be asked to briefly describe my spinal cord injury then fill out a questionnaire regarding how I coped with the situation. As a participant without spinal cord injury I will be asked to briefly describe a major stressor then fill out a questionnaire regarding how I coped with the situation. This should take me no longer than 1 hour.

2) The possible risks of this study are that I will be forced to examine the most difficult issue of my life,

and that the time necessary to complete the procedures may be an inconvenience.

3) The possible benefits of this study to me are knowing that this research may help others in a similar situation down the road, and realizing a sense of accomplishment regarding my own coping processes.

4) Alternative procedures include writing answers on a piece of paper and having the researcher transfer these to a computer form later, if fine motor coordination indicates this.

5) The results from this study may be published, but any information from this study that can be identified with me will remain confidential and will be disclosed only with permission.

6) Any questions about my participation in this study will be answered by Becky Gardner, (415) 524-5136. Complaints about the procedures may be presented to Dr. Gordon Burton, Graduate Advisor for the Department of Occupational Therapy, at (408) 924-3074. For questions or complaints about research subject's rights, or in the event of a research-related injury, contact Dr.

Serena Stanford, Associate Academic Vice President for Graduate Studies and Research, at (408) 924-2480.

7) My consent is given voluntarily without being coerced; I may refuse to participate in this study or in any part of this study, and I may withdraw at any time, without prejudice to my relations with San Jose State University, Santa Clara Valley Medical Center, Shriner's Hospital, Emmanuel Rehabilitation Center, or the Rehabilitation Institute of Oregon.

8) I have received a copy of this consent form for my file.

I HAVE MADE A DECISION WHETHER OR NOT TO PARTICIPATE.
MY SIGNATURE INDICATES THAT I HAVE READ THE INFORMATION
PROVIDED ABOVE AND THAT I HAVE DECIDED TO PARTICIPATE.

DATE

SUBJECT'S SIGNATURE

INVESTIGATOR'S SIGNATURE

AGREEMENT TO PARTICIPATE IN RESEARCH
SAN JOSE STATE UNIVERSITY
CONSENT FORM FOR MINORS

RESPONSIBLE INVESTIGATOR: Becky Gardner

TYPE OF PROTOCOL: Descriptive survey of adolescent
coping skills

Your son or daughter has been invited to participate in
a research study that is investigating the ways in
which adolescents cope with stress. The results of
this study should further our understanding of how
adolescents, both spinal cord injured and non-spinal
cord injured, cope with the major stressor of their
lives.

I understand that:

1) As a participant with spinal cord injury my
son/daughter will be asked to briefly describe the
spinal cord injury then fill out a questionnaire
regarding how he/she coped with the situation. As a
participant without spinal cord injury my son/daughter
will be asked to briefly describe a major stressor then
fill out a questionnaire regarding how he/she coped
with the situation. This should not take longer than 1
hour.

- 2) The possible risks of this study are that your son/daughter will be forced to examine the most difficult issue of his/her life, and that the time necessary to complete the procedures may be an inconvenience.
- 3) The possible benefits of this study to your son/daughter are knowing that this research may help others in a similar situation down the road, and realizing a sense of accomplishment regarding his/her coping processes.
- 4) Alternative procedures include writing answers on a piece of paper and having the researcher transfer these to a computer form later, if fine motor coordination indicates this.
- 5) The results from this study may be published, but any information from this study that can be identified with your son/daughter will remain confidential and will be disclosed only with permission.
- 6) Any questions about your son/daughter's participation in this study will be answered by Becky Gardner, (415) 524-5136. Complaints about the procedures may be presented to Dr. Gordon Burton,

Graduate Advisor for the Department of Occupational Therapy, at (408) 924-3074. For questions or complaints about research subject's rights, or in the event of a research-related injury, contact Dr. Serena Stanford, Associate Academic Vice President for Graduate Studies and Research, at (408) 924-2480.

7) My consent is given voluntarily without being coerced; I or my son/daughter may refuse to participate in this study or in any part of this study, and may withdraw at any time, without prejudice to relations with Sam Jose State University, Santa Clara Valley Medical Center, Shriner's Hospital, Emmanuel Rehabilitation Center, or the Rehabilitation Institute of Oregon.

8) I have received a copy of this consent form for my file.

HAVING READ THE INFORMATION PROVIDED ABOVE, I HAVE MADE
A DECISION WHETHER OR NOT MY SON OR DAUGHTER MAY
PARTICIPATE. MY SIGNATURE INDICATES THAT MY
SON/DAUGHTER MAY PARTICIPATE AND IS WILLING TO
PARTICIPATE.

DATE

PARENT'S SIGNATURE

ADOLESCENT'S

NAME

RELATION TO ADOLESCENT

APPENDIX C:
QUESTIONNAIRE FORM

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APPENDIX D:
LETTERS TO CALIFORNIA'S INDEPENDENT LIVING CENTERS

- 1 - LETTER TO COORDINATORS
- 2 - LETTER TO RESIDENT OF ILC

June 10, 1991

Center for Independence for Disabled, Inc.

Eldon Luce, Director

875 O'Neill Avenue

Belmont, California 94002

Dear Mr. Luce:

I need your help. I am conducting a study on the ways in which adolescents who were spinal cord injured coped with this major life event. Enclosed are five "Ways of Coping Questionnaires" (which I am sending to all 28 Independent living centers in California) with the hopes that they will be completed and returned.

The results of this study should increase our understanding of how adolescents cope, which can be later used to improve the quality of occupational therapy treatment.

Would you please distribute these to five people, and ask that they spend about 30 minutes to complete the questionnaire and consent form? I need persons who

were spinal cord injured between the ages of 13 and 19, inclusive, and who are at least one year post-injury at this time. If people fitting this description decide to participate in this study, they should be clear that their participation is voluntary and will in no way affect their relations with San Jose State University, and that any information that could be identified with them will remain anonymous and could only be disclosed with their permission.

Participants need to fill out a consent form (if younger than 18, parents need to fill out the Consent Form for Minors), the questionnaire, and the additional information sheet. The additional information sheet asks for the names, addresses and phone numbers of two friends (same age) who are not spinal cord injured, as I wish to compare the way persons without spinal cord injury coped with a major life event. Therefore, I will contact at least one of them and ask them to fill out the same questionnaire. Once everything is filled out, please return it in the envelopes provided.

If you have any questions about this study, I would be happy to talk with you. Please call me at (415) 355-3565. I hope that you and those in your center can find the time to participate in this study, to help us better understand what adolescents go through, and to improve the quality of Occupational Therapy treatment.

Sincerely,

Becky Gardner
Graduate Student,
Occupational Therapy

June 10, 1991

Dear Independent Living Center Member:

If you were spinal cord injured between the ages of 13 and 19, inclusive, and are at least one year post-injury, I need your help. I am conducting a study on the ways in which adolescents who were spinal cord injured coped. The results of this study should increase our understanding of how adolescents cope, which can then be used to improve the quality, and possibly even effectiveness, of occupational therapy treatment.

You should be clear that your participation in this study would be voluntary, and non-participation would in no way affect your relations with San Jose State University. Also, any information that could be identified with you will remain anonymous and could only be disclosed with your permission.

Would you please spend about 30 minutes and complete the attached consent form and questionnaire? If you prefer, your lettered answers can be written on the sheet provided instead of on the computerized answer

form. Participants aged under 18 need to have their parents complete the Consent Form for Minors. Finally, as I wish to compare the ways in which adolescents with spinal cord injuries coped to ways in which adolescents without injuries coped, I am also asking that you supply names, addresses, and phone numbers of two friends (same age) without spinal cord injuries. I will contact at least one of them and ask them to fill out the same questionnaire. Please return all of this information in the attached envelope.

If you have any questions about this study, I would be happy to talk with you. Please call me at (415) 355-3565. I hope that you can find the time to participate in this study, to help us better understand what adolescents go through, and to improve the quality of Occupational Therapy treatment.

Sincerely,

Becky Gardner
Graduate Student,
Occupational Therapy