THE ADJUSTMENT PROCESS OF THE SPINAL CORD INJURED: CASE STUDY REPORTS

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Submitted to the Faculty of the Graduate College
of the Oklahoma State University
in partial fulfillment of the requirements
for the Degree of
DOCTOR OF EDUCATION
May, 1983

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ACKNOWLEDGMENTS

The author would like to express appreciation to Dr. Vicki Baker for her assistance, encouragement, and patience while service as major adviser in the development of this research. I am grateful, also, to Dr. George Oberle, Dr. Betty Abercrombie, and Dr. Bill Adrian for their wise counsel, friendship, and support of my endeavors.

Many thanks go, especially, to the four subjects involved in the case studies who gave freely of their precious time to provide me with the substance of this research. Their cooperation is greatly valued.

I would be remiss if I neglected to thank the many friends who provided encouragement and support throughout the duration of this endeavor.

Finally, it is my husband, Ron; son, Brandon; and daughter, Shannon, who are most deserving of my gratitude. They have sacrificed the most during this endeavor, and yet they have also contributed the most through their continual support and understanding. They have my deepest appreciation.

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INTRODUCTION

> Spinal cord injury shatters the crystal of human experience in every facet. Social relationships, intrapersonal dynamics, and neurological control or function, seen and unseen, are all affected. Nothing is spared (Stewart, 1977, p. 541).

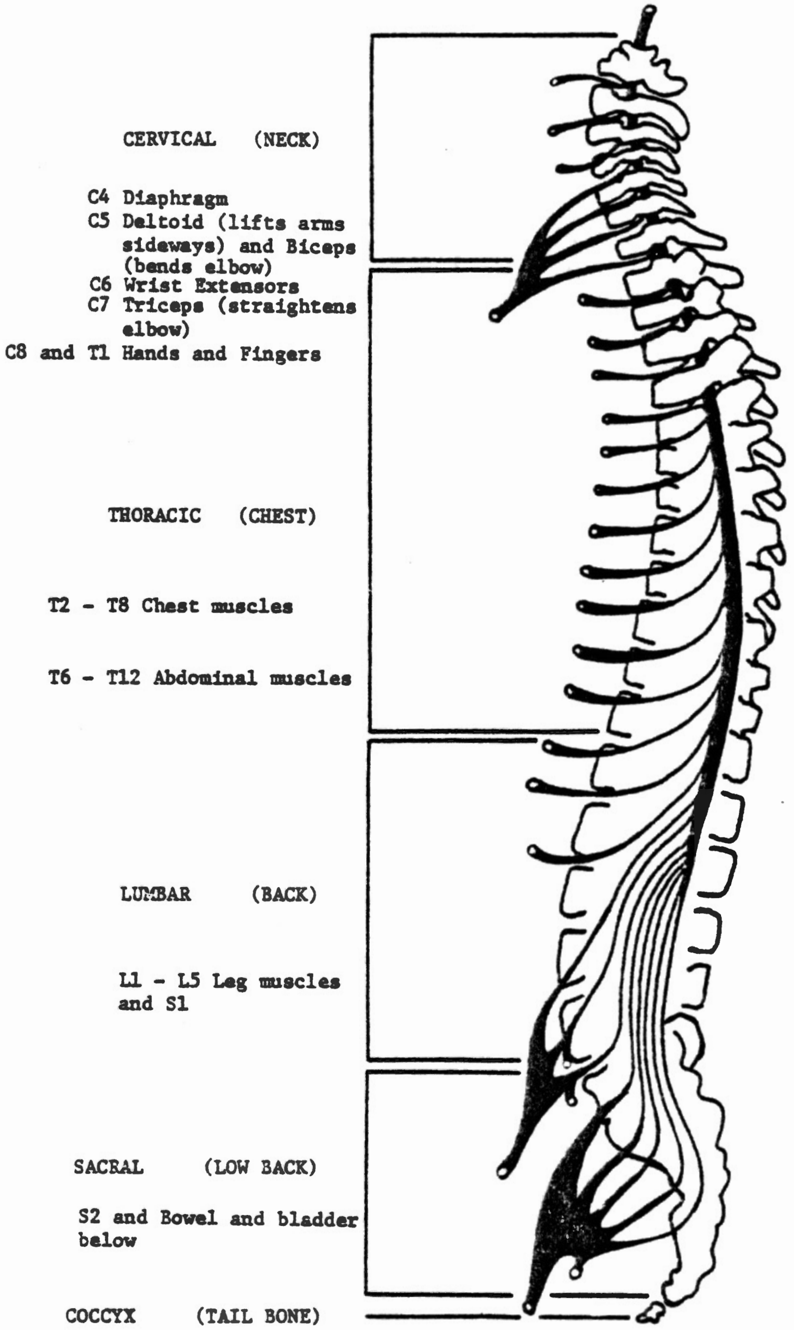
During the past three decades, sophisticated medical knowledge has increased the survival rate of spinal cord injured persons. Prior to World War II, few individuals survived for extended periods following spinal cord injury, and even fewer were able to resume roles as contributing members of society. With this increased life expectancy has come a change in the scope and nature of the demands placed upon society, medical and rehabilitation teams, and on the spinal cord injured. Persons with spinal injury have become less content to lead lives that deny them the opportunity to have satisfying professional, social, and personal lives, as well as the opportunity for challenging and enjoyable use of leisure time.

It has been estimated that there are 150,000 persons with spinal cord injury in the United States and that 7,000 to 10,000 new spinal injuries occur each year (Barker, 1953). Approximately 80% are active males, with 62% of these being between the ages of 15 and 30 (Seybold, 1974; Fitting et al., 1978; Stewart, 1977). Spinal cord injury resulting in paralysis is clearly a major and increasing problem today, with automobile accidents being the leading cause of its incidence in

America (Trieschmann, 1980; Fitting et al., 1978; Singh and Magner, 1975). Other causes include motorcycling, trampolining, diving, and skiing accidents.

The term "spinal cord injury" identifies injuries in which the spinal cord is severely damaged, often totally severed. Non-traumatic spinal cord injury is caused by a number of diseases. While the medical treatment of non-traumatic lesions may be different in some respects, the functional consequences for the victim are often the same as in traumatic cases. Following current usage in the literature, the term "spinal cord injury" (SCI) will be used primarily to refer to traumatic injuries.

The spinal cord is a bundle of nerve fibers surrounded by bone or vertebrae which carries messages to and from the brain to muscles, skin, and internal organs. The 33 vertebrae, protecting the spinal cord, are divided into 7 cervical, 12 thoracic, 5 lumbar, and 5 sacral vertebrae (Figure 1). When a complete lesion occurs, impulses cannot be transmitted either down or up fiber tracts past the point of injury, whereas a damaged or partially severed cord or incomplete lesion may result in partial paralysis of the affected extremities and organs. Patients whose lower extremities and abdominal functions are affected are called paraplegics. Their lesion is at the thoracic level or below. Patients whose lesions are in the cervical region of the spine have paralysis of the upper extremities as well, with effect on higher body organs. They are called quadriplegics or tetraplegics. The most important muscles and the functions they serve at each of the spinal cord levels are listed in Table I. Shown in Table II are the



Source: Virginia Spinal Cord Injury Care and Teaching Manual (1980).

Figure 1. Relationship of Nerve Roots to Specific Muscles and Functions

TABLE I

MUSCLES SUPPLIED AND FUNCTIONS SERVED BY SPINAL NERVE MOTOR ROOTS

Root Segment	Representative Muscles	Function Served
C1 & C2	High Neck Muscles	Aid in head control
C3 & C4	Diaphragm	Inspiration (breathing in)
C5 & C6	Deltoid Biceps	Shoulder flexion, abduction (arm foward, out to side) Elbow flexion (elbow bent)
C6 & C7	Extensor Carpi Radialis Pronator Teres	Wrist dorsiflexion (back of hand up) Wrist pronation (palm down)
C7 & C8	Triceps Extensor Digitorum Communis	Elbow extension (elbow straight) Finger extension ("knuckles" straight)
C8 & T1	Flexor Digitorum Superficialis Opponens Pollicis Interossei (intrinsics)	Finger flexion (fist clenched) Thumb opposition (thumb brought to little finger) Spreading and closing the fingers
T2–T6	Intercostals	Forced inspiration (breathing in) Expiration (breathing out, coughing)
T6–T12	Intercostals Abdominals	Forced inspiration (breathing in) Aid in expiration (coughing) Aid in trunk flexion (sitting up)
L1, L2, L3	Iliopsoas Adductors	Hip flexion (thigh to chest) Hip adduction (thigh to midline, legs together)
L3 & L4	Quadriceps	Knee extension (knee straight)
L4, L5, S1	Gluteus Medius Tibialis Anterior	Hip abduction (thigh out to side, legs apart) Foot dorsiflexion (foot up, walk on heels)
L5, S1, S2	Gluteus Maximus Gastrocneumius	Hip extension (thigh in line with trunk, hips straight, e.g., standing) Foot plantar flexion (foot down, walk on toes)
S2, S3, S4	Anal Sphincter Urethral Sphincter	Bowel function (fecal continence) Bladder control (urinary continence)

Source: W. M. Donovan, "Spinal Cord Injury," in *Handbook of Severe Disability* (1981).

TABLE II

FUNCTIONAL EXPECTATIONS AND EQUIPMENT REQUIRED FOR SPINAL CORD INJURY PATIENTS

Activities	C5	C6	C7–C8	T1–T5	T6–T12	L1–L3	L4–S1
Self-care:							
Eating	D/P_1	P_2	P_2/I	I	I	I	I
Dressing	D	P/I	P/I	I	I	I	I
Toileting	D	P_2/I	P_2/I	I	I	I	I
Work with hands:							
Writing	D	P_2	P_2	I	I	I	I
Typing	$P_{1,3}$	$I_{2,3}$	I_3	I	I	I	I
Operating telephone	P	I	I	I	I	I	I
Bed Independence:							
Rolling over; sitting up	$P_{4,5}$	P_5/I	I	I	I	I	I
Wheelchair Independence:							
Transfers to/from wheelchair	D	P/I	I	I	I	I	I
Propel wheelchair	I_6	I_7	I	I	I	I	I
Ambulation	O	O	O	D_8	P_8	I_9	I_{10}
Driving with hand controls	P	I	I	I	I	I	I
Public transportation:							
Bus	O	O	O	O	O	O	P/I
Train	D	D/P	P	I	I	I	I
Plane	P	I	I	I	I	I	I
Public toilets	O	P_{11}	P_{11}	P_{11}	P_{11}	$P_{11,9}$	I

LEGEND

I	Complete independence is possible
P	Partial independence is possible with use of special equipment
D	Dependence is to be expected
O	Not possible

1 With electric or CO_2 powered splints
2 With nonpowered hand splint
3 With electric typewriter
4 With loops, balkan frame—electric bed
5 With electric bed
6 With electric wheelchair
7 With adapted hand rims (special lugs or hose wrapped)
8 Not practical
9 With long leg brace and crutches
10 With short leg braces and crutches
11 With zipper-back wheelchair

Source: W. M. Donavan, "Spinal Cord Injury," in Handbook of Severe Disability (1981).

functional expectations of and equipment required for spinal cord injury patients.

The medical complications and functional disabilities of SCI are even more serious than might be apparent. Paralysis of the legs does more than prevent walking. It can cause severe and painful muscle contractions, spasticity, and orthopedic deformity. The sensation of pain is lost in the affected area; consequently, an important safety mechanism is removed. Lacking sensation in large areas of the body, the paralyzed person readily develops decubitis ulcers. The mechanism of perspiration is also affected. This vital safety mechanism helps to cool the body automatically under conditions of severe heat, both external and internal (fever). The paraplegic is dangerously vulnerable to hot weather and to fever caused by even mild infections.

Paraplegics lose voluntary control of bowel and bladder elimination because they have no control of the sphincter muscle. Genital sensation is also lost and sexual function is impaired, though not necessarily lost. Urinary infections, kidney stones, and gastrointestinal disorders are frequent complications. Bladder catherization is usually needed, either continuously or on an intermittent basis, and catherization itself is a frequent cause of infection. Respiratory disorders are another dangerous complication, especially for quadriplegics. Quadriplegics with high lesions may require mechanical respiratory aids.

These physiological complications often produce massive social and psychological problems. Guttman (as cited in Cormack, 1967), a pioneer in the case of the SCI, is reported to have said that spinal cord injury is a socio-psychological problem with medical complications.

Few people would be prepared to cope with the overwhelming difficulties imposed upon the traumatically paralyzed person. The suddenness of the onset and the youth of the greatest number of its victims make spinal cord injury especially tragic. Rusty Miller, a quadriplegic for 10 years, made the following statement regarding the magnitude of the implications of SCI:

> The experience was completely new and quite obviously alien to any of my previous life experiences; and as one might expect, the number of problems was so large that were it not for the period of time between each individual problem, they could have easily been overwhelming. Even such a small detail as getting in and out of my own home was a problem, for we lived in a trailerhome. Fortunately, my parents were in the process of building a new home, so until it was completed, I lived in my grandparents' home. Setting aside all of the routines of daily living and adjustments of family schedules to accommodate these changes, however, it guess the most difficult problem to adjust to was the easily noticeable change in my family, friends, and others' attitude towards me. It was like a butterfly changing to a caterpillar, or a metamorphosis in reverse.
>
> Before my accident I was the 'superstudent.' I was salutatorian of my freshman class, an all-conference running back in football, an all-regional band member, a competitive participant in basketball, track, and many athletic activities, and an active member in FFA, church, and other social activities. In addition to these activities, I worked on the family farm. No one ever doubted any of my abilities, whether physical or mental. When I emerged from my cocoon nine months after the injury, the transformation from pupa to larva was complete. I was like a child who felt reincarnated. Each time I confronted a person, family member, or previous friend to develop a new relationship, I sensed a disconcerting, discomfiting, and sometimes even an embarrassed feeling not altogether unlike the chilled feeling one has when in a place or event where he has never been before but feels he has. My old image was shattered. The new image of myself that grew out of this metamorphosis, although I suppressed an extreme amount of disdain for it, wass the traditional old-fashioned 'helpless cripple.' Rather than accept my condition as a long-term fact of life, my family (notwithstanding the two notable exceptions of my brothers) and others were instinctively looking for a 'cure'

> regardless of whether it was legitimate or not. The remainder of their time was spent looking for what they could do FOR me, instead of simply accepting my condition and looking for ways to help me cope with it; and beneath almost all interpersonal relationships, whether spoken oir unspoken, was an obviously over-protective instinct to insulate me from any difficult situations (Personal Interview, 1982).

It is obvious that the "self" is subjected to severe stress at the time of spinal injury. As society's feelings of devaluation become apparent to the disabled, his attitude begins to deteriorate into feelings of inferiority characterized by shyness, anxiety, and a loss of self-confidence and personal dignity. All this tends to undermine the patient's self-concept and his feelings of being a whole individual. Loss of independence and possible decline in the quality of life may create intense psychosocial adjustment problems. Although the evidence is not conclusive, it appears that between 11% and 46% of deaths among persons with SCI may be related to self-destructive behavior including suicide, self-neglect, and abuse of alcohol and other drugs (Trieschmann, 1980). Most of these deaths occur within five years of injury. Therefore, because our rehabilitation efforts are not completely successful, it is important to study the process of adjustment, and to identify those variables most conducive to successful re-entry into life following traumatic SCI.

Statement of the Problem

The purpose of this study was to identify and evaluate, as far as possible, all the factors influencing the physical, social, and emotional reintegration of the person disabled by traumatic SCI. This was achieved by a review of related literature and a case study of four SCI persons who have made an apparently successful adjustment to their disabilities and have re-entered society as contributing citizens.

Significance of the Study

Rehabilitation of the person disabled by SCI is a long and costly process. It is without doubt more demanding and time consuming than the treatment of any other type of physical disability. Intensive efforts of a large treatment team must be extended over months, and, not infrequently, years. Sizable expenditures may be required for various kinds of mechanical devices such as electric wheelchairs, lifts, braces, and specially equipped automobiles, which enable the SCI person to drive. Extensive programs are necessary for teaching personal care and activities of daily living, and for assistance in adjusting socially and vocationally. With the ever-increasing population of persons having spinal cord dysfunction, it is important to strive for maximum efficiency in helping them adjust to the changes in their lifestyles.

This study was made in an attempt to contribute to what at present is a small body of knowledge about the effects of traumatic spinal cord injury upon the individual and those factors most influential in determining successful readjustment. Until more research in this area has been done, data on variables affecting this adjustment must continue to be inconclusive.

Limitations

The following conditions are viewed as limitations of this study:

The subjects were not randomly selected, but were a select, voluntary group SCI males.

2. The study was limited to four individual cases. [illegible] [illegible]

3. No standardized test instruments were used.

Delimitations

This study was delimited in the following ways:

1. The sample group was small and carefully selected according to their success in coping with SCI.

2. Because of the high incidence of SCI among males, all subjects were men.

Definition of Terms

ADL - Activities of Daily Living. Those skills required for everyday functioning, such as dressing, eating, transferring from bed to wheelchair, etc.

Adaptive Equipment. Items or tools that are either commercially available or are modified to assist one in performing activities of daily living.

Ambulate. To walk, with or without the aid of special equipment.

Areflexia. No reflex present (see "Reflex).

Autonomic Dysreflexia. A reaction including headache, chills, sweating, and high blood pressure, which may occur in persons with a spinal cord injury above the sixth thoractic level. It is most frequently caused by an over-distended bladder and can lead to severe complications.

Bladder Training. A method by which an individual with a neurogenic bladder trains the bladder to empty without the use of a catheter.

Bowel Program. Establishment of a "habit pattern" or a specific time to empty the bowel so that regularity can be achieved.

Catheter. A specially designed rubber tube which is placed in the bladder to drain urine out of the body, or for injecting fluids such as intravenous feedings.

Central Nervous System. The part of the nervous system normally thought of as the brain and the spinal cord.

Cervical Region. The part of the spinal cord containing the first seven vertebrae (C-1 to C-7).

Coccyx. The "tailbone," which is a common area for a pressure sore.

Complete Injury. A spinal cord injury causing total loss of muscle power and sensation below the level of injury. Normal functional ability is not recovered with this type of injury.

Contracture. Permanent limitation of joint movement caused by infrequent range of motion, poor positioning, and/or severe spasms.

Decubitus Ulcer - Pressure Sore. A breakdown in the surface of the skin.

Disability. The actual dysfunction or limitation caused by a disease or injury. The disability is a handicap only to the extent that a person is not able to function normally in employment, education, recreation, and other activities of daily living.

Flaccidity. Complete lack or absence of muscle tone.

Hand Splint. A support for the hand, wrist, and/or fingers. It is used to improve positioning and function.

Incomplete Injury. A spinal cord injury which does not cause total loss of motor (muscle) power and/or sensation. There are several combinations of motor power and sensation that may result from an incomplete injury. For example, one may not have motor power but have partial sensation. Usually, the amount of function one may recover will occur in 6 to 12 months after the injury.

Incontinent. Inability to control bladder and/or bowel function.

Ischium - Ischial Tuberosities. Two bony prominences in the buttocks which are common sites for pressure sores.

Lumbar Region. The part of the spinal cord from the waist to the sacrum, including the five vertebrae, L-1 to L-5.

Long Leg Brace. An appliance used to support the leg for ambulation.

Mobile Arm Support. Equipment used to help a person whose shoulders are weak move arms and hands. Neurogenic Bladder. A bladder which does not function normally due to abnormal nerve control, either from the central nervous system or from peripheral nerve abnormalities.

O. T. - Occupational Therapy. Treatment to improve strength, range of motion, coordination, and balance, in order to accomplish skills of ADL such as eating, grooming, dressing, and transfers. The goal of O. T. is to assist an individual in becoming as independent as possible in his self-care and daily activities.

Pain. A sensation in which a person experiences discomfort, distress, or suffering.

Paraplegia. Paraspinal cord injury to thoracic, lumbar, or sacral areas. Generally there is paralysis of the legs and trunk.

Paralysis. A loss of movement and sensation.

Physical Therapy - P. T.. Treatment to improve strength, range of motion, coordination, balance, and mobility, either in a wheelchair, or by ambulation. The physical therapist might also assist with special respiratory care. The goal of P. T. is to make a person as physically independent and mobile as possible.

Pressure Sore. The same as a decubitus and refers to dead skin caused by excessive pressure.

Quadriplegia Quad. Spinal cord injury to the cervical ara of the cord resulting in loss of function and sensation in all four limbs and trunk. The paralysis varies in degree according to the level of injury.

ROM - Range of Motion. The amount of movement of any body joint or exercises designed to maintain this normal range and prevent contractures.

Reflex. A nerve reaction whereby a stimulus, touch, pain, or pressure causes movement of muscles.

Reflux. The backflow of urine from the bladder via the ureter to the kidney. The pressure can create kidney damage, a major concern of the SCI.

Sacral Region. The area containing lower abdomen structures including the last five vertebrae that are fused together (S-1 to S-5).

Self-Concept. Individual's perceptions of themselves. Self-concept is an important psychological construct that influences attitude and behavior.

Sensation. A feeling or awareness of body parts.

Sip and Puff. A drive mechanism used on some wheelchairs. Operations involve only the ability to sip and puff into a tube.

Sling. Simplest arm support. Attaches to a bar fastened to the wheelchair or to an overhead frame.

Spasm. A sudden, often uncontrollable, contraction of a muscle (a muscle jerk).

Spasticity. An increase in muscle tone (usually due to some damage to the nervous system) that is involuntary and may affect only a few muscles or a number of large muscle groups. Spasms may be minimal and aid in maintaining muscle bulk or may be maximal and totally inhibit function. Increased spacicity may be elicited by a variety of factors (anxiety, pain, cold, movement, or medical complications).

Spinal Cord Injury (SCI). An injury that results in damage to the spinal cord.

Spinal Shock. The absence of reflexes below the level of spinal cord injury. The time period is controversial, ranging from days to months. As spinal shock subsides, involuntary reflexes return, such as muscle spasms and "kicking off."

Suprapubic Catheter. A tube which is inserted through the skin above the pubic arch into the bladder as one way to drain urine.

Tetraplegia. A term which is synonymous with "quadriplegia," using the Greek prefix "tetra" for four, rather than the Latin "quadra."

Thoracic Region. The area of the body that includes structures from the shoulders to the last rib and five vertebrae (T-1 to T-12).

Tilt Table. A mechanical table used by physical therapists to assist in getting an individual, who has been flat in bed, to an upright position. This is done gradually to allow the body to adjust to changes affecting the circulatory system.

Transfer. Movement from one place to another, as from bed to wheelchair, wheelchair to toilet, or wheelchair to car.

Trochanter. The bony prominence at the hips which can be the site of pressure sores from the side-lying position.

Urinary Tract Infection (UTI). An infection of the bladder or kidneys which can lead to severe complications in the SCI.

Vertebrae. Any one of 33 bony segments of the spinal column; the vertebrae surround and protect the spinal cord.

CHAPTER II

REVIEW OF THE LITERATURE

The newly paralyzed person faces two monumental tasks--he must endeavor to overcome his physical disability and he must move from a position of total dependence on the hospital staff back to a position of self-esteem and to a new position in the home, as well as in interpersonal relationships. He has, in other words, lost his identity and must find it again (Kerr and Thompson, 1972).

Several different explanations for the relative adjustment or maladjustment of the SCI person are given in the literature. Explanations have varied from the contention that the perception of the disability and self-concept are highly linked (Wachs and Zaks, 1960; Linkowski and Dunn, 1974; Mayer and Andrews, 1981), to the suggestion that a disability may not affect self-esteem at all (Coleman, 1977; Cogswell, 1968; Phillips, 1964; Goffman, 1963). Other authors (Price, 1973; Cook, 1976; Garrett, 1952; Kaplan et al., 1966; Mueller and Thompson, 1950; Rusk, 1963; Siegal, 1969; Felton and Litman, 1965; Dvonch et al., 1965) have related adjustment to pre-injury personality traits, pain, family reinforcement, financial concerns, vocational success, and attitudes of society.

Stages of Adjustment

In the literature on adjustment to SCI, opinion is mixed as to whether there are stages to the process. Many authors describe the stages of adjustment but vary as to how explicitly they state that everyone must go through these stages (Seybold, 1974; Nagler, 1950; Wittkower et al., 1954; Siller, 1969; Price, 1973; Fink, 1967; and Shontz, 1968). Other authors (Robertson and Guttmann, 1963; Cogswell, 1968; Comarr, 1956; Kerr, 1977; Trieschman, 1980; Tucker, 1980) discuss the psychological problems of persons with spinal cord injury without specifically stating that there are stages in the adjustment process; yet they seem to imply that all persons with spinal injury will exhibit these difficulties at some time. Still other authors emphasize the tremendous variability in the response to SCI, and challenge the stage theory of adjustment (Mueller, 1962; Athelstan, 1981, Hohmann, 1966; Dinardo, 1971; Hobermann, 1958; and Klas, 1970).

Fink (1967) described a typical cycle as beginning with shock used as an emergency defense against being overwhelmed, followed by defensive retreat, acknowledgment, and eventual adaptation. He described the first three stages as involving safety or security, while the last is growth-oriented and can result in self-actualization. Shontz (1968) conceptualized the adaptation process as successive approach-avoidance cycles that decrease in intensity and frequency until the cyclical nature becomes unnoticeable. Tucker (1980), speaking from personal experience, viewed the cycle as characterized by severe depression, anger, confusion, withdrawal, and then noticeable acceptance leading to gradual reinvolvement in life. She stated that a feeling of strong detachment from one's human self prevails until the reintegration occurs. The process never seems to result in complete acceptance, since the losses and inconvenience persist. Instead of total acceptance, there is adaptation via major value changes.

Based upon observations of 37 SCI patients in rehabilitation, Weller and Miller (1977) identified and described the progressive reaction stages as consisting of shock, denial, anger, and depression. They stated that these stages may vary in order, fluctuate, overlap, or be omitted, and may culminate in the fifth stage of adjustment to the changed physiological state, which usually occurs two to three years after injury.

Shontz (1962) and others (Nagler, 1950; Mueller, 1950; Price, 1973) agreed with Weller and Miller (1977) in their contention that while there are definite stages in the adjustment process, these stages may vary in order and intensity. They described three distinct phases: first, the individual experiences withdrawal and isolation mechanisms that minimize the focus on self and a lack of spontaneity and initiative; second, the individual experiences a situational depression associated with disability and future life role; and third, the individual attempts to compensate for loss of prestige in the face of dependency upon others. Berger and Garrett (1952) did not find that all persons with spinal cord injury react to their disability in the same way; however, they asserted that certain behaviors such as depression, anxiety, and immature emotional expressions occur frequently.

Kerr (1977), a psychologist who is paraplegic, described five major stages in the process of adjusting to permanent disability: shock, expectancy of recovery, mourning, defense, and finally, adjustment. She pointed out that the stages are points on a continuum, not discrete categories, and that they describe common, but not inevitable behavioral phases. She described the shock stage as that period of time during which the individual has not fully comprehended the implications of his injury and, therefore, little anxiety is present. The realization that something significant has happened is often accompanied by expectancy of recovery, including preoccupation with improvement of the condition. During this stage, the patient lacks motivation for learning to live with the disability because it is "temporary." When the patient becomes aware that the disability is permanent, mourning sets it. Acute distress, readiness to "give up," and thoughts of suicide are common during this stage. The defense stage follows in which the patient begins the attempt to cope with a new and different lifestyle.

Gunther (1971) identified the stages as an initial chaotic disruption (one to three days after injury) and then the stage of passive adjustment leading to defensive denial; at which time, the massive and extensive consequences of the injury are finally confronted. Next, hope for recovery is abandoned, and is followed by regression-depression. Finally, gradual working through of the crisis merges with the acceptance and stabilization of a new self and with a gradual alteration of self-image and identification.

Seybold (1974) reported that there are three phases a paraplegic or quadriplegic goes through, to some degree or another, before any progress can be made. These phases include: (1) the initial physiological shock and adjustment to the body's inability to function normally and the mind, in disbelief, witnessing this; (2) the psychological depression and emotional anguish of realizing that one is paralyzed forever and will never walk again or enjoy the full and vital force of a whole body; self-esteem lost and the ego shattered; and (3) final acceptance of the situation for what it is and nothing more, and the realization and belief in what can be done instead of what cannot be done.

Using a framework suggested by David (1963) and Shontz (1976), Eisenberg and Falconer (1978) described the stages of adjustment as being a cyclic process. The first stage, shock, they described as being a depersonalized emergency reaction marked by feelings of detachment. The person often reports feeling as though he were observing events in which he is not actively participating. The second stage, impact, was observable behaviorally when the individual panicked; disorganization and helplessness manifest themselves during this stage. The emotional content of the impact stage was described as despair. Generally, the impact stage does not end suddenly; grief and a sense of loss are gradually replaced by attempts to evaluate the situation, explore its implications, and adjust to demands it imposes. The next stage observed was a type of avoidance referred to by some as retreat or denial. During this stage, the patient characteristically tries to fend off the finality of the diagnosis. The final stage, adaptation, is the longest. Once the physical deficit is acknowledged, the individual begins to hope that mastery of a new situation will solve all problems. The authors noted that the cycle is never complete, for as the individual faces failure or disappointment, he tends to retreat into a previously passed through adjustment phase.

Caywood (1974), speaking from personal experience, described the stages of adjustment in very different terms than other authors. His descriptions of the adjustment process included:

1. Having no choice as to what was being done to his body.

2. Realizing that it was his responsibility to put family, friends, and visitors at ease.

3. Learning how to deal with people who appeared uncomfortable around him.

4. Learning to rely on assistance with the simplest physical functions.

5. Becoming accustomed to the "relative indifference" of the staff, once he moved to the rehabilitation center and was no longer a special case.

6. Realizing the extensiveness of the work ahead of him if ultimate adjustment (potential) was to be attained.

7. Coping with the tremendous fatigue at the end of each day of therapy.

8. Learning to assess his progress by the comments of visitors who had not seen him for awhile.

9. Not quitting in the face of frustration.

Depression

The stage of adjustment cited most frequently was that of depression (Nemiah, 1957; Nagler, 1950; Cook, 1976; Siller, 1969; Trieschmann, 1980). Cook, citing Knorr and Bull (1970), stated that situational depression in the acute phase of treatment is common and can even be expected. Nagler (1950) and Nemiah (1957), writing from clinical experience, suggested that the SCI go through a period of depression or "mourning" in their efforts to work through the grief over their loss. They indicated that patients who do not experience such a depression are probably denying the reality of their situation. If such a reaction is not noticed, the patient is said to be using denial as a defense mechanism against depression. This denial or failure to face up to the effects of disability is thought to slow down the rehabilitation process. Nemiah (1957) further indicated that it may be necessary to confront the patient and force him into a period of depression so that he can work out his acceptance of loss.

Wittkower et al. (1954) stated that denial of disability is the first response to the SCI. They found in a study of 50 cases that in the early months of their disablement all patients, without exception, showed deep depression. They noted that there were no functional psychoses in this group and only one case of psychoneurosis, and that in each of the 50 cases there was an intensification of basic personality structure.

Siller (1969) related that anxiety and depression are the foremost reactions to physical traumatization. He cautioned that if the superficial clinical picture suggests an absence of anxiety and depression, a more thorough observation will usually reveal their presence. He further stated that a person should be depressed because something significant has happened, and not to respond in such a way is denial; grief and mourning behavior are necessary to the adjustment process.

Hohmann (1966) and McDaniel and Sexton (1971) challenged the assumption that depression and, by association, the requirement of mourning are prerequisites for psychological adjustment to the SCI. They suggested that one reason that depression and grief over loss may not be experienced by some SCI persons is that the nature of the disability may, in and of itself, modify such feelings. They further suggested that spinal cord transection disrupts the affectual arousal of the injured person. Hester (1971) reported that spinal cord transsection disrupts but did not necessarily moderate cognitive related task performance. He also reported that the emotional changes in the SCI may not entirely relate to lack of physiological arousal but may be related to cognitive goal-oriented behavior. These findings suggest that depression exhibited by some SCI persons may be a learned reaction to fulfill staff and family expectations and achieve certain personal needs. The studies of Hohmann (1966), Hester (1971), and McDaniel and Sexton (1971) indicated that: (1) the requirement of mourning may not be an a priori stage in the adjustment to spinal injury; (2) depression may not be a necessary precondition to adjustment; (3) there may be a physiological as well as a psychological rationale for SCI persons to deny, at least initially, the effects of their injury; and (4) SCI persons may learn from staff attitudes and expectations that they are required to enter a period of mourning.

Dinardo (1971) also tested the hypothesis that depression is a necessary precondition in adjustment to SCI. His findings suggested that, on the contrary, the absence of depression is related to good adjustment. In fact, those labeled as deniers make the best adjustment to disability. Mueller (1962) reported a clinical study in which nearly 50% of the 109 SCI persons studied did not even experience temporary depression. Both Trieschmann (1980) and Athelstan (1981) agreed with Dinardo in challenging the stage theory of adjustment. Trieschmann indicated that there is no evidence that all SCI persons experience the denial stage, although many writers characterized by denial of disability. She suggested that this may be an oversimplification and that pain, fear about survival, sensory and perceptual deprivation, sleep disruption, and drugs may account for a large part of the person's behavior during the early period. Trieschmann (1981) also stated that sophisticated behavioral, biomechanical, and personality measures of depression currently used indicated that although people with SCI are not happy about their injury and its implications for the future, they are not in a state of depression. She further stated that the onset of SCI is not a minimal event in one's life, yet many persons with spinal injury relate that it is not the most important thing that has ever happened to them. She suggested that professionals have stressed the negative emotional aspects unnecessarily and have underestimated the strengths and coping ability of people in crisis.

Athelstan (1980) stressed the danger of expecting a person to conform to stages. He stated that since individual differences characterize the adjustment to disability as well as to every other important aspect of life, spinal cord injured persons must be dealt with individually.

McDaniel and Sexton (1971) showed that persons with higher level lesions show greater depression, anxiety levels, physical complaints, irritability, and use of denial mechanism. Furthermore, quadriplegic patients showed less satisfactory socialization responses to other patients and staff during the course of rehabilitation at every stage of study, and manifested less acceptance of loss and functional limitations than did patients with lower level lesions. Also notable among findings of these reports was that all indicators of stress, affective and hormonal, increased dramatically just prior to discharge from the rehabilitation center. The increase resulted from the patient's awareness of the problems and adjustments that must be made in order to function in a setting not designed for the disabled.

Ruge (1969) stated that other than anxiety and depression, psychological reactions to SCI included a wide variety of psychoneurotic syndromes such as hysteria, paranoia, and somatization. Hostility, dependence, combativeness, negativism, and helplessness are among common responses observed. They often become incapacitating and block the rehabilitation process. Defense mechanisms such as denial, withdrawal, regression, fantasy, and repression are commonly employed in crises situations. Although at times these are necessary and useful to the individual, it is the intensity with which they are employed that determines the extent of adjustment and rehabilitation that can be achieved.

There are many specific problems that the SCI person must meet after he has made the initial global adjustments just discussed. These adjustment stem from pressures exerted from three directions. The first involves pressures of the pre-traumatic personality; the second centers around physical disabilities and the inevitable psychologic complications arising from them (sexual identity, self-concept, body image, etc.); and the third consists of the pressures evolving from social, economic, and vocational problems.

Pre-Traumatic Personality

It is a recognized psychologic fact that continuity and consistency are two outstanding characteristics of the personality. This does not mean that they are fixed characteristics that cannot be changed or re-directed; it does mean, however, that a given person's personality organization remains fairly consistent throughout life (Mueller, 1952; Comarr, 1956). Much of the literature on SCI suggests that the person's pre-traumatic or pre-morbid personality traits determine the response to spinal innury (Seymour, 1955; Cook, 1976; Kaplan et al., 1966; Hohmann, 1975; Mueller, 1962; Thom et al., 1950).

Kaplan et al. (1966) reported that an individual reacts to disability in a manner that, to some degree, depends on the makeup of his personality. The reaction is modified by such factors as the number, extent, and location of neuropathological lesions; the social implications of physical limitations; and the economic, mental, and environmental significance of all these things to him.

The manner in which a specific individual adjusts to physical disability is perhaps best summarized by Garrett (1952):

> What we psychologically observe . . . is an exaggeration of problems which are common to the disabled. Where the person has always been mature and well-adjusted he will react in just that manner. Where the person has always been infantile and poorly adjusted there will be just that type of reaction to disability (p. 63).

Nickerson (1971) postulated that a person experiences a sequence of feelings and attitudes as he attempts to cope with spinal cord injury. He called these normal reactions to an abnormal situation. After these reactions have been worked through there will usually be a return to the pre-injury personality. Hohmann (1971) reported that if a person has a pre-injury history of severe depression or suicidal attempts, the prognosis for adjustment will be poor. In a similar fashion, any evidence of pre-injury inability to cope with stress over a significant period of time does not appear to portend well for coping with disability.

Because the pre-traumatic personality continues to set the pattern for post-traumatic goals and behaviors, there will be numerous conflicts and frustrations due to pressures exerted by the pre-traumatic personality in its effort to maintain its integrity. Mueller (1961) observed that the more intelligent patients, with a strong drive to achieve, adjust more readily, find satisfaction in living despite their limitations, and do constructive planning for the future. They achieve what Nagler (1950) has termed the so-called normal reaction. On the other hand, Nagler (1950) described those patients who adopt an attitude of indifference, passivity, and complete hopelessness as the indifferent group.

Individual differences in attitudes toward disability were found in the studies of Thom et al. (1946) and confirmed by Mueller and Thompson (1950). They found that generally, when the pre-traumatic personality is sound and is characterized by extraversion, high feeling tone, and little intellectualization, the patient reacts well to disability and responds well to rehabilitation. On the other hand, when the pre-traumatic personality is characterized by strong inner feeling, effort, and ambition, difficulty in adjusting and responding to rehabilitation is increased, as are depression, anxiety, irritability, and anger.

Athelstan and Crew (1979) suggested that psychological adjustment to SCI is related to the manner of onset of the disability, and that people who have more control or responsibility for their accidents are more likely to have better adjustment to their disabilities than those who feel little or no responsibility for their conditions. In an earlier study, Fordyce (1964) found objective evidence of traits of impulsiveness, rebelliousness, and non-conformity in 58 men with SCI. He suggested that these characteristics may be typical of SCI people and that these people may have suffered injury as a result of their "imprudent behavior." Meyer, Rosen, and Hamilton (1975) found that 75% of their 24 SCI adult patients were undergoing significant psychological disruption at the time of injury. Steinberg, Birenbaum, and Stoddard (1978) noted that the young SCI persons who had pre-injury behavior disorders did less well and were prone to develop more medical complications than were those who were previously better adjusted.

Psychosocial Implications

Because many of the psychological effects of SCI are a result of social attitudes, it is necessary to consider some of the immediate consequences. According to Athelstan (1981), one of the most predictable changes following SCI is that of social status. Disabled persons in our society assume a special kind of minority status and occupy a socially devalued role. In numerous studies (Singh and Magner, 1975; Trieschmann, 1980; Vash, 1981; Albrecht, 1976) it has been held that people tend to attribute negative characteristics to the disabled and that the tendency generalizes well beyond the direct effects of the disability. Because of their visible disability, SCI persons are often assumed by others to be less attractive, less desirable, and less capable in ways that are totally unrelated to their disability. In a recent study, Dion, Berscheid, and Walster (1972) reconfirmed the existence of the stereotypic, "What is beautiful is good." Physically attractive persons are judged to be more socially desirable, to hold more prestigious jobs, to have happier marriages, and to have better prospects for happy social and professional lives than those less physically attractive. Lack of achievement, poor health, and failure connote deficiencies in virtue and morality.

A loss of social status may also result from the indirect effects of disability, such as its economic consequences (Stewart and Rossier, 1978). The cost of acute and long-term medical care may be so great as to deplete all of a family's assets. Furthermore, the impact of disability on an individual's earning capacity can produce a long-range change in socioeconomic status. Athelstan (1981) stated that when the principal breadwinner of a family is disabled, an average reduction of 40% in total family income results.

Disability usually causes profound changes in close social relationships. Nagi and Clark (1964) demonstrated the effects of disability on the family, including divorce rates, which sometimes rise but may also decline. Cogswell (1967) showed that it is typical for predisability friendships to dissolve. In fact, in the early stages of social adjustment for paraplegics, after their initial hospitalization, there is often a marked reduction of: (1) social contacts; (2) frequency of entering community settings; and (3) the number of roles played. It has been suggested that much of the individual's predisability mode of social adjustment must be discarded before new roles can be assumed and a new adjustment worked out. Cogswell further hypothesized that following discharge, persons with spinal injury tend to phase out relationships with pre-trauma friends, develop new friendships with lower status others, and then finally acquire new friends of similar pre-trauma status. She contended that situations in which both persons have social handicaps allow the person with the disability the opportunity to experiment with new behavior in less threatening situations.

Similarly, Davis (1963) contended that as newly disabled persons begin to acquire friends, they may tend to choose people of lower social status, decidedly younger or older than themselves, or less attractive in other ways. If in these relationships they are successful in projecting themselves as persons of worth, and if they become skilled in eliciting this definitnion from others, they proceed to more difficult relationships, eventually forming new relationships with individuals of equal status.

Vash (1981) stated that some people resolve to associate only with other disabled individuals who will understand. This may issue from self-derogation, a belief that one will not prove worthy to non-disabled friends. She contended, however, that many disabled persons, although fully confident of their ability to attract friends regardless of disability, may find that their firmest ties are with those who have shared a similar experience. This reflects a positive choice rather than a defense.

Some empirical evidence (Phillips, 1964) suggested that people suffering orthopaedic disabilities tend toward psychological maladjustment, and similar evidence exists with respect to other kinds of physical disabilities (1960). Undoubtedly, the most popular explanation for these findings, more often implied than stated in the literature, is what Colman (1971) called the social-rejection hypothesis. This hypothesis points to the psychological stress placed upon the individual as he becomes aware that people react negatively toward him and reject him socially. According to Goffman (1963, p. 19), who has done much to popularize this view, social rejection, along with shame which results from it, is "the central feature of the stigmatized individual's life." Goffman went on to state that the concept of self undergoes a change as the individual learns that people respond differently now that he is visibly disabled. But more importantly, the self-concept changes because, upon becoming disabled, a person perceives himself with the same degree of negativism as he viewed others with disabilities prior to injury. The idea that attitudes of others affect attitudes toward self is succinctly expressed by Siller, Chipman, and Vann (1967), who stated that a person with a handicap reflects prevalent social attitudes of self-deprecation of self-hate. In the newly disabled, on the other hand, negative attitudes previously focused on members of a devalued group may refocus on the self with devastating results.

Caywood (1974), in describing his own reaction to traumatic quadriplegia, discussed social isolation as being a very frequent feature of post-discharge life. He also referred to resocialization as being his biggest problem in attempting to resolve the conflict between what he is now--disabled--and the demands of society. Caywood stated that:

> Society demands that people act and be 'normal,' not deviate. At the same time, I was constantly reminded that I was not 'normal' through interpersonal relationships, architectural barriers, and vocational goals (p. 25).

Thus, Caywood outlined some of the social changes that occurred in his life because of visible disability and physical limitations. As a result, social isolation is a frequent feature of post-discharge life unless the person actively fights against it.

Thornton (1979) supported this view by pointing out that it is paramount that the newly SCI person become aware of the reality of the world outside of the hospital. Inevitably, the person will be asked personal questions, be stared at, hear negative comments, or be pointedly ignored. Coping with unwanted sympathy, obtaining help when needed, and handling help or offers of help when not needed will have to be learned.

In view of the problems of social interaction that the disabled persons face, it is not surprising that their behavior tends to be somewhat more strained and stereotyped than that of the able-bodied. As Albrecht (1976) stated, people are a product of their social interaction environment. The behaviors and expectations of others mold the behaviors and expectations of self.

Vance (1973) observed that disability occurs within a social context. Although an individual may experience a physical disability, he must function within both a social and physical environment. A definite interaction and interdependency exists between the organism and the environment. He contended that poverty, cultural deprivation, lack of education, and a depressed job market do influence the impact of physical disability on the disabled person, those who are close to him, and society.

It is clear from this review that the success of social integration is contingent upon the ability of the disabled to interact with his environment. This may be facilitated through changing goals and values, identifying specific problems, assessing resources, and modifying behavior. No longer can the individual be dealt with as the primary unit of anaysis (McDaniel, 1969). He must be conceived of as an attribute of the entire family and of society (Hrubec, 1959).

SCI and the Family

Just as injury disrupts the physiological and psychological homeostasis of the affected individual, so is the homeostatis balance of the family unit disrupted. When disability occurs, the family begins to struggle to regain its equilibrium. Although only one member of the family "owns" the disability, all family members are affected and, to some extent, handicapped by it. Catastrophic injury of any member of a family can have as far-reaching and intense an impact on the others as on the individual who becomes disabled. All experience shock and fear over the event or recognition of disablement and the pain and anxiety of wondering what the implications for the future are. The disability of one may alter the lifestyles of family members as much or more than that of the disabled individual; schedules, duties, plan, and roles all change. All experience loss--of a fully functioning cog in the family wheel, and that generates disappointment, frustration, and anger as freedom and time for fun disappear. Basically, the family members must learn to deal with the world and other people. Although guilt is an issue with which disabled people often must deal, especially when responsibility for the injury is theirs, it is an almost universal problem for the loved ones of a person who becomes disabled (Vash, 1981).

The literature showed that reactions of the family may be similar to those of the injured person, including feelings of denial, disbelief, anger and hostility, depression, and cognitive confusion (Tucker, 1980; Versluys, 1980; Christopherson, 1962; Trieschmann, 1980). Rappaport (1965) contended that emotional reactions are experienced by the family as well as the patients. The family initially presents a crisis reaction to the injury that parallels the patient's experience of shock. Babcock (1963) noted that a set family response is commonly observed following traumatic SCI. These responses include: guilt, shame, overcompensation, heavy reliance upon religious or cultural beliefs, denial, and depression. Romano (1974), observing patients with severe disabilities, found that families exhibited prolonged and persistent denial of the disability. This was frequently manifested in imagining the presence of improvement when none actually occurred. Other reactions frequently reported in the literature include:

1. Relief that the patient did not die or was not more severely injured.
2. A primary concern for the recovery of the patient.
3. Fear and anxiety in dealing with patient behaviors, such as depression and hostility.
4. Distrust and hostility toward medical pesonnel.
5. Family disappointment at results that the medical staff may consider good (return of some function).
6. A struggle for psychological preparation for the future (beginning to look at lifestyle change for the total family).
7. Concerns about continued pain and difficult treatment procedures.

8. Trying to deal with the patient's disclosure of feelings such as frustration and grief (the family may discourage such venting of feelings to preserve its own comfort).

9. The family may cling to unrealistic optimism--searching for cures.

10. The family may tend to overprotect the patient, thus increasing and encouraging dependence (Brodland, 1977; Litman, 1966; Weller and Miller, 1977; Versluys, 1980).

The direct influence of the family on the attitudes and behaviors of the handicapped person is frequently indicated in the literature (Klausner, 1969; Rosentock and Kutner, 1967; Margolin, 1971; Christopherson, 1962). Ironically, less is known about the dynamics of family reaction to traumatic disability than any other problem encountered.

Erba (1969) stated that family relationships and adjustment may determine the ultimate outcome of the rehabilitation process; therefore, the function of the family should be of pivotal concern from the onset of acute medical care to rehabilitation to therapy. Versluys (1980) stated that excellent treatment programs may never realize their potential because of the collapse of concerned but overwhelmed family members, and that the family's success or failure in coping with SCI is a major determinant in the patient's adjustment. If the family is positive and supportive, the patient will tend to do well in his rehabilitation program; whereas, if the family is unable to deal with the many problems and changes accompanying a disability of this magnitude, the patient too may find the problems of insurmountable proportions.

Margolin (1971) indicated that when a family communicates an attitude of essential worth to the patient, the stability of his self-concept is maintained and may even lead to enhanced self-esteem as he accepts the challenges of rehabilitation. In a 1972 study, Kerr and Thompson (1972) also found that all persons who were rated as having made an excellent adjustment to SCI came from exceptionally supportive families and had warm and loving backgrounds. Miller (1983), Smith (1983), Crawford (1983), and Collins (1983), all speaking from personal experience, contend that the quality of interpersonal relationships within the family is far more important than the disability itself. They further suggest that family reactions may be a crucial determinant of the overall adjustment of the SCI person.

An indication of the degree of family disruption that occurs as a result of disability is provided by Marra and Novis (1959) in a study of 52 disabled husbands and fathers. The subjects perceived the principal changes in their family relationships to be, in order of importance: (1) their wives had to assume greater responsibility for home management; (2) social and recreational activities were reduced; (3) children assumed more household duties; (4) they went into debt; (5) they changed plans for a larger family; (6) their wives' employment became a necessity; (7) marital discord increased; (8) plans for the children's education changes; and (9) living accommodations changed.

McDaniel (1976) contended that the patients' personality, strength, and original social role in the family appear to be the best predictors of home success. Safilios-Rothschild (1970) stated that married women with children, even if severely disabled, are usually taken back by the family unit because they can maintain some of their usual role functions. Role tasks such as planning and organizing family activities, participating in decision-making and problem-solving, and in encouraging other family members makes their presence a benefit. Active homemaking tasks can be carried out by others. Deutsch and Goldston (1960) studied 39 patients and their families in an investigation designed to determine the relationship of family attitudes and willingness of the family to care for a disabled member. Results showed that the patient's position in the family was important in determining which patients would return home and which would continue to reside at the rehabilitation center. The disabled child, women, and girls were most likely to return home. Married and unmarried men and adolescent boys were less likely to receive home care. The researchers stated that there were too few patients in the various subgroups to allow a completely reliable conclusion to be drawn based on family role. Deutsch and Goldston (1960) also studied the attitudes of family members of their groups of patients and found that those preferring to leave the care of the patient to the hospital or rehabilitation center were more unrealistic in that they tended to minimize the disabling effects and placed a higher value on the ability for voluntary movement. Expectations of the family for future improvement seemed strongly related to willingness to provide home care. Research by Safilios-Rothschild (1970) showed that the single disabled person tends to be more independent in activities of daily functions than the married disabled person. The greater the necessity to perform tasks and roles, the greater the probability that the persons will use all their abilities in striving for ultimate independence.

Litman (1962, 1966) reported that there is no appreciable relationship between the degree of family solidarity and rehabilitation response. Family support, however, in terms of active interest, acceptance, and encouragement bore a significant relationship to the patient's response during rehabilitation. Litman (1962) concluded:

> While the family may promote the patient's rehabilitative response through continuous supportive interest, the ultimate aims of the therapeutic staff may be gravely disturbed when the family fails to provide an atmosphere of warmth, acceptance, and encouragement or is unwilling to accept either performance or limitations of the disability (p. 253).

Another interesting finding of Litman's study was that the threat to the economic security of the family did not seem to bear an important relationship to the patient's progress in rehabilitation.

Marriage

The marriage and divorce rates of SCI persons have been extensively studied by Comarr (1962). In his study of 858 male veterans with SCI, 73% were paraplegic, 27% were quadriplegic, and 69% had complete and 39% had incomplete lesions. Before their injury, 48% were married, and 26% were not married, either before or after injury. Of those married before their injury, 29% were divorced before their injury and 33% of those married before they were injured were divorced after their injury. Of the 26% who married for the first time after their injury, 21% were divorced. These percentages compared to a 26% divorce rate of the general population of the United States in 1962, and a 45% to 49% divorce rate in California and Los Angeles County.

Guttmann et al. (1963) showed that 65% of the men and 48% of the women in their study of 47 subjects were married prior to injury.

After injury, 33% of the men and 77% of the women were still married, and 14% of the single women married within two years after their injury. Guttmann (1964) reported a study of SCI men and women in Great Britain where the national divorce rate was 1%. He found that 65% of his sample of 1,505 were married, and the divorce rate was 7.3%. He concluded that SCI does not preclude a happy married life.

The question of whether paraplegic patients can achieve a successful marriage has been one of speculation for some time. In the light of medical knowledge today, as well as the accumulated experiences of the many SCI persons who have married, the question has been answered affirmatively. When entered into in good faith and with an understanding of all the factors involved, such marriages apparently have as good a chance of succeeding as any others (Mueller, 1962). Obviously, coitus is not the only factor in the preservation of marriages involving a disabled partner, because many couples remaining together report no continuing sexual intercourse (Griffith et al., 1973). Comarr (1962) identified educational level and income adequacy as significant factors in marriage-divorce statistics. Tucker (1980) indicated that pre-injury marital adjustment seems to be the best predictor of quality post-injury marital relationships. Mueller (1962) listed, as other factors in the success of marriage, personality features, ability to communicate, community of interest, emotional maturity, and willingness to give and take.

Bors (1967) reported that marriages that take place after injury are usually secure because the marriage contract, as such, has not been broken. Vash (1981) agreed that disablement impacts differently on marriages that began before injury occurred than on those that begin afterward. In the former case, the disablement of a spouse may materially alter the basis of the partnership both parties made commitments to. In the latter, both have more realistic views of what to expect. Crewe, Athelstan, and Krumberger (1978) gathered information on the marriages of 128 SCI persons, 35 of whom had been married at the time of injury, and 35 who had since married. Eleven of the pre-injury marriages ended in divorce, and four of the post-injury marriages failed. Vash (1981) pointed out that the failure of these marriages cannot be attributed totally to the onset of disability because the general population statistics show that a high proportion of marriages are failing at any given time; therefore, when a married person becomes disabled, a high probability exists that the marriage was in trouble already. She stated that the additional stress placed upon the marriage by the disability could easily be the ultimate blow to the marriage.

Sexuality

For many years, little was published on the subjects of sexual functioning and the sexuality of SCI persons. Hohmann (1972) described the situation:

> In the past there has been a general feeling among some professional staffs that the less said to the cord injured patient regarding sexual functioning, the better, and the repressive mechanisms should be allowed to take their course in stifling thoughts and preoccupations about sexuality (p. 50).

In recent years, however, sexual functioning and adjustment in persons with SCI has been the subject of considerable investigation.

In fact, it is the best researched aspect of SCI and certainly one of the greatest psychological concerns of this population.

Talbot (1949), in a study of paraplegic veterans, recognized the important role sexual functioning plays in the total rehabilitation process. He noted that it was not the absence of somesthetic, pleasurable sensation that distressed those patients who were impotent as much as it was the accompanying sense of inadequacy. Talbot further emphasized that sexuality is one of life's major forces that helps to guide and shape the patient's psychosocial rehabilitation; however, there are two sides to sexuality--the psychic and the physical. Where physical sexual experience is no longer possible, the psychological element continues. Therefore, it is conceivable that the SCI person who has lost mobility and sensation in the genital areas can enjoy sexual experiences through compensation. Ford and Orfirer (1967) reported that while drive and frequency of performance may be altered, sexual activity and impulses continue to be of vital importance in the lives of the spinal cord injured.

Helsinga (1974) found in a discussion group of people with SCI, that the first question the patient asked after surgery for spinal cord trauma was, "Am I going to live?" The second question was "What are my sexual responses now?" Cole et al. (1973, p. 111) stated, "For some, regaining sexual performance is more important than regaining the ability to walk, and in the vast majority of patients, psychosexual content remains substantially normal in spite of loss of sensation." Trieschmann (1975, p. 19) added that "the onset of a physical disability does not eliminate sexual feelings any more than it eliminates hunger or thirst."

Although it has been proven that up to 70% of all SCI persons are capable of having some degree of sexual activity (Zeitlin, 1957), many do not indulge in any type of sexual activity and actually have a poor attitude toward the idea of a person with this type of injury engaging in sex. There are many reasons for this attitude, all of which go back to the idea of self-concept. When one's sense of self is seriously disrupted by the trama of a spinal injury, it is more important than ever to re-establish a positive self-concept. Diamond (1974) believed that meeting an individual's sexual concerns can go a long way in re-establishing a general feeling of self-worth conducive to general rehabilitation. Hohmann (1971) found a great improvement in the self-concept of the paraplegic men he counseled when they discovered they could be meaningful sex partners. Similarly, Lovitt (1970), Singh and Magner (1975), Crigler (1974), and others (Shontz, 1965; Bors and Comarr, 1960; Thornton, 1979; Hohmann, 1971) have reported that the impact of SCI on a person's sexuality will be closely related to the impact on his self-concept and self-esteem, and will be highly influenced by his skill and confidence in interpersonal relationships. Cole (1975) stated that a person's feelings of self-worth are basic to the total rehabilitation process. Crigler (1974) alluded to the fact that a person's sense of sexuality is interwoven with feelings of self-esteem, attractiveness, and functional adequacy to perform. Wright (1960) stated that:

> Since sex identification is often a central personal characteristic that serves to define a person to himself and others, it can be expected that any circumstance that alters or endangers this identification will have marked effects on the self-concept (p. 82).

Weiss and Diamond (1966) indicated that one of the reasons for difficulty in sexual adjustment following SCI lies in the fact that sexual interest and desire continue and that, while sexual abilities may be impossible or somewhat limited, sexual drive is as strong as ever. This drive is many times fulfilled through fantasy and dreams. Interestingly, if the individual had an active, fulfilling sex life before injury, his dreams tend to follow that trend. Bors et al. (1960) also studied the dream patterns of paraplegics and found that 46% of their subjects had some type of sexual dreams and in none of them did the paraplegic see himself as disabled in any way.

It is generally accepted that the male subject has a relatively more difficult sexual identity readjustment than the female subject (Teal, 1975). The loss of the capacity for normal sexual function and fertility has an emasculating effect and forces a role reversal into a relatively passive figure (Weiss and Diamond, 1966). These effects are especially devastating in view of the fact that most men have, in their pre-trauma life, placed a high value on sexual activity as both a way of life and as a measurement of manhood. Berger and Garrett (1952) described loss of sexual function for men as a tremendous loss that influences every aspect of life. They believe that impact of loss is not so much in terms of physical pleasure, but in terms of a sense of inadequacy. Berger (1952) also found that many impotent paraplegics regard their own bodies as useless and malfunctioning organisms and their feelings of inadequacy are especially reflected as they attempt to deal with readjustment problems in their normal home environment. Many of them experience a dreadful apprehension at the thought of having to return home to their wives and families. Berger went on to state that some of these patients made much better relationships with SCI females than with non-disabled women because the demand upon their adequacy as masculine sex partners was greatly reduced in this kind of relationship.

Berkman et al. (1978) found that only 41% of males who were sexually active rated their relations as satisfactory, although 76% believed that their partners were satisfied. These authors found that higher sexual adjustment scores were correlated with younger age, higher income level, better physical function, positive attitudes of self-acceptance and independence. Berger (1952) found that potent compared to impotent male paraplegics showed less self-deprecation. Lindner (1953) found that the impotent SCI male retreated into concerns with his body and had more physical complaints than did potent SCI males. On the other hand, Hetrick (1967) reported that five out of seven women in his study stated that their feelings of femininity had remained the same as before injury. One woman even professed an increase in feelings of femininity and attributed this to her injury, which encouraged her to "grow up." Furthermore, no women changed their definitions of femininity or womanhood, while 45% of the men in the study changed their definition of manhood.

At all levels and degrees of injury in the male, fertility is profoundly affected. In addition to problems with erection and ejaculation, hormonal influence may alter sperm formation and vitality (Geiger, 1979). Talbot (1955) reported fertility among paraplegic men as around 5%, which seriously limits chances of paternity. Talbot stressed, however, that potency was of greater interest to these patients than paternity.

Until recently, there has been a scarcity of information regarding the sexual attitudes, abilities, and adjustments of women who have SCI. Griffith and Trieschmann (1975) stated:

> A review of the available information might lead to the erroneous conclusion that women have no sex drive, that they engage in only one set act (intercourse in the supine position) and that their sexuality is defined as the ability to conceive and deliver babies (p. 19).

Instead of any defined research, authors seemed to assume that it really does not matter how a woman with SCI sees herself sexually because she can "continue" to be a passive partner in sexual intercourse, thus ignoring all other avenues of sexual experession and assuming that she was a passive partner prior to injury. Romano (1975) stated:

> We must remember that the disabled woman is first a woman and second disabled; she has desires, needs and feelings just like any other person and has the right to express them in ways that are acceptable to her. Sexuality is composed of many things, has many ways of expression, and requires the possibility of compromise just as other facets of life do; it offers satisfaction in giving, as well as getting, and while its expression may present certain problems, these problems need not be hopeless (p. 167).

Bergman and Hadley (1976) found that women who appear to feel good about themselves psychologically also claim to be adjusting well sexually. As they begin to like themselves again, their social relationships begin to improve and their sexual relationships improved. Those who appear to have poor self-images seem to have difficulty adjusting sexually.

Fitting et al. (1978) found a positive relationship between a SCI woman's self-concept and her sexuality. The women in their study perceived themselves as more assertive, more independent, more active as sexual partners, more intelligent, more honest with themselves after injury than before. Although their images of themselves as women changed since the injury, many felt these changes were related to maturation rather than to the injury itself.

Thornton (1979) suggested that because our culture values physical perfection, the woman with a SCI may find a scarcity of available sexual partners. She may be considered asexual by others who see only her wheelchair. Cole et al. (1973) found that the most serious sexual problem of SCI women was the unavailability of sexual partners. He stated that the disabled are not in demand in the "sexual market place" of our culture.

The sexual adjustment of women is assumed to be less difficult because of pre-trauma attitudes toward sexuality, the relatively more passive role identity, and the genital function less impaired than in men (Teal, 1975).

Weiss and Diamond (1966) found, in their study of SCI women, that sexual activity can continue or even increase following injury for a majority of women. They noted that 47% of all female subjects reported some form of sexual activity before injury, while 62% described such activity following injury. They further claimed that women are less disturbed than men in maintaining their sexual and social relationships with the opposite sex following SCI. A number of reports have been made on the fertility, pregnancies, labor, and deliveries of women with SCI (Hohmann, 1972; Daw, 1973; Goller, 1972; Robertson, 1972; Comarr, 1966; Robertson and Guttman, 1963; Desmond, 1970). Most women had no major alteration in hormonal function, and thus resumed menstruation within six months of injury; reproductive capacity was the same as it was prior to injury (Comarr, 1965; Robertson, 1972). Despite increased risks of anemia, urinary tract infections, premature or rapid labor, dysfunctional uterine contractions, decubiti and autonomic dysreflexia, pregnancies usually result in normal vaginal deliveries (Comarr, 1966; Guttmann, 1969; Desmond, 1970; Robertson and Guttmann, 1963; Cole, 1975).

Bowel and Bladder Function

The nature and meaning of paralyzed parts constitutes a powerful determinant of the emotional reactions that occur as a result of SCI. Paralysis usually involves the extremities and/or the sacral area, thus impairing bowel and bladder function as well as sexual abilities (Stewart and Rossier, 1978).

Loss of bowel and bladder control causes great frustrations, leading to feelings of shame, embarrassment, and inferiority (Thom et al., 1946; Weiss and Bors, 1948; Bors, 1955; Comarr, 1956, 1970). Comarr (1970) reported that reflex or neurogenic bladder develops in over half the patients with complete lesions and about three-fourths of those with incomplete lesions; the remaining 25% to 50% may require several surgical procedures before satisfactory bladder functions can be attained. Similarly, he stated, lack of voluntary bowel control is present in all patients with complete lesions and is a constant source of anxiety accompanied by feelings of shame and inferiority.

Erickson (1968) reported that the sense of autonomy and pride in being able to control bowel and bladder functions are present as early as 12 to 18 months of age. He equates the loss of this control by an adult with feelings of doubt and shame. This shame comes from within the child and is frequently reinforced by parental and societal criticisms when an accident occurs. Stewart and Rossier (1978) stated that there can be little doubt that the loss, later in life, of voluntary control over these functions reactivates feelings of shame associated with poor sphincter control during a much earlier period of life.

In a society that places a high value on independence, the transition from able-bodied to disabled, with subsequent changes in bowel and bladder function, may further alter self-concept. Rush (1971) and Heslinga et al. (1974) believe this to be a serious threat to the marriage and sexual lives of the person with SCI. The able-bodied partner's assistance in the disabled partner's excretory function may be an inhibiting factor in the couple's sexual expression. Contrary to this, Hetrick (1967) reported that bowel or urinary incontinence during sexual activity was generally denied as a concern. Bregman (1978) reported that although newly injured women found bowel and bladder problems to be inconvenient, incontinence during sexual activity was not felt to be a serious problem because it did not bother their partners.

Pain

In the acute stages of a SCI, pain is very often the main problem, outweighing all other considerations in the patient's mind (Harris et al., 1973). Trieschmann (1980) stated that the pain begins to diminish within several weeks unless there is extensive scarring from surgeries, or unless the person is not managed well in the early stages. There is also some evidence to suggest that persons who have not received proper psychological management may have more pain complaints than those who have received proper counseling and care (Fordyce, 1976). Fordyce (1981) went on to state that SCI persons report two different forms of pain. The first is a sharp, burning pain that occurs episodically and often lasts only a few seconds. These episodes usually occur several times a day, although several days may pass without any occurrence. The second type of pain is a deep dull aching pain that tends to persist for hours, days, weeks, or even months, and generally increases with activity.

Hazouri and Mueller (1950) described three types of pain experienced by paraplegic patients: (1) root pain, which is sharp and excruciating and radiates along the distribution of the nerve roots; (2) burning pain, which is poorly localized and diffuse, and does not follow any root distribution; and (3) visceral pain, which is dull and poorly localized and has a sickening quality.

Hohmann (1975) described four kinds of pain problems: (1) phantom sensations that are frequent in the early stages of injury but are not usually perceived as painful unless this expectancy has been set by the staff or other patients; (2) burning-tingling sensations--these are almost universally described as similar to the sensation of feeling that the body part has "gone to sleep"; (3) radicular pain--this type of pain radiates along the extremities and usually diminishes in a few weeks; and (4) caudal-like pain is described almost exclusively by patients with cauda equina or incomplete lesions and is described as a shooting or electric pain. Hohmann stated that this is the only type of pain that responds favorably to neurosurgical intervention.

The psychogenic component of pain problems has been best shown by studies of pain thresholds by Hazouri and Mueller (1950) and studies of "phantom limb" by Bors (1951). Hazouri and Mueller showed that prior to surgical intervention for pain relief patients showed distinctly elevated thresholds for perception and for reaction to pain, but after relief from pain by lateral spinothalmic tractotomy, both thresholds returned to normal. These authors hold that a critical disparity exists in thresholds of reaction to pain between neurotic and non-neurotic patients. The complicated physiologic and psychologic mechanisms in the production and alleviation of pain bear out the need for understanding the patient as a whole: physically, mentally, emotionally, and attitudinally. Bors (1948) suggested that a good psychologic approach might achieve more in alleviating pain than surgical procedures. He pointed out that because frustration plays a major role in the sensation of pain, improved nutrition, occupational therapy, education, and recreation tend to decrease pain in paraplegic patients.

Munro (1948), also working in this area, felt that physical pain was not a major problem, and emphasized the need for educating the patient and family as well as the public as to the necessity of training paraplegics for gainful use of time and for rewarding vocational roles.

The role of drugs was mentioned by Burke (1973), who noted a higher incidence of alcohol and other drug abuse among pain patients. Dunn and Davis (1974) described an informal survey of 10 patients with spinal injury who admitted to using marijuana. Of the group, 50% reported a decrease in spasticity and headache pain after smoking marijuana. The authors suggested that a controlled study be conducted to replicate these findings and that these results should be considered as hypotheses only until confirmed by further research. Vash (1981) stated that alcohol and other drugs become a means for dulling what an individual sees as unpleasant realities, tensions, and boredom and pain.

Recreation

The place of leisure and recreation in the rehabilitation process is an issue that has received relatively little attention. Rehabilitation has focused extensively on attaining physical and mental stability and community independence; however, one important ingredient is often overlooked in this process--the individual's use of leisure and recreation. This becomes increasingly critical as rehabilitation professionals focus on services to the severely disabled, such as quadriplegics.

Guttmann (1976) was among the first to recognize the importance of recreation and athletic competition in the lives of persons with SCI. He emphasized that participation in sports can improve physiological functioning and general health and can be a means of maintaining cardiopulmonary conditioning. He also supported the theory that sport can be successfully employed to complement conventional methods of physiotherapy in developing the compensatory function of paralyzed muscles. He stated:

> The purpose of sport as remedial exercise is to mobilize dormant neuromuscular mechanisms in the normal part of the body to compensate for the lost function in the paralyzed part. This is achieved by bypass sensory motor innervation of those muscles that have their segmental innervation above the spinal cord transection (p. 195).

Weiss and Beck (1973) conducted a clinical study on 100 SCI patients at Poland's Konstancin Rehabilitation Institute. In this study, instead of traditional physical therapy, patients began physical training prepartory for various sports within 10 days of hospitalization. Clinical examinations revealed that preparatory sport training followed by exercises in various sports resulted in a 100% faster increase in the strength of upper extremities and shoulder muscles than was achieved with conventional bedside therapy. They stated that regular exercises are essential for helping compensatory functions during the treatment process.

Nugent (1971) indicated that recreation has more tools than any one discipline in the rehabilitation process because it can effectively draw from all professions and disciplines in all areas of interest and endeavors. Guttmann and Michaelis (1969) demonstrated that regular practice of sports and special training in various branches of performance sports helps reduce the number of complications and varieties of disturbances observed in the pathology of SCI.

Haun (1965), Knudson (1962), Martin (1962), and Menninger (1948) have indicated that recreational experience is an essential to man's psychological and spiritual well-being as food, sleep, work, and protection from environmental hazards. O'Morrow (1970) views recreation as an avenue for reinforcing comradeship, group belonging and esteem, mutual interest, and concern for one's fellow being. The outcome of recreation, as observed by Meyer (1975), is so closely related to positive mental health that one may consider it synonymous.

Litman (1962) conducted a study using a sample of 100 orthopedically handicapped patients. His investigation revealed tht there was a significant relationship between a person's previous participation in organized and leisure time activities and his subsequent therapeutic performance. On the whole, a prior history of extensive physical activity seems to be an asset to treatment, whereas pre-injury inactivity is likely to result in little incentive for independence and self-care. Similarly, the patients with high social participation scores tended to react favorably to treatment, while those less active in organizational affairs were neither enthusiastic nor conscientious in their response to rehabilitation.

Donovan (1981) contended, however, that if the pre-injury personality was primarily motor-manipulative centered and the principal reinforcement came from physical movement and sports, that person will find it more difficult to adapt to a life of relative immobility than a person who is accustomed to a more sedentary lifestyle.

Weiss and Beck (1973) and others (Guttman and Michaelis, 1969; Menninger, 1948; and Knudson, 1962) contended that clinical sport counteracts the development of adverse psychologic reactions such as loss of self-confidence and mental inactivity that follow with almost monotonous regularity in the wake of severe SCI and result in self-centered isolation. Sport becomes a driving force for many SCI persons as they seek to restore the contact with the world around them.

Vash (1981) mentioned that many SCI persons, failing to find other sources of recreational gratification, choose socially unacceptable pastimes, such as the recreational use of alcohol and other drugs or constant television viewing. Both are well-known favorites among the disabled and are viewed as escape rather than as a rewarding activity.

Andrews (1980), Recreational Therapy Director at the Rocky Mountain Spinal Cord Injury Treatment Center, summed up the value of physical activity in the rehabilitation process:

> It is important because not only do these people achieve new dimensions of confidence in their abilities, they also demonstrate to other disabled people that competition is possible and that they, too, can compete successfully under pressure in athletics and day-to-day activities of life (p. 2).

Vocation

Vocational rehabilitation of the SCI individual had been thought to be almost impossible until various research studies conducted less than 30 years ago demonstrated this to be a misconception. In 1955, a study by the Paralyzed Veterans of America (Wilson, 1972) showed that 84.3% of a total of 318 paralyzed veterans were either studying, seeking employment, or working. Of this group, 47.8% reported steady employment. Among the quadriplegics surveyed, 50% belonged to the highest income group. Rusk (1963) reported a follow-up study of 355 quadriplegics who had attended the Institute of Physical Medicine and Rehabilitation (IPMR) between 1948 and 1960. Of the 177 respondents, 69 were employed and 18 were attending college. A later follow-up of 131 quadriplegics discharged from IPMR between 1962 and 1967 revealed that 44, or 34%, were in competitive employment; 3, or 2%, were homemakers; 62, or 47%, were in high school; and of the 44 persons in competitive employment, 36 worked in regular places of employment, 5 performed all or some of their work at home, and 3 operated small businesses. Of the 62 persons in school, 59 were in college, while the remaining 3 were in vocational training programs. Of the persons surveyed, 17% (22) were unemployed.

A report from Stoke-Mandeville Hospital in England (Comarr, 1956) indicated that 2,912 of the first 3,000 paraplegic and quadriplegic patients admitted prior to 1963, were employed. While studying paraplegics who had been trained at the Joseph Bulova School of Watchmaking, Hoberman and Lipton (1958) found that 85% of the 88 graduates were employed. Of the 64 persons employed, 20% owned and operated their own jewelry and watch repair businesses.

In a Canadian study (Geisler et al., 1966), of the vocational rehabilitation of 343 quadriplegics, 34% were employed and 10% were in school or in training. Walker (1961) indicated that the limited information on quadriplegics indicates that they are employed at home in vocational activities that are often unsatisfactory.

Predictors of vocational adjustment after disability vary according to several conditions. Several studies show that persons with higher educational levels tend to have a better chance of employment. Dvonch et al. (1965) found that pre-disability employment was predictive of post-disability employment. Felton (1965), however, found that pre-disability employment was an effective predictor only when it was combined with an educational level of high school or better. He pointed out that the pre-disability occupation is not as important as the level of education in determining post-disability employment.

The extent of the disability did not appear to be a really significant factor in determining the percentage of quadriplegics employed. Geisler et al. (1966) suggested that the higher the lesion the more difficult it is to achieve vocational success, and that educational achievement for the complete quadriplegic is felt to be the most important single determining factor for employability. They concluded that the prognosis for rehabilitation is much better if onset occurs before the age of 40.

Other successful predictors of vocational adjustment were: shorter duration since disablement, vocational training after disability, educational level raised above that of pre-disability, and ability to drive a car. Completeness of lesion has been demonstrated by Hallin (1968) to be related to productive activity and self-care; patients with incomplete lesions had more productive activity.

Summary

This review of the literature indicates that there are many different variables that enter into and influence the process of adjustment to SCI. Much of the research on the adjustment process has dealt with the individual's psychological reaction and adaptation to the paralysis. Early studies, most of which were clinical in nature, considered such psychological factors as depression, grief over loss, and working through a period of mourning as necessary to the adjustment process. More recent and empirically based research has questioned the assumption that the cord-injured person must pass through a stage of depression in order to form a satisfactory adjustment to injury. Some research has suggested that a large proportion of those who become SCI may have been experiencing social disruption and were prone to impulsiveness before injury. This line of research, although not conclusive, suggests that a number of the SCI may present difficult treatment-related problems. Other studies have pointed out that

SCI persons face problems in adjustment to new disability-imposed roles; that in facilitating adjustment to the effects of disability, professionals must consider not only the person's personality make-up, but the total environment in which the person will be operating (family peer groups, vocational settings, community, and the like).

Whereas the literature showed that many factors contribute to the degree of adjustment or maladjustment a SCI person reaches, there seemed to be general agreement among authors that previous personality type, abilities to cope with stress, and the support of a close-knit family group may be the major factors in successful adjustment to traumatic SCI.

Several serious methodological problems exist in many of the studies reviewed. The overall lack of experimental research is a serious deficiency in the literature on personality and adjustment to SCI. Most of the studies presented were based on clinical impressions of the particular author and were obviously more speculation than fact.

Another weakness of the studies reported in the literature reviewed concerned the question as to whether there is a unitary SCI personality. To date, there is no evidence of this, yet researchers, clinicians, and professionals continue to regard and treat the entire SCI population as a homogeneous group. Because of these inadequacies, the findings should be interpereted as suggestions for further research rather than as a basis for conclusion.

CHAPTER III

METHODOLOGY

The technique employed in this study was exploratory and descriptive. Information was collected by personal interview, questionnaire, direct observation, self-report, and a study of medical, psychiatric, and rehabilitation reports. The dominant thrust of the study was an inquiry into the socio-psychological variables affecting the process of adjustment to SCI. The study extended over a period of 18 months.

No formal hypothesis was advanced; rather, emphasis was placed on description of conditions, personal characteristics, and environmental factors related to and influencing adjustment.

Collection of Data

Personal Interview

Interviews were conducted with four persons who have experienced paralysis as a result of traumatic SCI (guiding questions are in Appendix B). Interviews were conducted privately, but informally, generally taking from two to three hours. Several interview sessions were held with each individual during the 18-month period. All interviews were conducted by the same researcher, and the information was narrated and recorded on an interview instrument form to insure uniformity of data. To allow the interviewer freedom to concentrate on the questioning process, a portable tape recorder was used with the respondent's permission. All respondents agreed to taped interviews because less time would be required. Immediately following each interview, subjective impressions of the interviewer were recorded in a field work journal concerning the appearance of the respondent, ease of the interview, body language of the respondent, any problems or interruptions encountered during the interview, and notations about any possible quotations that might be used later.

The interviewer began by explaining that the purpose of the interview was to determine how SCI persons had adjusted to and viewed life changes following injury. Four general areas were covered by the interview. First, a description of the person's life prior to the accident was obtained; second, a description of the accident and the circumstances surrounding it were explored; third, a description of specific changes in the person's life since the accident, as well as the methods used in accepting or coping with those changes; and fourth, a discussion of the family's role in assisting in the adjustment process, as well as factors contributing to their own adjustment. The interviewer attempted to learn of both positive and negative aspects of the person's experience, as well as the person's views of family and social relationships and vocational adjustments.

Although time consuming, the personal interview was used because it provided comprehensive and accurate information and allowed for the discussion and clarification of details when necessary. If respondents were unable to recall such items as admission and discharge dates, surgeries, and medical complications, medical and rehabilitation records were consulted.

Separate interviews with individual family members who were present during the initial adjustment period also provided information concerning various behaviors and responses of the SCI person. In each case, the parents were among those interviewed. Categories similar to those discussed with the SCI person were covered in the interviews with family members. The interviewer instructed family members to describe as clearly and objectively as possible their perception of the SCI person's adjustment process, and their ways of dealing with lifestyle changes resulting from the injury.

Questionnaire

Interviews were followed by a questionnaire designed to check responses and to gain complementary data (Appendix A). The questionnaire and an accompanying cover letter were mailed to each of the four subjects and to members of each subject's immediate family. Completed questionnaires were returned by all subjects and family members.

Field Work Journal

In an effort to gather as much information as possible, a log was kept during the 18-month period of the study. Notes were kept concerning observations; interviews; specific physical, social, emotional, vocational, or financial problems; and/or accomplishments of the subjects.

Study Population

The subjects of this study were four spinal cord injured males who had completed a program of rehabilitation at a regional model spinal cord injury treatment center. All subjects had sustained traumatic spinal cord injury and were paraplegic or quadriplegic. The ages of the subjects ranged from 24-44 years, and all had completed, or were in the process of completing, a program of higher education at the time of the study. One subject was married prior to injury and remained married; since their injury, two had married for the first time, and one had remained single.

Role of the Researcher

Sjoberg (1968) observed that field work can be hindered or facilitated by the status and role of the researcher. He stated:

> The report methodologists strive to establish is actually in the nature of a social bond between interviewer and interviewee, a bond that develops . . . because he is a friend, or at least an acquaintance, in need of information. . . . The objectifying interview, by clarifying the motives of the scientist, minimizes the possibility of exploitation, real or apparent, of the individual who cooperates with the researcher (p. 216).

The researcher in this study was known beforehand to all of the respondents as an instructor in adaptive physical education, and as a friend. This helped to establish rapport for the interview and other methods of collecting data. The researcher was also known to all the respondents as having experienced SCI, with the resulting physical limitations and adjustments in lifestyle. This shared experience helped build empathy between the respondent and the researcher and fostered cooperation with the study.

CHAPTER IV

CASE STUDIES

Introduction

This study constitutes a rich collection of information concerning the adjustment of persons with severe spinal cord injury. Each case study includes a detailed review of medical and rehabilitation reports so as to demonstrate the complexity of an injury of this type. Principle emphasis was placed on describing the activities, accomplishments, and problems of respondents in their attempt to cope with life with a disability.

The study was largely descriptive in nature. Presentation of findings depended heavily on descriptive summaries of information supplied by the respondents, and many direct quotations. Analysis was provided through the subjective interpretations of the researcher and through comparisons drawn with the findings of other studies.

Case Narrative "A"

On October 9, 1973, at the age of 15, "A" sustained a C-6 cervical fracture. According to initial admission reports, he was playing on his high school football team, apparently made a hard tackle, and immediately felt dizzy and was unable to move. He was taken to a local hospital where x-rays were made. No diagnosis was made, although x-rays were sent to a large hospital in a nearby city for evaluation. For the next 24 hours, "A" was placed in a regular hospital bed without traction, brace, or other devices to protect a potentially fractured spinal cord. When medical personnel at the larger hospital diagnosed "A's'" cervical fracture, he was immediately transferred to that hospital, where he was placed in cervical traction and anterior and posterior fusion was performed by surgery. Neurological examination reports after surgery state:

> The patient is awake, alert, and oriented, and is complaining of neck pain. Cranial nerves appear normal except for nystagmus. The boy appears to have very weak bicep function bilaterally and is quadriplegic below that level. Sensory examination reveals sensory level at C-6.

Following surgery, he was started on a program of routine Foley catheter care and bladder irrigation and placed on appropriate antibiotic therapy for chronic cystitis. On November 14, he was seen for an evaluation of renal status and was found to have a neurogenci flaccid bladder, normal upper urinary tracts, and chronic urinary tract infection.

Rehabilitation

On October 31, 1973, "A" was admitted to a comprehensive care rehabilitation center, where he was found to be quadriplegic at approximately the C-6 level. He was started on a program of physical and occupational therapy directed towards providing him with independence in the activities of daily living, in order to enable him to return to school. A physical therapy progress report made on December 10, 1975, describes "A's" slow but continuous progress:

> At present, 'A' demonstrates no limitation of joint range of motion throughout all extremeties. The lower extremities are increasing in spasticity. He has poor plus to good strength throughout shoulder musculature,

> biceps and wrist extensors bilaterally. All other upper extremity musculature is zero. 'A' is now up to 40 degrees on the tile table, which he can tolerate for only four minutes maximum. He is transferred to a reclining wheelchair in the morning and transferred to occupational therapy in a 45 degree angle position. Attempts have been made to place him in an electric wheelchair with a back extension on two separate occasions. Due to lack of trunk stability he must be tied to the chair. He has tolerated this for approximately 30 minutes maximum.

The therapist goes on to state that "The patient is now much more communicative and receptive to new ideas than when first admitted."

The physical therapist's report a month later shows:

> A's progress to date is slow but continuous. Upper extremity musculature continues to increase in strength. He appears now to have trace triceps bilaterally. He demonstrates good strength throughout shoulder musculature, biceps, and wrist extensors bilaterally. Joint range of motion is functional throughout all extremities passively. An increase in spasticity of the lower extremities continues to be noted.
>
> A continues to have difficulty tolerating sitting at a 90 degree angle. Attempts continue to increase tolerance to electric wheelchair. Trunk stability appears to be improving.

The occupational therapist's report for this date shows:

> Patient has been fitted with an orthoplast tendonesis splint to enhance his grasping abilities through the use of his wrist extensors. Patient has difficulty with feeling nauseated and cannot hold his head up for the entire time. He is able to feed himself with adaptive utensils if food is cut up and positioned for him.
>
> Short term goals: Begin desk and hand activities with splint in preparation for future education and self-care.

The occupational therapist reports on January 31, 1974:

> Patient is tolerating wheelchair as long as he desires and is independently ambulating at will. He is using a wrist-extensor-driven splint to write with, but as yet is not proficient enough for school work. His

> hypersensitivity in the thumb and index finger limits his tolerance for holding a pen for an extended period of time. Patient is able to handle books, turn pages, dial a phone, and type approximately eight words per minute.

The physical therapist's report on February 15, 1974, shows that he had progressed from an electric wheelchair to a manually powered one with "Quad Knobs." The therapist notes that "A" seemed very pleased with his progress. The occupational therapist's report for February 18, 1974 stated:

> Patient is able to write legibly and functionally, although slowly, with his right arm and with the use of a tendonesis splint. His prehension skills have increased; he types about 10 words per minute, and desk activities pose no problem.

The occupational therapist's report for June 27, 1974 states:

> Patient has moved into the state of needing to go home. His progress seems to be maximum for this time and he will probably gain more independence at home through his own innovation. Patient is equipped for school, proficient in desk activities, and is as independent as can be expected for his level of injury. He has been an excellent rehabilitation candidate and has done very well.

On June 28, 1974, the Rehabilitation Team Conference reported they felt that "A" was ready to go home. He had made good progress and was not independent with his wheelchair activities, able to transfer from bed to chair, and from chair to chair. The occupational therapist reported that not only was he doing desk activities well, he had progressed with his dressing program and was independent in many daily activities. Recommendations were made that he be discharged, and return in three months for physical therapy and occupational therapy reevaluation.

In May, 1975, "A" was admitted to the Rehabilitation Center for reevaluation. The following report describes his condition at this time:

> The patient reports that he has been attending school one-half day since his discharge from the Center. The only problem that has developed is a pressure area which has given intermittent problems over the left ischium. The patient has been asymptomatic for urinary tract infections since discharge.
>
> All extremities have good range of motion without pain or stiffness, with the exception of the shoulders where there appears to be slight tightness. The patient has limited function of the upper extremities; however, there appears to be some increase in upper extremity muscle strength from previous evaluations. There is no voluntary movement of the lower extremities. There is no sensory change noted from previous admission. Motor function is relatively unchanged, with the exception of some increased triceps function and some slight finger extension on the left. The patient remains incomplete quadriplegic.

Evaluation by physical therapy at that time revealed that "A" had gained in strength and some functional ability of the upper extremities. It was felt that the ischial pressure problem could be eliminated by doing more frequent weight shifts and with some change in skin care and regimen. He was able to bench press 95 pounds and pull 36 pounds on the pulleys. He was also exercising with 10 pound bar bells on each arm. He was completely independent in all transfers and doing sit-ups and push-ups with resistance. The report concludes: "Patient has plateaued."

Family Adjustment

The following is a statement by the patient as to family changes and adjustments:

> The changes thrust upon my family are simply beyond the scope of this survey. Its proportions are not unlike those experienced during a major earthly climatic change, because of a history of family problems. A bitter (even repugnant) divorce, custodial fights, numerous moves, remarriages and divorces, and deaths are just a few previous problems. All this was followed by the death of my father, more moves, and numerous other family problems.

Although other members of the subject's family were experiencing serious and complex problems of their own, he feels that they were his main source of motivation. In response to the effect of his family's adjustment on his own personal adjustment, he states:

> Without a doubt, if I pretended that my family's adjustment to my disability had no effect on my personal struggle, I would be exaggerating my character blatantly. That is not to say, however, that if they were unable to cope with this uninvited trauma, I would relent in despair. On the contrary, such an occurrence would most likely have made me more intrepid. The actual effect was similar to the loss of a close family member; i.e., everyone's role in the family structure changed. The difference, though, was each family member not only assumed some of my responsibilities, but also assumed some of the responsibility for taking care of me.

This descriptive statement clearly illustrates the upheaval in all aspects of family life as each member took on new responsibilities and attempted to deal with his or her own emotional feelings. The effect of severe disability upon siblings was clearly demonstrated in "A's" 13-year-old brother's response patterns. Following the death of his father in 1975, "A" went to live with his mother (who previously had lived alone with his younger brother). "A's" mother asserts that this brother strongly resented "A's" intrusion into their home. Prior to "A's" coming, he had been the sole recipient of his mother's attentions; this must now be shared with a totally dependent older brother whom he scarcely knew. "A's" mother states: "His brother resented

"A" because of his extensive demands on my time and finances; he felt rejected, unwanted, betrayed, and began to resort to his own defense mechanisms through behavioral problems and problems in school."

In discussing the financial crisis brought on by his injury, "A" indicates, as does his brother, that he was not aware of financial straits at this time; however, his mother states that the effects of the injury were

> disastrous, as my ex-husband had no insurance. When 'A' moved to Dallas with me in August of 1975, I did not have enough to handle the expenses as I was having problems before he came and had received no child support for the two after their father's death--and Social Security payments were six months in arriving.

"A" indicates that the one thing that has helped his family most in their adjustment has been time. He states, "Mending lives takes time. It requires hard work, plenty of communication, and lots of listening to yourself and to others."

Subject's Adjustment and Adaptation

"A" describes his stages of adjustment as follows:

> For the first two months following my injury, I was in a state of denial. I was unable to accept my paralysis as a permanent condition. I allowed myself to believe that one day soon the doctors would operate and fix me, and life would return to what I had been accustomed to prior to injury. No one ever really sat down to explain the gravity of the situation, and I never asked if I were going to walk--I just assumed I would. In retrospect, I wonder if some of the facts were not kept from me at my parents' request--in hopes of protecting me from further anguish.
>
> Denial was followed by depression. This came about one day when my head physical therapist decided he would stand me up and allow me to again view the world from 6'2". It was on that day that I realized there really is a difference in the way life is viewed, and that for the rest of my life I would probably be viewing life

> from a height of 4' rather than 6'2". On that day, when I realized I was going to have to deal with this, depression set in. This, however, didn't last long, because it was in my nature to be a fighter, and I saw a definite challenge before me. I knew that I had to make a choice--to either get the best of my disability, or allow my disability to get the best of me, and this was one battle I was determined to win.
>
> Oddly enough, the one person who was most instrumental after my 'rebirth' and during my physical and emotional infancy was not a member of my family or a close personal friend; never made any concerted effort to discuss my problems with me; and probably never knew about the role that he played in my growth and development. This mentor was a quadriplegic admitted to the Rehabilitation Center from an operation on a decubiti pressure sore which he had acquired while attending college as a result of too much time spent sitting in his wheelchair. And certainly, by no coincidence, he was living independently. His influence was merely by example. Small wonder that all the professional, institutional, and even familial tutelage appeared miniscule in comparison to the actions of a person already coping with a common problem.

"A" states that "Most of my success in adapting to my disability came after I was released from the Rehabilitation Center. Two basic human qualities account for my success: necessity and ingenuity." He further gives as the reasons for his success: "perseverance, persistence, tenacity, stubbornness, obstinance, doggedness, stamina, determination, and purpose, or, as Shakespeare said, 'the dauntless spirit of resolution' (with a pinch of humility)."

During his eight month Rehabilitation Center stay, "A" reports that neither he nor his family received individual counseling. He was, however, involved in group therapy on several occasions. The following consultation report shows his psychological status as perceived by a psychiatrist, whom "A" states "Really did not see me enough to know anything about how I felt."

> The patient was seen in group therapy on a number of occasions beginning in January and it would appear that group therapy has helped this young man to a great extent. While he had no unusual problems to begin with, he did have some difficulty in adjustment to his present situation. He was rendered quadriplegic as a result of a diving accident [sic]. He comes from a supportative familial background. I have talked with his father on several occasions and he appeared to be helping this young man in terms of adjustment to his illness. 'A' talked fairly openly with this examiner but no real significant relationship was established in order to facilitate the therapeutic process. He appeared to be of average to above average intellect and his vocational goals appeared to be realistic. He would appear to be an excellent rehabilitation candidate. There were no unusual thought disorders or processes noted and minimal anxiety during his stay here at the Center. The only benefit he derived from group therapy was primarily supportive counseling as opposed to in-depth psychotherapy.

The subject denies that group therapy helped him to a great extent. He reports that the only reason he attended the sessions was that he did not want to appear uncooperative. He felt the sessions were very general and directed toward the SCI patients as a homogeneous group, rather than as individuals with individual problems.

"A" uses as few adaptive devices as possible. He states that the fewer mechanical aids one depends on, the less possibility of breakdown. Two years ago, after being stranded on the lift of his van in subzero weather for a long period of time, he discarded it in favor of a five-door sedan with hand controls. He uses a lightweight wheelchair instead of an electric one because it is easier for him to pub into the back of his car. He also uses a device for buttoning shirts, jackets, etc. Otherwise, he depends on his own ingenuity to deal with most situations.

Current Status

Medical reports reveal that "A's" physical condition became somewhat stabilized as early as December, 1973. His physical therapist and occupational therapist reports, however, tell a different story. His drive and determination are seen in consistent and rapid progress in ADL and self-care activities as well as improvement in physical therapy skills. Notations are frequently seen in staff evaluation reports concerning his determination and drive. Evidently, his hard work paid off; "A" is the most independent quadriplegic of the four subjects. Now 25 years old, he lives alone in a two bedroom condominium and drives his own car. The only assistance he has is a cleaning lady who comes once a week to do his laundry, change linens, vacuum floors, and the like. He is capable of cooking his own meals, doing his own shopping, some light housekeeping, and attending to all of his personal care needs. He has had several roommates during the past few years, but has decided he manages better alone.

"A" states that he hopes marriage is in his future--but that it takes a very special person to be able to deal with marriage to a severely disabled person. He states that there is often more expected of the non-disabled partner than the disabled person can return. He feels that he is capable of carrying more than his share of the load emotionally; he no doubt would be little help in physical responsibilities.

When asked if he has seriously considered marriage since his injury, he responded affirmatively, ". . . but she did not feel the same way." He says he asked her if his disability were the problem and she denied that it was. "A" enjoys being with people and attempts to surround himself with those he cares about. He is currently involved in church activities and regularly attends social events with other young adults (all able-bodied). He plans to take entrance exams for law school in June, and states that his scores will determine where he goes to school, but that he will probably stay in Oklahoma in order to be near to family and friends.

Case Narrative "B"

"B" was injured in a diving accident in May 14, 1977. He sustained a serious scalp laceration and was rendered immediately quadriplegic. He was taken to a local hospital, examined, and immediately transferred to a comprehensive care center in a nearby city for further treatment. The initial admission report describes his condition as follows:

> The patient is a 23 year old, well developed Caucasian male. He is complaining of some pain in his shoulders and states that his right side feels numb but does not report numbness of the left hand; rather, he has essential absence of sensation involving most of his upper limb distribution and body and lower limbs. Patient is alert and well oriented; he has no focal cerebral deficits and the cranial nerves are intact. The patient has intact deltoid muscle function, weakness of the lift biceps, absence of the right biceps, contractions and no motor function below the C-6 level. On sensory examination he perceives pin prick as low as the sixth cervical dermatome on the left, and is barely able to discern pin prick perception in the C-6 dermatome on the right. Sensory function is absent below this level. He is areflexic below this level. Stretch reflexes and plantar responses are absent, as are the superficial abdominal reflexes. Satisfactory pulses in the limbs, no atrophy or fasciculations.
>
> X-rays of the cervical spine on admission showed a complete fracture dislocation with transection of the cord at C-5 and C-6. There was a small fragment of bone chipped off the anterior aspect of C-6. On 5-24-77, surgery was performed and open reduction, wire

> fixation, and fusion using a posterior approach were done. Following this, the patient was placed on a Stryker Frame, cervical traction tongs were inserted, and traction utilized. Post-op x-rays showed good position or C-5 on C-6 relationship and functions of the C-5,6 nerve roots returned on the right; he sustained no additional neurological deficits, although his spinal cord transection remained unchanged. On the fourth day following surgery, the patient had a temperature elevation of 102 degrees and developed some swelling of the knee joints. This swelling was attributed to a urinary tract infection which reached the knee joint vascularly.

The report goes on to state that the patient was noted to have a fairly adequate tidal volume despite his injury and was capable of moving air "fairly well."

The following report, made May 16, 1977, by a consulting physician, reinforces the already grim prognosis for the patient's future:

> The 23-year-old man was seen in consultation with Dr. _______ regarding fracture dislocation C-5 on C-6 with sudden onset of quad. He has slightly lower sensory and motor level in the right upper extremity compared to the right being able to strongly flex on the left forearm but not the right. Sensory level C-8 on the right and C-5 on the left. There is intercostal paralysis and diaphragmatic breathing only. I agree with Dr. _______'s evaluation and treatment, feeling that sudden onset of the paralytic lesion represents severe cord contusion or laceration. Prognosis very grim for any return of motor function below C-6 level.

Rehabilitation

On June 20, 1977, "B" was transferred to Hillcrest Rehabilitation Center, where he was started on a program of rehabilitation directed toward helping him to gain independence in the activities of daily living and self-care. He was given a trial on intermittent catheterization. This was discontinued because of the increased spasticity and recurrent urinary tract infection, and he was maintained on Foley drainage without difficulty.

"B" states that his time at Hillcrest was quite tramatic because he thought he went there to learn to walk again and to become independent. Little did he know that he was going to be taught such things as how to roll over without assistance; how to sit for extended periods of time; how to feed himself; how to dress himself; and so on. All these things he had mastered by the time he was four years old. Therefore, he was little motivated when reality finally was realized. He states that he sees, in retrospect, that had he been more motivated to learn while there, he might be more independent now.

The following occupational therapy progress reports reflect his lack of motivation and frequent lack of interest in attempting these minimal activities:

> June 21, 1977: Patient was seen and evaluated in occupational therapy on 6/21/77; at that time he appeared alert, oriented, and cooperative. Passive range of motion in both extremities was attempted. The left upper extremity is stronger and patient is able to actively flex the shoulder and elbow, extend the wrist, and shrug the shoulder. Sensation is slightly decreased in left upper extremity and nearly absent in the right. At this time, the patient is totally dependent in all dressing, self-care, and transfer. A tenodesis split in recommended for the left upper extremity immediately. Patient will begin a program of activities to increase strength and range of motion in both upper extremities until cervical brace is removed.

In July, "B" began working with overhead slings, pulling approximately 14 pounds with his left arm and 6 to 8 pounds with his right arm. Passive range of motion in his right was limited by tightness and pain. The therapist recommended that a flexar hinge splint be used to replace the previously used tenodesis split. At this point, he began sitting at approximately 90 degrees in his wheelchair for periods of three to four hours. The occupational therapy report shows progress was being made, although very slowly:

> 8/19/77: Patient continues to increase in functional skills with the tenodesis splint on the left upper extremity. The right upper extremity remains unchanged with no functional use seen in wrist or fingers. He is feeding himself using his splint with minimal assistance. We will begin dressing training next week for the upper extremities.
>
> 9/9/77: Patient continues to work at activities to increase coordination and skill in using tenodesis splint on the left upper extremity . He is quite skillful with the splint at this time, but needs a great deal of work with writing skills. He is able to use the right upper extremity assistively if he is encouraged, but generally will not use it; attitude and motivation remain excellent. He received his own manual wheelchair this week and is able to push it for short distances.
>
> 10/28/77: Patient continues to work at activities to increase functional use of his left upper extremity using the tenodesis splint. He demonstrates good manual dexterity with the splint and uses it for eating and craft activities. Writing is still poor and patient does not display a great deal of interest in this activity. Working tolerance is improving, but patient is still hampered by spasms in neck, shoulders, and arms. These appear to be painful, although patient denies this. Patient is also doing weight shifts, but this is somewhat limited. Work tolerance is now approximately one hour morning and afternoon. He is beginning to plan for discharge.
>
> 12/9/77: Patient requires moderate-maximal assistance for upper extremity dressing, maximal assistance for lower extremity dressing, minimal/maximal assistance for self-care. Patient is able to use the left upper extremity functionally with a tenodesis splint. He is able to write, eat, and manage light objects. He is able to manipulate the electric wheelchair quite well; working tolerance is good; he is able to work for one to two hours at a time. Does weight shifts quite well. Good attitude. Family has been given recommendations for altering the house where he will be staying. The right upper extremity still remains non-functional, except offering minimal assistance for bilateral activities.

During this six month period, "B" was also involved in a strenuous program of physical therapy, designed for attaining maximal functional independence. A physical therapy report reads:

> 7/29/77: Patient still complains of pain in the right shoulder. Breathing exercises and assistive coughing have been taught. Short term goals of teaching endurance and sitting tolerance have been met; isometrics and strengthening of upper extremities have progressed; patient can support weight on hands for 10-15 seconds; sliding board transfer from wheelchair to mat requires one man assistance.
>
> 8/23/77: Pain in right shoulder decreases range of motion to 90 degrees rotation. Tight hamstrings bilaterally. Neck range of motion is decreased due to tight musculature. Muscle strength in left upper extremity is good; normal. Right upper extremity is poor. Muscle spasms in all four extremities. All sensation at C-6 level. Deep and light touch on left are inconsistent below C-6. All other sensations are absent below this level. Endurance is decreased due to bed rest. He exerts maximum effort in his physical therapy rehabilitation program.

In early November, 1977, a Patient Care Conference was held to answer some of "B's" questions. A conference report states that:

> The patient seems to have established a more realistic view of injury and is now making practical plans for discharge. A 10 day pass is set to begin November 5; patient was reminded to bring back a list of problems he ran into during the pass.

By early November, 1977, "B" had reached a point where he could see little hope for improvement in his future, according to a physical therapy report.

> 11/17/77: Patient states that unless there is more to gain functionally, he would like to go home for good at Thanksgiving. Strength of upper extremities continues to increase slowly, more so on the right. Right shoulder motions are still moderately limited by pain. Patient maintains independent sitting balance indefinitely with arms extended for support and for short periods without arm support. Able to lower himself from sitting to supine with standby assistance only. He rolls from side to side and supine to prone

> independently. Balance on knees and elbows is fair and prone on elbows is good. Patient is able to move his trunk laterally when prone and supine by using his upper extremities. Presently, we are working on coming to a sitting position from supine by using reverse action of the biceps--needs moderate assistance. Also needs minimal assistance in removing armrests to prepare for transfers. All transfers are still a dependent pivot.

On December 9, 1977, the Rehabilitation Team Conference reported that they felt "B" was ready for discharge from the Center, as most of his goals had been met. It was recommended that the patient be readmitted in three months for further evaluation and that he should also return in May, 1978, for further urological evaluation. (He was tried twice on intermittent catheterization, but these attempts failed and he continued to have an indwelling Foley Catheter with an extremely spastic neurogenic bladder.)

Subject's Adjustment and Adaptation

The following are excerpts from the psychologist's reports on "B's" progress:

> 6/24/77: This 23-year-old male is seen for psychological therapy as per request of nursing staff. I think that this patient will probably show some mood swings secondary to injury. As active a person as he was, it is already proving difficult to handle his new self. He states that 'You have to live with it.' But I think that he will have a particularly difficult time in coping. He does know enough about physiology to know some realities of the injury.
>
> 6/29/77: Talks very easily about most topics; I think there is some anger starting to surface.
>
> 7/1/77: Appears really good today.
>
> 7/5/77: Will check with therapists about goal planning.

> 7/25/77: Patient still seems too happy. I think he is in denial.
>
> 8/8/77: Patient is dealing with reality of home life now.
>
> 8/17/77: Patient is beginning to look to future about vocational goals and possibilities.
>
> 9/13/77: "B" is finding it extremely hard to look at any option other than walking.
>
> 9/16/77: "B" is grasping to his knowledge of a .06% chance of walking again, as is his family.
>
> 10/6/77: Still having trouble looking to wheelchair life.

In discussing the above psychologist reports, "B" states that although he received no formal counseling, a staff psychologist did contact him periodically. Interestingly, "B" reports that rehabilitation personnel, as well as the psychologist, had much difficulty accepting the fact that he was indeed coping with quadriplegia so soon after injury. He states, "They were quite perplexed that I was happy." When asked, "To what do you attribute your degree of success in coping with quadriplegia?" "B" responded, "My wife and my family. I have been fortunate in being surrounded by positive people and trust that God is in control and can provide." Asked what was the most important factor in his family's adjustment to disability, he replied: "Faith--an immoveable determination to make the best of any situation." To the question as to whether his family's adjustment had an effect on his own adjustment, he responded:

> I am convinced that we become part of what we are around; that our reaction to any given situation is the reflection of our past and present environment; that adjustment ability is directly proportional to the ability of those from whom we are learning. Very fortunately, I believe my family's abilities were very advanced.

"B's" wife relates that his parents had more difficulty accepting his disability than other family members. She further states that they loved him enough to allow him to live his own life with his own family. She relates that her own two children had no problems accepting his disability because "he came into their family in a wheelchair and the children never knew him otherwise." Interestingly, "B's" wife states that "B" was the most instrumental person in her own adjustment before and since their marriage.

At the time of his injury, "B" was single, though involved in a more than casual relationship with a young woman. This relationship was not maintained following his injury (by his choice). In October, 1980, however, he married a long-time family friend with two children. Thus, he became at once husband and father for the first time. The two of them feel that theirs is a good marriage and feel they have adjusted well sexually. "B" stresses that prior to release from rehabilitation, he received no information or counseling concerning his sexual capabilities. He attributes the success of their marriage to their ability to communicate and talk openly with one another. He also states that his being able to provide financial support for the family has definitely helped his cope with the fact that he is physically dependent on his wife.

Current Status

Since discharge on December 9, 1977, this young man has had no medical problems other than an occasional bladder infection. Surprisingly, he has not been bothered by decubiti sores. Estimated medical expenses per month average $100. He is totally dependent upon his wife and children for all personal needs and self-care activities, with the exception of maneuvering his wheelchair, driving his van, and eating.

As for leisure time activities, because of the extensive traveling involved in their music ministry, "B" and his wife have very little leisure time. When at home, they like to spend as much time as possible with the children, watching television, listening to tapes, and playing video games. When on the road, leisure hours are spent visiting with other people.

"B's" wife recalls two short, but severe periods of depression--both quite soon after his injury. The first period came on the third day after the accident. "B" recalls that the doctors came into his room and very directly informed him that for the rest of his life he would be doing little more than he was doing "right now." This was quite a shock to a previously active young coach/athlete. The depression lasted about five days, until, as "B" states, "That got boring, and I decided to find something else to feel sorry for." The second depression came after the subject was transferred to the Rehabilitation Center. Apparently "B" was still in the denial stage at this time. Psychiatric reports consistently allude to the fact that, "The patient is too happy--patient not angry enough. Patient finding it extremely hard to look an any option other than walking." In "B's" mind, the move to the Center would bring him a step closer to walking and a return to normalcy. When he became aware that all he would be learning in rehabilitation were those skills previously learned as an infant, he finally understood that rehabilitation was not geared to total rebuilding but rather to assisting him to cope with his losses.

Again depression set in, lasting four or five days. At this time, "B" decided it was time to begin planning to return home. Psychiatric reports show that "While he continued to have problems facing life in a wheelchair, he worked harder in physical therapy and occupational therapy, and began to slowly but consistently improve in his skills."

Prior to his injury, the subject was a physical education instructor and coach, moonlighting as a custodian in an elementary school. He had been quite active in sports through high school and college. He, in fact, attributes his background in sports as having contributed to his ability to adjust to his paralysis. He states, "Previous participation in sports provided training in self-discipline skills and the ability to look beyond losses." This same self-discipline has been evident in "B" throughout his adjustment and has been invaluable as he looked past his own physical losses in search of other options.

Following his injury, "B" had no additional vocational training. Turning to a previously unused minor in music, he is now self-employed as an evangelistic singer, providing total financial support for his family. He takes care of all correspondence and scheduling by using a speaker telephone and an electric typewriter. He is able to drive a van equipped with hand controls and does all the driving to and from evangelistic crusades. Recent professional accomplishments include the recording of his fourth album. Personal observation and self-report reveal that he finds his work fulfilling. Both he and his wife state that they have never been better financially or emotionally. His wife, when asked if the subject has lived up to his full potential, replied, "No--none of us has. In a sense, we are all constantly rehabilitating. It is a lifelong process, whether you are in a wheelchair or able to walk."

Although his vocational plans were drastically changed by his injury, "B" feels that the changes have been positive in that his total personal skills have been more efficiently directed. His future vocational goals include becoming a nationally known Christian music vocalist.

Case Narrative "C"

"C" is a 26-year-old white male who sustained a cervical 4-6 dislocation fracture with resulting quadriplegia on July 24, 1976, at the age of 19. His injury was the result of a diving accident. He was taken to a nearby metropolitan hospital, where he remained for five months. Upon admission, he was put into intensive care for 21 days; halo traction was applied. He had no surgery, except for a tracheotomy necessitated by respiratory complications. Following the tracheotomy, he was put on a respirator for two months.,

"C" was described by medical personnel as "a slender, well-developed, 19-year-old white male who is alert, oriented, fully cooperative, and appearing to be in no acute distress." Six months later, he was evaluated by the same staff members as being "a slender, <u>fairly</u> well-developed, 20-year-old white male who is alert, oriented, fully cooperative, and appearing to be in no acute distress." At this time, however, evidence of gross muscle atrophy was noted in all extremities; the slightest stimulation caused mass muscle spasms in the lower extremities.

Early in his hospitalization, "C" had pneumonia, but that was the only complication. There was no history of skin problems or of urinary tract infection. The patient had been on a program of intermittent catheterization since his injury, being catheterized every six hours. Following his injury, "C" had a normal range of motion in the upper extremities, with some restiction in adduction of the shoulders, and fair bicep function on the right side with fair deltoid function. There was no intrinsic function of the hand. Examination of the lower extremities revealed flexion contractures with a fairly normal range of motion. The subject's knees and hips were extremely tight, but he was able to push them to full extension. Sensory testing revealed a T2-3 sensory level, with the functional level at the C4-5 level.

Rehabilitation

Personnel at the hospital report that early in his hospitalization, "C" experienced significant depression and withdrawal, and refused to cooperate with treatment. He developed multiple complaints ranging from sore throat, weakness, chest pain, and headaches, all of which interferred with orderly rehabilitation efforts. Following numerous counseling sessions with his parents, these symptoms gradually improved. In fact, midway through his hospitalization, he developed an abrupt improvement in motivation, and toward the end of hospitalization was strongly motivated to develop alternative skills. Interestingly, "C" insists that he did not experience depression while hospitalized, stating ". . . unhappiness maybe, but not depression." He attributes his appearance of depression to the fact that, during this time he was on a respirator, and consequently, unable to talk or communicate; eating was extremely painful as well as difficult because of tubes and the like. He also mentions that the massive doses of medication he was receiving may have given him the appearance of being depressed.

In mid-August, his halo traction was replaced by a halo vest, which was then removed in November. At the time of discharge (December), the cranial halo had been removed, and insertation sites were well healed.

Physical therapy reports show that upon release from the Rehabilitation Center in December, 1976, "C" was able to operate an electric wheelchair with a mouth control. Occupational therapists reported that he was dependent for all activities of daily living and self-care. Upon dismissal, he and his family were extensively advised concerning the importance of numerous changes in position and continued outpatient physiotherapy. Appointments were arranged for outpatient evaluation, therapy, and x-rays on a periodic basis. The status of final arrangements with vocational rehabilitation remained indefinite at the time of his discharge.

In February, 1977, after spending two months living at home with his parents, "C" was admitted to the Tulsa Rehabilitation Center. Upon his admission to the Center, a physical examination revealed

> The upper extremities have a normal range of motion with weak biceps function noted on the right and a possible trace of biceps function on the left. Examination of the lower extremities reveals gross muscle atrophy with no voluntary motor function noted.

The report stated that the patient's condition of quadriplegia was essentially unchanged.

"C" remained at Tulsa Rehabilitatin Center from February, 1977 to May, 1977. During this time he was on a program of physical therapy and occupational therapy. Physical therapy reports showed that muscle strength had increased in the upper extremities and in the neck muscles. At the time of discharge, physical therapy reports noted that he had minimal return to the right upper extremity with no change in the left side. Occupational therapists reported that the patient was dependent for self-care but was increasing in skills, especially with the mouth stick. They also reported that he demonstrated some resistance to further work with the mobile arm support due to the appearance of the device. A Family Care Conference was held with the patient to reemphasize the need for continued activity with the mobile arm support.

In August, 1978, "C" was admitted to the Tulsa Rehabilitation Center for reevaluation. On admission, he was complaining of shortness of breath, and in view of his history of upper respiratory distress, the patient was started on a program of postural drainage, which resulted in improvement in his respiratory condition. (At this time he and his wife requested marriage and financial counseling.) Physical examination also revealed a slight curvature of the thoracic spine that resulted from weakening of trunk muscles and gross muscular atrophy of all extremities. Reports showed no changes in the patient's quadriplegia and no skin or bladder problems.

In May, 1979, "C" was again admitted to the Tulsa Center for reevaluation. He reported two episodes of urinary tract infection since the previous August. He had been hospitalized and had an intravenous pyelogram on one occasion. He stated that he had continued to improve in upper extremity function. He had had some skin problems with breakdown over the right lateral malleolus and right heel secondary to wearing boots. Neurological evaluation was reported to be essentially unchanged, except for increased strength in the right upper extremity. Otherwise, the patient stated that he was doing quite well; he reported that he was attending college and he was doing well in his art work.

On January 4, 1981, the subject checked into the Tulsa Rehabilitation Center for evaluation. The admission report stated that:

> The patient has been living with his wife. He functions at a dependent level with the assistance of his wife. He has had no recurrent medical problems, no urinary tract infections, and no substantial skin problems. He has had increasing muscle spasms that have been difficult to control with normal dosages of valium. A physical examination revealed marked atrophic muscle changes. No change was made in the neurologic evaluation of C-5,6, complete quadriplegia.

On May 18, 1981, "C" was re-admitted to the Tulsa Rehabilitation Center for treatment of a decubitus ulcer on his left foot and right ankle, urinary incontinence, and an ingrown toenail--the ulcers had been present since January, 1981. Physical examination revealed the cranial nerves II through XII to be grossly intact. The report stated that:

> There is motor activity in the right arm; he can raise his hand to his mouth. There is no sensation below the neck. He has continued to improve in upper extremity function, also in strength, especially with the left arm. He has been able to change from a mouth-operated to an electric wheelchair but continues to require assistance for most activities of daily living and self-care.

Family Adjustment

"C" considers his family the greatest influence in his adjustment process. He states, "Since they accepted my disability so well, so did I." The important role his family played was apparent even in his early psychiatric reports when fear of failure was voiced--he did not want to let down members of his family or to disappoint them. Neither he nor his family feel that they were adequately prepared for coping with the many implications, both physical and psychoemotional, that accompany an injury as debilitating as SCI. He feels that both he and his family could have been helped considerably had there been more honesty and information from the beginning; he also feels that the family would have benefited from having him visit them on a short trial basis prior to his final dismissal from rehabilitation.

"C" discussed feelings of guilt he experienced following his accident. Apparently, less than a year after his injury, his father suffered a serious heart attack. "C" feels that his injury and the stress accompanying it contributed greatly to bringing on the attack. He considers his father's heart attack as the biggest problem faced by his family.

Subject's Adjustment and Adaptation

"C" feels that his decision to enroll in college and pursue vocational endeavors helped his family to adjust to, and accept his disability. He does not feel that his family was ever embarrassed by his appearance. It is important to note that, prior to February, 1977, "C's" family constellation included his parents and his brothers.

With "C's" marriage, however, this constellation was expanded to include his wife, whom he states has been the major contributing factor to his educational and vocational success. Since his marriage, he feels that his wife has been his best supporter and his best friend. He feels that they have a very good marriage--his major concern in their marriage is that he sometimes feels that he "ties his wife down." Interestingly, she denies any feelings of forced confinement, stating, "My security is here with 'C.' Because of him I do not feel that I have to go out into the public." It appears that they have a good marriage and a mutually fulfilling relationship. Regarding children, they both definitely plan a family. "C" hopes that he can father a child; however, if this proves impossible, they are considering adoption. "C" emphasizes that he does not want to start a family until he is fully employed and more financially secure.

"C's" vocational plans have changed since his injury. Prior to his injury, he and his family planned that he would become a radiographer and join the family business. Plans now include becoming a vocational rehabilitation counselor. In response to the question concerning his most important future goals, he states that they are "to become a productive citizen and support my own family."

In discussing his major problems at this time, "C" states that they are "the restrictions placed upon me because of financial problems." (He has not been able to obtain a driver's license and become independent in transporting himself because the expense of equipping a van to meet his needs is too great.) He and his wife exist on $295/month (Social Security) and $70/month (Welfare). His medical expenses average $60/month. He states that he does not like accepting public financial assistance, but likes even less the rules and regulations he must observe while accepting this assistance. "C" feels his problems are 90% financial, 5% sexual, and 5% excess time.

"C" does not feel that his social life has suffered since his injury. He states that he began "making a play" for the nurses as soon as he came out of intensive care following his injury. While still wearing the halo vest, he and a date sneaked out of the Rehabilitation Center and attended a rock concert. Social activities of this type continued until his marriage in 1978. All social activities now include his wife, family, and close friends. He states that he has never felt intimidated or embarrassed because of his disability, and that his feelings of self-confidence seem to put others at ease with his disability.

In March, 1977, a psychiatric consultation was requested because "C" had been having difficulties with depression as well as conforming to the requirements of the Rehabilitation Center. Records state:

> Depression has been especially prominent recently, worse in the afternoon with initial insomnia, loss of interest with increasing depressed affect. There is increasing noncompliance from the patient. Patient states that he also experiences pain which is interpreted by the staff as 'his way out' to avoid dwelling on his future. There have also been suicidal ruminations but no plannings or attempts. His interest is low. Appetite fluctuates, as does his affect. He states he always had a difficult personality, especially in getting along with others. Friends and making friends was a problem for him, though in his words, 'I did not realize I had as many friends as I do.' He is used to being on his own. Also states he is used to getting things his way and being independent. He has a history of multiple car accidents, approximately three. Some drinking but no symptoms of alcohol addiction at this time. He is very concerned about what his family's response would be if he were forced to leave the Center, though he has difficulty expressing motivation and interest, on his own, for being here. He is a likable, cooperative male during the interview. Answers questions readily. He gives a good, fairly detailed history; expressed a difficulty in talking and

> confiding to others. He has been meeting with a psychologist who [sic] he seems to have a good rapport with, and it seems to have been of benefit to him. One of his problems is maintaining interest and involvement in the program here. The more activity he can obtain the better, to avoid ruminations and dwelling on his predicament, which then results in noncompliance as behavior.

An interesting observation concerning the above psychiatric report is that "C" denies having experienced any periods of depression of this magnitude, and he does not recall every having considered suicide. He feels there is a disparity between staff definition and patient definition of experienced depression. Concerning this report of depression, and similar reports while hospitalized, "C" states that while he certainly was not happy about the situation, as something quite drastic had happened to him and to his life, depression was not the right term to describe his condition. He feels that the perceptions of the medical staff may have been distorted as they viewed his condition. For two months, he had been on a respirator and had had a trachea tube in his throat--he was unable to talk and eating was quite painful. Psychiatric reports stated that he suffered from loss of appetite (a symptom of depression). His response to this:

> Sure, I lost my appetite; to begin with I was totally inactive and I was loaded with drugs. I was on a respirator, and attempting to eat in a supine position with a tube in my throat. That is enough to kill anyone's appetite.

While at the Rehabilitation Center, "C" was referred for psychological reevaluation by the medical staff. The following consultation report describes his psychological state as perceived by the consulting psychiatrist:

> The patient is alert and well-oriented. He is quite pleasant, cooperative, and highly verbal. He denies any significant emotional problems since his last

> admission; in fact, he states he has never been happier or more contented in his life. He is doing quite well in college. Financial matters, while still a concern, are less of a problem than previously. He is pleased with some return in movement of his upper extremities.
>
> The patient and his wife have done some traveling when possible, are anticipating a trip to Colorado to visit his parents, and have been investigating further educational and/or vocational opportunities in other parts of the country.
>
> Generally, he appears to be in good emotional health, has a positive attitude, and seems to be making an excellent adjustment to his disability.
>
> Plan: Reinforce patient's excellent attitude and motivational level. Provide guidance and counseling as indicated.

At the time of dismissal, the patient remained dependent for all activities of daily living, self-care, and wheelchair manipulation with the exception of manipulation of an electric wheelchair with a mouth control. He continued on a program of intermittent catheterization, being catheterized every six hours.

"C" was released from the Tulsa Rehabilitation Center in May, 1977, and in August of that year he moved to a nursing home, with plans to enroll in college. While living at the nursing home, he met and became interested in a young employee of the home. In February, 1978, they were married. Interestingly, their friendship developed and deepened as "C" became involved in helping his future wife sort through personal problems of her own. (His foresight and ability to help her ultimately led to his choice of a vocational future--that of rehabilitation counseling.) After their marriage, "C" continued in his course work; he will graduate with a degree in sociology in May, 1983.

Concerning the time he spent in rehabilitation, "C" states that he can look back and see that he was not motivated to acheive occupational therapy or physical therapy goals because he did not really see how they pertained to his life. The only activities or skills he could perform were so boring and "low key" to one previously so active, that he had no desire to accomplish them. He says that one of his major adjustments since release from rehabilitation is that "I have learned to enjoy and appreciate sedentary activities previously unknown to me."

Since his injury, "C" has developed an interest in sketching and painting and has become quite proficient at it, holding the paint brush between his teeth. He says he first became interested in art work one year after his accident when his aunt, who had been impressed by the artistic accomplishments of another quadriplegic, gave him some art supplies and encouraged him to try. Since that time, he states, painting and drawing have provided him a creative outlet and have given him a fulfilling way of using his time. "C" says he had no interest whatever in art prior to injury. His pre-injury hobbies included mountain climbing, swimming, fishing, camping, pool, and archery. Prior to his injury, "C" did not participate in competitive athletics, because, in his words, "There are too many rules and guidelines."

While attending college, "C" has been active in several campus organizations, especially those concerned with helping the cause of the handicapped student population. His activities include serving as president of the Handicapped Student Organization, member of the Safety Committee, Affirmative Action Committee, and the Architectural

Barriers Committee. He has been actively involved in eliminating many of the structural and architectural barriers on the campus.

Upon receiving his degree in sociology, "C" plans to work as a counselor for an oil company; he also mentioned continuing in college and pursuing a master's degree in counseling and becoming a rehabilitation counselor as another possibility.

"C" describes himself as being determined and not liking to be confined by rules and regulations. In his words, "Where there is a rule, there is a way to break it." He considers himself to be a "high risk" personality. Prior to his injury, he was active in a great number of recreational activities--many of them considered to be high risk (mountain climbing, diving, etc.). He was a very determined, independent person who abhorred failure and enjoyed any challenge; these very characteristics appear to be the ones that have kept him going in the face of adversity.

Current Status

"C" likes to surround himself with people; especially people with emotional needs. He feels that he is unusually perceptive and capable in helping others sort out and deal with their problems. He takes pride in the fact that several of his "projects" have been able to straighten out their lives as a result of his counseling and guidance. He wishes more people would ask him for help in dealing not only with their emotional problems, but in performing any tasks he is capable of performing. (For instance, he enjoys caring for his wife's two young brothers when assistance is needed.)

"C" is presently in good physical condition, except for frequent upper respiratory complications. In spite of his respiratory weakness, he smokes two-thirds of a pack of cigarettes per day. When asked if this was his way of committing "psychological suicide," he responded, "No, I just enjoy smoking and its something I can do without assistance." He and his wife are currently receiving physical assistance from an attendant (non-technical medical care) who helps take care of ADL and personal care, as well as helping in daily physical therapy and exercise routines. His wife feeds him; he manages to smoke without assistance. He says he can feed himself, but that he prefers to spend his time doing other things. The only mechanical devices he uses are an electric wheelchair, a special device to hold his cigarette, and a van that is equipped with a lift but is not sufficiently equipped to enable him to drive.

"C" and his wife recently faced yet another traumatic event in their lives when their home was destroyed by fire. No one was injured, but all of his paintings and pencil drawings were destroyed. They had no insurance, so everything was lost. He currently spends several hours a day painting and drawing (by mouth) to replace those pictures lost in the fire. When asked if he was discouraged over the loss of their home, he responded, "I simply considered it another challenge."

Case Narrative "D"

"D" was injured at the age of 35 when he fell from the roof of his home. Upon admission to a nearby metropolitan hospital, he was diagnosed as having sustained an L1, T11, and T12 compression fracture with resultant paraplegia. To better enable the reader to understand the psycho-emotional, as well as physical trauma involved in "D's" injury, the following medical summary is provided:

> The patient was admitted to ________ Hospital on the afternoon of June 30, 1975, having sustained a fall from a roof, impacting some 30 feet below on the evening of the 29th. The patient was not found until the morning of the 30th, 18 hours later. After the fall, the patient was unable to rise, was variably conscious for periods of time, and suffered definite exposure from the cool evening. He attempted to get aid by rolling himself around the building to the more accessible areas in front. Finally, he obtained aid at 11:00 a.m. The patient was admitted on a stretcher, maintained in the same position for myelography and surgical decompression of the spinal cord compression at L1-2. The patient was alert and conscious and in extreme pain. Neurological examination of the upper extremeties was normal. Flaccid paralysis in the lower extremities bilateral and loss of cutaneous sensation over all the areas of the lower extremities with the exception of the immediate proximal thihg anteriorly. Besides spinal fracture, primary consideration was that of exposure syndrome, dehydration, and acute renal failure. Following surgery, the patient was placed on a Stryker Frame and remained on the Frame until 7/18/75, at which time he was placed in a regular bed, and on 7/19/75 was fitted with a back brace.

"D" stated in an interview that the pain was so bad during his 18 hour period that he thought he "was going to die and wished he would." In fact, he relates that he contemplated taking his own life, emphasizing that this was the only time he ever considered suicide as an alternative to life in a wheelchair.

In addition to the pain and the many physical effects "D" suffered, there were many psycho-emotional factors with which to deal: at the time of his accident, "D's" wife was traveling in another state, and could not be located for several hours; also, in the midst of "D's" pain, fear, and general confusion, he was trying to shield his parents from as much pain as possible. He credits his brother-in-law with taking charge and performing the many routine details which had to be taken care of (admitting him to the hospital, calling relatives and insurance companies, communicating with doctors and other medical personnel), thus relieving the immediate family of performing these minute tasks.

Prior to injury, "D" was a 6'2", 235 pound steelworker. He and his wife had been married for 11 years, had bought a home and acreage with plans to improve their property, and enjoyed the advantages it offered. Their hobbies were horseback riding, fishing, camping, gardening, and generally being outdoors.

"D" had completed 11 years of formal education and neither he or his wife had a desire to continue their education. His wife had been employed outside the home for some time, but was currently enjoying her role as housewife. Needless to say, "D's" traumatic spinal cord injury and paralysis resulted in tremendous changes in their plans and hopes for the future.

Rehabilitation

During his stay at the hospital, "D" experienced only minor complications: on August 13, he was discharged for transfer to the Tulsa Rehabilitation Center with the following diagnosis:

1. Acute cord compression - L1-2, due to traumatic fracture.
2. Dehydration profound.
3. Acute renal trauma versus tubular necrosis ruled out.
4. Paraplegia, secondary to above.
5. Recurrent urinary infection.

Upon admission at the Tulsa Rehabilitation Center, "D" was evaluated by an attending physician. His impression of "D's" condition was: "L-1-2 sensory level, flaccid neurogenic bladder with pin prick sensation of the peritoneum. Patient should be able to have psychogenic erections and probably an 80% chance of having satisfactory sex control." The physician's report also stated that the patient should be started on a program of intermittent catheterization, and that there was a possibility that "D's" lesion was partial and that he might later be able to voluntarily control bowel and bladder functions.

"D" was started on a program of physical and occupational therapy directed toward gaining independence in activities of daily living and and wheelchair manipulation. On August 14, 1975, initial occupational reports showed that he was dependent in dressing, bathing, and other personal care areas. Longitudinal goals were to achieve total self-care--short term goals were to achieve balance when sitting and to improve upper extremity strength. ADL evaluation showed that he was limited to these activities, due partially to the back brace.

Physical therapy reports stated that the patient was "able to sit in a standard chair for approximately 30 minutes and is beginning to transfer himself with the aid of a sliding board. He is able to do wheelchair pushups for weight lifts." Physical therapy goals at this time included: independent transfer and independent wheelchair ambulation; upper extremity strengthening and lower extremity passive range of motion exercises; rolling from supine to prone and back, sit-up from supine position.

On August 29, 1975, he was issued his first weekend pass, and his wife was instructed in his personal needs and care. On return to the

Center, "D" denied having any problems. Every weekend thereafter, he went home.

On October 20, 1975, "D" was reevaluated for self-care activities; at this time he had achieved total independence in all areas except bowel and bladder care and control. The treatment plan at this time included:

- Maintaining upper extremity strength.
- Aiding in adjustment to disability (no specific plan was given).
- Managing masculine activities from his wheelchair.

The report stated that he still needed some assistance with transferring from wheelchair to bed.

Progress reports continued to relate satisfactory progress in physical and occupational therapy. On several occasions there were reports of "a fair amount of pain in the mid-back and a burning sensation in the legs." Medication was prescribed to relieve this pain, but the patient declined because he did not feel that it helped.

Physical therapy reports in October of 1975 showed that:

> The patient is independent in wheelchair transfer to mat and bed. He is able to roll over independently and sit up from a supine position. Sitting balance has improved but still needs to be improved. He is able to get from floor to wheelchair with moderate to maximal assistance.

An interesting note attached to this report stated, "Patient complains that he is being overworked. Does not like to remain for therapy on Friday afternoons." The key phrase here is "does not like to remain on Friday afternoons." In a recent interview with "D," the researcher was told that he lived "from weekend pass to weekend pass." Thus, it was not the work of physical and occupational therapy that "D" minded, but the shortening of his weekend, and time with his family.

An October 20, 1975, occupational therapy report showed that "D" was continuing to improve in functional capabilities--he was now cleaning and repairing his wheelchair; transferring to and from his car, putting his wheelchair in the car, and becoming quite competent in kitchen activities.

On October 31, 1975, "D" was discharged for one month to enable the rehabilitation team to evaluate his capabilities at home and for "D" to check his "in home function." On November 16, he returned from his extended visit home--reporting no problems. On November 21, he was discharged to return home permanently. The discharge summary included the following notes:

> The Rehabilitation Team Conference on November 21, 1975: physical therapy reported that the patient was independent in all activities. Occupational therapy reported that the patient was totally independent. It was recommended by the team that the patient be discharged to return to his home with plans to enroll in college and pursue a career.

On August 15, 1977, "D" returned to the Tulsa Rehabilitation Center for reevaluation. Reports showed that: "The patient has gained a significant amount of weight. There is essentially no change in his paraplegia. At this time, a perforation of his left tympanic membrane was found. No other apparent physical problems." At this time, "D" was found to be ambulatory, with the aid of long leg braces, with standby assistance. He tried using a walker with a four-point gait, and was able to walk approximately 15 feet. His endurance was rated as poor. Occupational therapy reported that he was independent in all ADL.

The following evaluation report of the Rehabilitation Team Conference clearly shows the progress "D" had made since June, 1975:

> This is a 38-year-old male admitted August 15, 1977, for braces and reevaluation. Paraplegia at the L-1,2 level. Physical therapy--short-term goals are to begin gait training in bars and possible progress to walker. The patient has good upper extremity strength and trunk-strength. Functional range of movement in lower extremities. Working on gait training in bars, crawling, and getting from wheelchair from floor. The patient needs minimal assistance in the bars to get up and stand-by assistance while walking. Tried walker today for about 15 feet using a modified four-point gait pattern. The patient's endurance is poor. He has some hip flexion bilaterally and has difficulty coming to standing from the chair with braces on. Will continue therapy in Stillwater to perfect the gait training. Occupational therapy--the patient is independent in all ADL. Bathroom equipment has been ordered. He is doing well at home. Nursing-the patient is on ICP every eight hours and having no problems. The patient is independent. Social Services--the patient is enrolled at Oklahoma State University in chemical engineering and states that he is happy there. He attributes his success in handling disability to his wife. He feels being busy and productive has helped also. The wife is also enrolled at Oklahoma State University in chemical engineering. The patient helps with the housework at home and is receiving Social Security disability.

An addendum to this report made by the doctor stated: "This is one of the best adjustments we have had. Recommendaton: discharge and reevaluate in one year."

An attached occupational therapy report showed the following notation: "Patient appears to be doing very well at home and states he has learned to cope, but he hasn't given up hope." In an interview, "D" clarified this statement:

> Where there is life there is hope. The hope I now feel is the realistic hope that I can reach my own maximal potential, and continue to develop physically, mentally, and emotionally. I no longer spend time searching for and hoping for a miracle cure. If, and when, a cure is found, I will consider it a bonus; but until then, my main goal in life is not getting out of this

> chair, but rather to live life to its fullest and take each day as it comes.

Family Adjustment

"D" discussed the role his family played in his rehabilitation process. He considers his wife the most influential person in this process. In addition to his wife, "D" says he was constantly surrounded by, and supported by, the entire family. During the first frightening weeks, at the hospital, he says he was never alone. His mother, father, brother-in-law, and sister were always available, in addition to his wife, who spent 16 hours per day with him. Family support was provided in many ways: besides financial, physical, and emotional support, there were many other services provided by the family. For instance, "D" recalls that his father helped make his home more accessible for a wheelchair resident--widening doorways, installing ramps, lowering counters, etc. Also, his father installed hand controls in his car, enabling him the independence of being able to drive unaided. In addition to being available for "D", the family was also supportive of his wife, spending time with her, listening to her, generally showing love and concern.

One characteristic frequently seen in a "family in crisis" was evident in "D's" family. Each individual, while dealing with his or her own problems, was also attempting to shield and protect other family members from further pain and anxiety. This began when "D" was being transported by ambulance to the hospital. He assured his mother that he was "okay," and that his injuries were minor, thus relieving her of the pain and fear of knowing the seriousness of the injury. His mother was also protected from the fact that he lay unattended for

18 hours after falling. She later stated that it would have been damaging had she been told the truth from the beginning. On another occasion, "D" related another incident in which a paraplegic on his floor began gaining return, and eventually was able to walk out of the hospital. "D's" wife and mother tried to keep this information from him, fearing disappointment or possibly jealousy that he too had not experienced return. "D" says they could not have been more wrong; he states, "I was so happy he was going to be okay, and thanked God that one of us had been spared life in a wheelchair."

While "D" feels that many of these situations could have been handled better--all were dealt with in good faith and with the best interest of the person involved at heart. "D" feels that his entire family could have benefited from some type of counseling while he was in the hospital and prior to his return home. He states: "Perhaps they (hospital staff) felt we didn't need counseling because we were apparently adjusting on our own."

Subject's Adjustment and Adaptation

"D" and his wife feel that they have a very good marriage and that their relationship has grown as a result of his injury. His wife is very supportive and understanding as she assumes some of the responsibilities designated by society as those performed by the man of the house. They both relate that they experienced considerable problems in adjusting sexually--and interestingly, neither of them received sexual counseling at any time following "D's" injury. "D" states: "We had no idea what to expect--fortunately, we talked openly about this from the beginning--keeping the lines of communication open."

They both emphasize that maturity at the time of the injury, and the ability and desire to communicate were the key factors in the continued success of their marriage. Interviews with family members and self-report indicate that "D" and his wife had a strong relationship and a good marriage prior to the accident, which provided them with a solid foundation to face (for enduring) a crisis such as spinal cord injury.

Prior to "D's" injury, unable to have children of their own, the couple had planned to adopt a child. They now have hopes of adopting a "family of children." "D's" wife, being a native American, received financial backing from the Indian Bureau while attending college. She feels that by taking in a family of homeless Native American children, she can in a way "repay" the government. She states that she would like to adopt "10 little Indians"--"D" adds: "three will be plenty."

In reponse to the question, "What is your biggest frustration?" "D" stated:

> Sitting back and watching my wife do things I should do, or that I did prior to my injury. . . . One thing that really bothers me is when she puts the gas in the car, while I sit behind the wheel. On some occasions I have been the recipient of looks of hatred, disgust, and deplorement.

This is one of the frequently seen affects of invisible disability; where others may not perceive that there is disability present, an individual's behavior may be misinterpreted by others in the environment, which may result in negative feedback.

Another frustration "D" faces is having his wife support him. Although for the past five years he has been making preparation for re-entry into the vocational world, he feels that she, by necessity, is forced to carry more than her share of the workload. At the present time, she is employed outside the home because "D" is unable to find work in the field of chemistry. He does, however, contribute to the financial support of the family by means of a monthly disability check in the amount of $600, helps with domestic chores at home, and does the family shopping.

"D's" wife states that returning to work after "D's" injury was not extremely stressful in her situation; in fact, it removed some of the stress. She initially returned to work, not so much because of financial strains as a need to keep busy. During "D's" hospitalization, she spent 16 to 18 hours a day at the hospital. However, when he was transferred to the Rehabilitation Center, she was no longer allowed to stay with him, as visiting hours were strictly limited and enforced. This left her too much idle time to think and worry about "D" and wonder about their future. At this time she returned to work, keeping weekends free so as to be available for "D's" weekend home visits. Thus, in her words, "work became a haven." It was at this job, in which she was surrounded by engineers, that she made the decision to go to college and major in engineering. "D" states, "I became interested in chemical engineering because of my wife, and eventually followed her to OSU and an engineering degree."

They both speak of the transition from hospital to rehabilitation as being the most traumatic time of "D's" hospitalization. "D" attributes this to the fact that he was so abruptly cut off from his family. Physical and occupational therapy routines were quite vigorous and demanding; yet, he had many empty hours in which to reflect on the past and wonder about the future. He states that while he was never in what would be called a state of depression, he was often low.

In his words, "I felt sorry for myself occasionally, but then I would realize that I was the only one at that pity party, and the feeling quickly passed."

"D" credits another paraplegic as being a positive enforcement and source of encouragement through his rehabilitation program:

> Day after day I watched him doing things I couldn't do, and didn't think I would ever be able to do. This gave me something to hope for and a model to follow; hence, I began attempting many of the things he did, at the same time figuring out more expeditious ways of doing them.

Current Status

"D" is not currently involved in a program of physical activity. While in college, he did enroll in several leisure/recreation classes including: archery, riflery, swimming, weight training, body mechanics, and raquetball. He says he enjoyed these classes and especially benefited from the weight training and body mechanics classes. During this time, he lost a considerable amount of weight and credits an increase in activity, in addition to a lowered caloric intake, as facilitating this weight loss. One reason for current inactivity is the lack of availability of facilities in the small town in which he resides.

Financial reasons, while an ever present problem, have not been the source of stress and anxiety experienced by most persons (families) paralyzed by SCI. "D's" occupational insurance paid all medical bills beyond the first $300, in addition to continuing to pay "D" a full salary for one year following the injury. This relieved them the trauma of having to face severe financial crisis during the first traumatic months of the injury. They both relate that this removed one source of stress--allowing the family to deal with physical and emotional problems present by "D's" condition, and spared him additional feelings of dependency so often experienced when a non-working spouse is required to take on the responsibility of supporting the family. This freedom also allowed his wife to devote all her time and attention to meeting "D's" needs.

"D" does not feel that his personality has changed since his injury. He does admit that he is more in control of his temper than prior to injury, but he attributes the change to more maturity (and to his wife) than to the injury. He feels he has learned to be more patient with and understanding of others as they attempt to meet his needs.

While the physical implications of paraplegia are not as debilitating as in quadriplegia, many adjustments must be made in adapting to life in a wheelchair. The paraplegic is essentially able to accomplish any task requiring the use of the upper extremities. He must, however, face the same psychological and emotional problems often associated with other visible handicapping conditions. As seen in "D's" case, total physical independence is often possible; however, "D" indicates that physical independence is of little value unless accompanied by psychosocial self-acceptance. He stresses that proper counseling throughout hospitalization and rehabilitation would certainly have facilitated his own adjustment process.

Narrative Analysis

When all of the theoretical formulations, research, and clinical experience with spinal cord injured persons are considered, adjustment appears to be a complex process that normal persons undergo in attempting to cope with the severe psychological stress of a major life crisis. This should be viewed as an evolutionary, changing, and highly individualized process rather than a stable state. The problems faced by the newly paralyzed person are those of coping with physical and psychological loss, changes in self-image, social status, and family role expectations; the anxiety and grief accompanying these sudden changes, and the need to learn new roles are quite often overwhelming to the patient as well as other family members.

The findings of this study indicate that it is not the inability to walk and ultimate confinement to a wheelchair that distresses the SCI, but the psychosocial difficulties and feelings of inadequacy resulting from total dependence on others for their every need.

It appears that while medical and rehabilitation teams are meeting the physiological needs of the SCI, psychosocial needs are often neglected. The respondents in this study indicate that psychosocial counseling services are nonexistent, or at best, superficial, and all indicate that they could have benefited from guidance and/or counseling, especially concerning the resocialization process and sexuality.

While social milieu, vocational capabilities, and wealth or lack thereof, are important factors in the adjustment process, family support appears to be the most important variable in ultimate adjustment to SCI. In spite of reports by respondents that family support and encouragement increased their motivation in working toward rehabilitation goals, all indicate that family counseling was not available.

Three important characteristics of SCI emerged as a result of this study:

1. There is no one-to-one correlation between SCI and the spectrum of associated disability problems. Identical injuries can produce separate sets of disability problems.

2. There is no one-to-one relationship between an injury and the amount of residual disability. Disability-associated problems can be removed even though the disease remains unchanged.

3. The ability of a patient and the total health care team to remove disability in the face of paralysis is dependent upon the person's residual capacity for physiological and psychological adaptation. Residual strength must be evaluated and enhanced to "work around" an impairment in order to remove disability.

No two persons with SCI have the same problems. Their individual disabilities depend upon the functions desired or required, the environment in which these functions are to be performed, and the level of and severity of the lesion. Although functional capacity cannot be altered, losses can be minimized by enhancing unaffected body parts and through modification of environmental factors.

If progress in the functional and emotional aspects of SCI is to be made, the individual must not fear failure, rather he must daily attempt the impossible--focusing on capabilities rather than inabilities. The following quote perhaps best summarizes the choices facing a person with SCI: "I would have to realize that I had nothing to be ashamed of . . . I began to see that its not what you've lost that counts, but what you have left" (Russell, 1949, p. 266).

CHAPTER V

CONCLUSIONS AND RECOMMENDATIONS

This study was conducted to survey the accomplishments of spinal cord injured individuals in physical-functional, educational, vocational, sexual, and social-cultural areas, and, where possible, to relate these levels of accomplishment to specific factors. The information should be valuable in assisting the new SCI patient in reaching maximum potential, and in gaining the capacity to be reintegrated into family, vocational, and community activities. The results should provide hope and encouragement to persons recently paralyzed, to medical and rehabilitation personnel, and to family members who assist these individuals as they strive for maximum independence.

Because of the small sample size and possible interviewer bias, the study does not permit the formulation of definitive guidelines for better psychosocial adjustment. It does, however, serve to demonstrate the role of social and psychological variables in the rehabilitation of four successful rehabilitated SCI persons. Such factors as the individual's self-concept, family reinforcement, pre-injury personality, financial status, vocational potential, and social reinforce-forcement were found to be significantly related to rehabilitation response.

Findings of the Study

The findings of this study showed that the physical, emotional, and sociological implications of SCI can be devastating. Patients and their families must make the tremendous adjustments to the sudden changes in their lives. The case studies also showed that total and successful rehabilitation is possible even in severe SCI, and that the process could be greatly facilitated if adequate counseling were provided from the acute care phase to release from the rehabilitation center.

The results of the study also indicated that confinement to a wheelchair is not the greatest problem facing the person having a spinal cord injury; rather, the vocational and social restrictions placed upon them by society pose the greatest problem. Unless a head injury accompanies SCI, impairments of intellect, learning ability, verbal skills, numerical skills, form and space perception, or motor coordination, should not be present; yet, society frequently associates a disabled body with a disabled mind, thus further handicapping the individual. Results of this study showed that while physical capabilities may be greatly affected by SCI, mental capacities remain intact. In fact, a decrease in functional abilities often results in the development of keener mental capabilities and potentialities as the individual searches for vocational alternatives through educational and vocational training programs.

Finally, the study indicates that the spinal cord injured can develop a long-term interpersonal relationship including love, respect, affection, and a mutually satisfying relationship with another person. As with able-bodied persons, the development of such a relationship requires communication and mutual understanding between the persons involved.

Applicability of Results to Current Practice in Rehabilitation

This study appears to be applicable in at least eight different ways. First, the results of the survey provide an outline of the various activities being performed by quadriplegics and paraplegics. The case studies allow for an in-depth review of selected cases and will provide professional means for comparing some of the clients with whom they are working to the case studies.

Second, the process of adjustment for the spinal cord injured person is a continuous one, as the individual daily faces new and different situations and problems created, and often magnified, by disablement.

Third, the findings of this resarch demonstrate that a great deal of time in a facility is often required in rehabilitating this disability group, and that peer support and counseling while in the facility can be beneficial.

Fourth, the results suggest that a significant percentage of paraplegics and quadriplegics can achieve all or partial self-care, do not necessarily require nursing home care, and therefore can allow other family members to retain employment outside the home.

Fifth, the information reported in this survey substantiates that the spinal cord injured can be successfully employed. Further, the study suggests that increased vocational and social opportunities, as well as increasing public awareness, have resulted in less self-destructive behavior among the SCI.

Sixth, this study supports other research findings in the premise that the relative adjustment or maladjustment to SCI is very much affected by the person's pre-injury personality and coping abilities.

Seventh, the findings of the study indicate that a concerned and supportive family is the most important component of the rehabilitation process. Wright (1980, p. 586) stated that "When disability occurs, the whole fanmily is adversely affected." Buscaglia (1975) further stated that the family, in turn, will frequently have a more influential and lasting effect on the disabled person than all the professionals who work with the individual. Erba (1969) agreed that although family relationships may determine the outcome of rehabilitation, the family as a whole is not addressed in the rehabilitation counseling process.

Eighth, there is a need for educating the public as to proper care and management of individuals immediately following any injury involving possible spinal cord damage. The literature and the case studies showed that irreversible damage may be inflicted as a result of instability and improper transfer techniques during the rescue and acute phase of treatment.

Ninth, the subjecty of sexuality and sexual functioning continues to be an area that is minimized, if not ignored. The case studies supported reports in the literature that this is an area of much concern to the newly injured person, and must be dealt with simultaneously with other aspects of the injury.

Tenth and last, reduction in physical and functional capabilities often result in a keener awareness of mental and social potentialities. The literature and the case studies suggested that the majority of SCI persons enter advanced educational or vocational training centers in order to increase their vocational opportunities.

It is felt that this research may give selected individuals insight into a number of areas involving the spinal cord injured person and may possibly provide guidelines for facilitating the rehabilitation process. It is also hoped that the demonstrated success of the four individuals involved in the case studies will provide inspiration and hope to other persons having spinal cord injury.

Recommendations for Future Research

This study serves to demonstrate that there are still a number of other facets to the problem that warrant further examination. This investigator proposes an extension of the present study, both intensively and extensively, to include a larger number of spinal cord injured persons, as well as a continuation of the investigation throughout the various stages of the rehabilitation process, up to and beyond discharge.

Particular attention needs to be focused upon a multitude of problems, including:

1. The role of the family in the rehabilitation of the patient with SCI.
2. The effects of SCI on the family.
3. Family counseling: its effect on the ultimate adjustment of the family as well as the SCI person.
4. The influence of the environment on the person with SCI.
5. Staff response and interaction with the patient's family.
6. Peer counseling and patient motivation.

7. Socio-psychological implications of traumatic SCI.

8. SCI: its impact on the self-concept.

9. The manifestations and implications of role reversal on adjustment.

10. Financial crisis: its effect on the coping abilities of the family of the spinal cord injured person.

11. The role of and impact on the spouse of the SCI person.

12. Determinants of marital success in pre-injury marriages.

13. The significance of previous participation in sport and recreational activities and subsequent therapeutic performance.

The results of this study suggest that the process of adjustment is not a static process; rather, one of constant challenge and adaptation. Likewise, rehabilitation programs and services must continue to change in order to better meet the needs of the SCI. No simple blueprint of future development can be readily sketched at this time, yet this study indicates that many needs and expectatons of the spinal cord injured population are not being adequately met. It is the hope of this researcher that the recommendations presented here will encourage further research into the factors influencing and facilitating adjustment to SCI.

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APPENDIXES

APPENDIX A

QUESTIONNAIRES

AGE ______________________________

RACE ______________________________

MARITAL STATUS (circle one) ______________________________

single   married   divorced   separated   widowed

NUMBER OF CHILDREN ______________________________

DATE OF INJURY ______________________________

LEVEL OF LESION ______________________________

ARE YOU A PARAPLEGIC OR A QUADRIPLEGIC? ______________________________

CAUSE OF INJURY ______________________________

I. GENERAL INFORMATION

Do you feel you have "accepted" your disability and are making maximal use use of your life? Yes No Explain ______________________________

____

____

In which life area have you noticed the most change since your injury?

vocational   social   recreational/leisure

family relationships   spiritual   other

Where are you currently residing? (circle one)

own home   boarding house or residential home   rehab center

home of relatives or friends   other

With whom do you live? (circle one)

parents   spouse & children   hired attendent

spouse   friend(s)   alone   other

Do you need assistance with personal care? Yes___ No___. If so, who provides this assistance? ______________________________

In what personal care needs do you require help? (circle one)

cooking   cleaning   dressing   eating   bathing   driving

shopping   bowel & bladder control   other(please list)

____

Do you use an electric wheelchair? Yes___No___

Do you feel that you were well-prepared by hospital and/or rehab. personnel for life in the "real world"? Yes No If no, what do you feel could have been done to better prepare you? ______________________________

____

____

Do you feel your family was well prepared by hospital and/or rehab personnel for coping with the implications of spinal cord injury? Yes___ No___. If no, what do you feel could have been done to better prepare them? ______________________________

____

____

What was your biggest adjustment problem following discharge from the hospital?

____

Which of the following people was most instrumental in your adjustment to your disability? (circle one)

doctor nurse aides family physical therapists
friend social worker rehab counselor other (explain)

What major changes took place in your family following your injury? ________

____

What was the biggest problem faced by your family?______________________

____

Which members of your family had the most difficulty accepting your disability?

____

Do you feel your family has adjusted to your disability? Yes___ No___. If yes, what do you think has helped them most in this adjustment?_________________

____

To what do you attribute your degree of success and rehabilitation as compared to others with similar disabilities?_______________________________.

____

In which one of the following "life areas" do you encounter the most problems?

work friends finances family marriage other people
health architectural barriers other (explain)

II. <u>EDUCATIONAL</u>

Are you currently enrolled in any kind of educational program? Yes___No ___
If yes, what kind? (circle one)

high school university (undergrad) university (graduate)
business school community college vocational technical other

What do you plan to do after completion of this program?_________________

____

Were you enrolled in an educational/training program prior to your injury? Yes___ No___. If yes, what kind? ____________________________________

What level of education had you completed prior to your injury. (circle one)

high school junior college bachelor's degree
grad. school (masters, Ph.D., M.D.) Other

Had you completed any business, trade, or technical courses at the time of your injury? Yes___ No ___If yes, what? ____________________________

How many hours per week do you now spend in class?______________________

III. VOCATIONAL

At the time of your injury, were you employed? Yes___No___; Fulltime___Part-time___. What did you do? ______________________________

Do you plan to return to this job (or this type work) Yes___No___

Are you now gainfully employed? Yes___No___. If yes, how many hours per week do you work?____If no, why are you not employed?____________________.

Has your injury changed your vocational plans?Yes___No___. If yes, how?____
____

What is your primary source of income? ______________________

If married, does your wife/husband work outside the home? Yes___No___. If yes, was he/she employed prior to your injury? Yes ___No___.

Do you contribute to the finalcial support of the family? Yes___No___

IV. LEISURE

List any leisure time activities in which you are involved? ____________
____

Approximately how many hours/week do you spend in the following activities?

1) Outdoor activities such as hunting, fishing, etc.
none 1-3 4-6 7-9 10-12 13 or more
2) Hobbies & crafts (coin collecting, sewing, painting, drawing,)
none 1-3 4-6 7-9 10-12 13 or more
3) Watching t.v., listening to radio or tapes, playing video games
none 1-3 4-6 7-9 10-12 13 or more
4) Visiting friends
none 1-3 4-6 7-9 10-12 13 or more
5) Attending social activities
none 1-3 4-6 7-9 10-12 13 or more
6) Reading books, magazines, newspapers, etc.
none 1-3 4-6 7-9 10-12 13 or more
7) Attending school or taking courses
none 1-3 4-6 7-9 10-12 13 or more
8) Attending religious services, or church activities
none 1-3 4-6 7-9 10-12 13 or more
9) Participating in sport and athletic events; or attending as a spectator
none 1-3 4-6 7-9 10-12 13 or more

At the time of your injury were you a member of an organized competitive athletic team?Yes___No___. If so, what sport(s)?____________________

What level?High school, college, professional, other (circle one)

How important were your athletic skills or capabilities? (circle One)

0 – very unimportant 5 – very important 0 1 2 3 4 5

How many hours per week were spent participating in athletics or other physical activities? ______

Since your injury, have you become involved in recreational or athletic pursuits? Yes___No___. If yes, what sports or activities?______

Do you feel that participation in sport and recreational activities has contributed to your adjustment to disability? Yes___No___. If yes, in what ways? ______

V. SOCIALIZATION

Are you active in any social or fraternal clubs or organizations?Yes__No____

Of your closest friends, excluding relatives, how many are disabled?______

Before your injury, did you enjoy interacting with other people?______

Since your injury, do you prefer being with people, or do you prefer being alone? ______

Are you comfortable and self-confident in social situations? Yes___ No___

Are you self-conscious about your appearance? Yes___No___. Do you feel your family is embarrassed about your disability? Yes___No___

VI. SEXUALITY

Were you involved in a meaningful relationship with another person at the time of your injury?Yes___ No ___ Has this relationship been maintained? Yes___No___. If no, have you developed a meaningful relationship with another person? Yes___No___.

Were you married at the time of your injury? Yes___No___. If yes, are you still married? Yes___No___.

Do you feel you have adjusted well sexually? Yes___No___.

Prior to release from rehabilitation, did you receive information and/or counseling concerning your sexual capabilities? Yes___No___

VII. MEDICAL

How is hour physical health aside from your disability? (circle one)

Excellent Good Fair Poor

How is your general mental health or emotional adjustment? (circle one)

Excellent Good Fair Poor

Have you been hospitalized during the past year? Yes___No___. If yes, why? ______ How long? ______

Estimate the cost of your medical expenses per month.____________________

Drugs or medications presently used:__________________________________

During the past year, did you take sick leave (or miss classes) because of injury related ilness? Yes___No___. If yes, how often and how many days were missed?____

______

What do you consider your most important future goal?____________________

____

____

____

What would you say was the major factor contributing to your success thus far? ____

____

____

Did your family's adjustment (or lack of adjustment) affect your acceptance of your disability? Yes___No___. Explain____________________________

____

____

RELATIONSHIP TO THE SPINAL CORD INJURED ______________________

AGE ________ RACE ______________________________

VOCATION ______________________________________

HOW LONG HAVE YOU KNOWN THE SPINAL CORD INJURED? ______________

Did you spend time with him during hospitalization and rehabilitation? ____

____

Do you live with the spinal cord injured? ______________________

Have any other members of your family experienced serious spinal cord injury? Yes ____ No ____. Explain ______________________

____

What did you find most difficult in adjusting to having a spinal cord injury in the family? ______________________

____

What do you think was the most difficult adjustment he/she had to make? ____

____

Describe any changes which have taken place in the spinal cord injured person's family since his injury (divorce, death, health problems, financial crises, etc.).

Discuss the spinal cord injured's adjustment to these changes. ____________

____

____

Which of the following services do you think were most helpful in the patient's adjustment process? (0 - very unimportant ; 8 - very important)

Physical therapy
occupational therapy
vocational training
vocational counseling
personal counseling
recreation & leisure counseling
Driver training
ADL training

How would you describe the patient's general physical health aside from his disability?

Excellent Good Fair Poor

How would you describe the patient's general mental mental health and emotional adjustment? (circle one)

Excellent Good Fair Poor

Discuss the spinal cord injured's "coping ability" prior to injury - How did he deal with "lifes obstacles"? ______________________________

____

____

In which one of the following "life areas" did he encounter the most problems? work ____ sex ____ transportation ____other people ____ education ____. Describe these problems ______________________

____

____

Do you feel he is content with life ....

Does he demonstrate a happy appearance? _____ Is he pleasant to be with?—

Does he strive for independence?

Is he living up to his full potential?

What does he do with his leisure time?______________________________

Does he pursue "pre-injury" recreational interests?______________________

With whom does he spend the majority of his time? ______________________

Does he refrain from doing things he enjoyed prior to injury? (Things he is capable of doing) Yes ____ No ____If yea, why do you think these activities are avoided? ______________________________________

____

Is he self-concious about his appearance? Yes ___ No ____

Are you embarrassed about his appearance? Yes ____ No ____

How important was physical attractiveness (to the patient) prior to injury? (0 - very unimportant : 5 - very important) 0 1 2 3 4 5 How important is it now? 0 1 2 3 4 5

What, specifically, has he done since injury to make himself more physically attractive? ______________________________

____

What does he do to make himself attractive to others, in a social context?

____

____

Do you feel he has developed to the fullest his physical and socio-emotional potentials? Yes ___ No ___, Explain ______________

____

____

Do you feel the family played an important role in the ultimate adjustment of the spinal cord injured? Yes ___ No ___ Discuss ___________

____

____

____

Did your family receive counseling during hospitalization and /or rehabilitation? Yes ___ No ___. If yes, what type of counseling? ______

____

Did you feel this counseling helped in the adjustment of family members? ___ Yes ___ No ___

How have siblings (wife, children, Parents) reacted and adjusted to the changes which have evolved as a result of having a disabled person in the family? ______________________________

____

____

____

____

Discuss the degree of adjustment you feel family members have reached? (Where is the family in the adjustment process?) ______________

What do you feel are the most important needs of the spinal cord injured person? ______________________________

____

____

In what area of life have you noticed the greatest change in the spinal cord injured? (circle one)

vocational goals   family relationships   spiritual relationships

social activities   recreational & leisure activities   other

Do you feel that faith in God has aided any member of your family in accepting disability and its implications? Yes___ No___.

Do you feel your family (including the spinal cord injured) has grown spiritually since the injury? Explain ______________________________

____

Which of the following people was most instrumental in your adjustment to having a spinal cord injured person in the family?

doctor   physical therapist   occupational therapist   the patient

nurses   family counselor   pastor   friends   other

Did (do) family members have a tendencey to be overprotective? Yes ___ No ___. To promote and encourage dependency? Yes ___ No ___.

How did the injury affect your family financially ? ______________________________

____

What specific adjustments were required as a result of financial pressures?

____

____

Which members of the family had the most difficulty accepting the disability?

____

What were the biggest problems faced by your family? ____________________

____

What was the biggest adjustmene your family had to make following the return home of the spinal cord injured? ______________________________

____

Which of the following people do you think were most instrumental in the patient's adjustment to his disability? (circle one)

doctors physical therapist occupational therapists

nurses family members friends rehabilitation counselors

pastor family counselor other

Did he experience a period of depression? Yes___ No___. If yes, how long did it last? ____

Does he blame some (or something) else for his injury? Yes ___ No ___

Is he currently employed? Yes ___ No ___

Does he contribute to the financial welfare of the family? Yes ___ No___

If employed, does he enjoy his job? Yes ___ No ___

Did the injury alter his vocational plans? Yes ___ No ___ If yes, explain

____

____

How important were athletic and recreational skills prior to his injury?

(0 - very unimportant - 5 very important) 0 1 2 3 4 5

How many hours per week were spent participating in athletics or other physical activities? ______________________________ ____________

Specifically, in what sports or recreational activities was he involved?

____

Has he become involved in any type of sport or recreational activity since his injury? Yes No . If Yes, what sports? ____________________

____

Do you feel he has benefited from participating in these activities?

Yes ___ No ___. Explain ______________________________

____

Did your family enjoy taking part in recreational activities prior to the injury? Yes ___ No ___. As participants or as spectators? __________

____

Has this changed since the injury? Yes ___ No ___. Explain __________

____

Have family social patterns changed since the onset of the injury? Yes ___ No___. If yes, explain.

Prior to the injury, did the patient enjoy interacting with other people?

Yes ___ No ___.

Since injury, does he prefer being alone or with people? __________

Is he comfortable with himself in social situations? Yes ___ No ___.

Does he project this feeling of confidence to others? Yes ___ No ___/

Does he make the first step in making others feel at ease with his disability? Yes ___ No ___. If yes, how? ____________________

____

How did spinal cord injury.alter your dreams and goals for the injured person;s future? ________________________________

____

Do you feel you have fully accepted these changes? Yes ____ No ____

What do you think the future holds for the spinal cord injured person in in your family? (vocationally, physically, personally, socially).____

____

____

____

____

What do you feel are the most important needs of the spinal cord injured person? ____

____

____

In what area of life have you noticed the greatest change in the spinal cord injured? (circle one)

vocational goals   family relationships   spiritual relationships

social activities   recreational & leisure activities   other

Do you feel that faith in God has aided any member of your family in accepting disability and its implications? Yes___ No___.

Do you feel your family (including the spinal cord injured) has grown spiritually since the injury? Explain ____________________

____

Which of the following people was most instrumental in your adjustment to having a spinal cord injured person in the family?

doctor   physical therapist   occupational therapist   the patient

nurses   family counselor   pastor   friends   other

Did (do) family members have a tendencey to be overprotective? Yes ___ No ___. To promote and encourage dependency? Yes ___ No ___.

How did the injury affect your family financially ? ____________________

____

What specific adjustments were required as a result of financial pressures?

____

____

Which members of the family had the most difficulty accepting the disability?

____

APPENDIX B

INTERVIEW INSTRUMENT

AGE ____

RACE ____

MARITAL STATUS (circle one)

single married divorced separated widowed other

NUMBER OF CHILDREN ______________________________

DATE OF INJURY ________________________________

LEVEL OF LESION ________________________________

ARE YOU A PARAPLEGIC OR A QUADRIPLEGIC? ______________

CAUSE OF INJURY ________________________________

I. GENERAL INFORMATION

Considering the best and worst things that could happen to you in your lifetime, where does your present disability fit into the scale? (0 - not at all happy, and 5 - extremely happy).

Where are you currently residing? (circle one)

own home	boarding house or residential home
home of relatives or friends	other

With whom do you live? (circle one)

parents	spouse & children	hired attendent
spouse	friends	other

Do you need any assistance at home? (stairs, getting into bed, self care, etc)

Yes ____ No ____. If Yes what kind?

Is your home arranged so that you are able to move around comfortably? ______

Do you feel that you were well-prepared by the hospital and/or rehabilitation staff for your life at home? Yes ____No _____. If no, what do you feel could have been done to better prepare you?

Do you feel your family was well prepared by hospital and/or rehabilitation staff for coping with having a spinal cord injured person in the family? Yes_____No_____. If no, what do you feel could have been done to better prepare them?______________________________

Do you feel your family has adequately adjusted to your disability? Yes ____

No ____. If yes, what do you think has helped them most in this adjustment? ____

Which members of your family had the most difficulty accepting your disability? ____

What was the biggest problem faced by your family? ________________________

____

What major changes took place in your family following your injury? ________

____

What was your biggest adjustment problem following discharge from the hospital?

____

Which of the following people was most instrumental in your adjustment to your present disability? (circle one)

doctor nurse aides family physical therapist

social worker rehabilitation counselor other

To what do you attribute your degree of success and rehabilitation as compared to others with similar disabilities? ________________________

____

In which one of the following "life areas" do you encounter the most problems?

work friends finances family transportation

health sex architectural barriers other people

Describe these problems briefly ________________________

____

Rank in order of importance (to you) the following components of your rehabilitation process. (0 - unimportant/ 8 - very important)

Physical Therapy Vocational Counseling Driver's Trng.

___Vocational Training ___Personal Counseling ___ADL Training

___Occupational Trng. ___Recreation & Leisure Counseling

II. EDUCATION

Are you currently enrolled in any kind of educational program? Yes___No____

If yes, what kind? (circle one)

high school university undergrad. other

business school university grad. school correspondence course

community college vo-tech

What do you plan to do after completion of this program? ________________

____

How many hours per week do you spend in class? __________________________

What level of education had you attained prior to your injury? (circle one)

high school graduate school (masters Ph.D., M.D.)

junior college bachelor's degree

others

Had you completed any business, trade, or technical courses at the time of yor injury? Yes ___ No ___, If yes, what ? ______________________________

III. VOCATIONAL

At the time of your injury, were you employed? Yes ___No ___, What did you do?____

Were you satisfied with this job? Yes ___No___.

Do you plan to return to this job (or this type work?)Yes___No____

Are you now gainfully employed? Yes ___No ___ If yes, how many hours per week do you work? ____

If no, why are you not employed? ______________________________

If employed, what is your level of employment in relation to your ability?

a) Using my full ability

b) Doing less than I am capable of

What is your primary source of income? (circle one)

your salary public assistance (what kind) ____________________

your spouse's salary other (describe) ________________________

Does your wife work outside the home? Yes ___ No ___. Was she employed before your injury? Yes ___ No ___.

Do you contribute to the financial support of your family? Yes ___ No ___

Do you receive income other than from work or family? Yes ___ No ___ If yes, what kind? (V.A., Workman's compensation, other public assistance)

____

Has your injury changed your vocational plans? Yes ___ No ___ If yes, how?

____

What was your yearly income prior to injury? ______________________________

What is your present income? ______________________________________

How do you plan to spend the majority of your time during the next 6 months?

____

IV. LEISURE TIME

List any leisure time activities in which your are involved? _______________

____

Approximately how much time per week do you spend in the following activities? Circle the appropriate number.

1) Outdoor activities such as fishing, hunting, etc.

none 1-3 4-6 10-12 13

2) Hobbies and crafts (coin collecting, sewing, drawing, painting etc,)

none 1-3 4-6 10-12 13

3) Watching t.v., listening to radio, tapes, etc.

none 1-3 4-6 10-12 13

4) Visiting friends

none 1-3 4-6 10-12 13

5) Attending social activities

none 1-3 4-6 10-12 13

During the last year, did you take sick leave (or miss classes) because of injury related illness? Yes ___ No ___; if yes, how often and how many days were missed? ______________________________

Estimate the cost of your medical expenses per month. $ ____________

Drugs or medications presently used; ______________________________

____

If you need assistance with personal care, who helps? ______________

In what personal care needs do you require help? (circle) ~~[illegible]~~

cooking   cleaning   dressing   eating   bathing

shopping   driving   bowel & bladder control   other

Do you use an electric wheelchair? Yes ___ No ___

Do you consider your wheelchair an enemy or a friend? ______________

Why? ______________________________

What do you feel are the most important needs of the spinal cord injured? ___

____

____

____

In which area of your life have you noticed the most change since your injury?

vocational   social   spiritual

recreational/leisure   family relationships   other

How important has your faith in God been in your ability to adjust to paralysis? ______________________________

____

Do you feel that you have grown spiritually since your injury? Yes ___ No ___

Explain ______________________________

____

How much effect did your family's adjustment (or lack of adjustment) have your acceptance of your disability? ______________________________

Explain ______________________________

____

6) Reading Books, magazines, newspapers, etc.

none 1-3 4-6 7-9 10-12 13

7) Attending school or taking courses

none 1-3 4-6 7-9 10-12 13

8) Attending religious services, or church activities

none 1-3 4-6 7-9 10-12 13

Can you transfer from wheelchair to couch, car, bed, etc? Yes ___ No ___

Can /Do you drive an automobile? Yes ___ No ___. If so, what make or model is your automobile? ___

At the time of your injury were you a member of an organized competitive athletic team? Yes ___ No ___. If so, what sport? ___

___ What level? High school - Collegiate - Professional YMCA - Other

How important were your athletic skills or capabilities? (circle one)

0 - very unimportant 5 - very important 0 1 2 3 4 5

How many hours per week were spent participating in athletics or other physical activities? ___

How many years had sports played an important part in your life prior to your injury? ___

Since your injury, have you become involved in recreational or athletic pursuits? Yes ___ No ___. If yes, what sports or activities? ___

___

How many hours per week do you now spend in sports or other recreational activities? ___

Do you feel that participation in sport and recreational activities has contributed to your adjustment to disability? Yes ___ No ___. If yes, in what ways? ___

V. SOCIALIZATION

Are you active in any social or fraternal clubs or organizations? Yes___ No ___

Of your closest friends, excluding relatives, how many are disabled? _________

Before your injury, did you enjoy interacting with other people? ____________

Since your injury, do you prefer being with people, or do you prefer being alone? ______________________________

Were you socially active before your injury? ____________________

Do you consider yourself socially active now? ____________________

Are you comfortable, and self-confident in social situations? ____________

Do you project this feeling to others? ________________________

Do you make the first step in making conversation with others? __________

In making others feel at ease? _______________ How? _____________

____

Are you assertive - outgoing? ____________________________________

Do you demonstrate a happy appearance? Yes ___ No ____________________

Do you refrain from doing things you enjoyed prior to injury, even though it may still be possible? Yes ___ No ___ If yes, specifically what? _____

____

Are you self-conscious about your appearance? Yes ___ No ___ . Do you feel that your family is embarrassed about your disability? Yes ___ No ___.

How important was physical attractiveness before your injury? 0 - very unimportant; 5 - very important. 0 1 2 3 4 5

What specifically, have you done since your injury to make yourself more attractive? ____

How do you keep yourself attractive to others in a social context? _________

____

VI. SEXUALITY

Were you in a close, personal, meaningful relationship with another person at the time of your injury? Yes ___ No ___

Has this relationship been maintained? Yes ___ No ___. If no, have you developed a meaningful relationship with another person? Yes——No___

Were you married at the time of your injury? Yes ___No ___. If Yes, are you still married? Yes ___ No ___.

Did you have any sexual experiences prior to your injury? Yes ___No ___

Do you feel you have adjusted well sexually? Yes ___ No ___

Since your injury, what has been the importance of sex to you?

1) increased 2) no change 3) decreased 4) unknown

What were your sexual attitudes before your injury? 1) Mostly conservative 2) Mostly liberal, 3) Other

Prior to release from rehabilitation, did you receive information and/or counseling concerning you sexual capabilities? Yes ___ No ___

VII. MEDICAL

How is your physical health aside from your disability? (circle one)

Excellent	Fair
Good	Poor

How is your general mental health or emotional adjustment? (Circle one)

Excellent	Fair
Good	Poor

Have you been hospitalized during the past year? Yes ___ No ___. If yes, why were you hospitalized? ______________________________

____

How long were you hospitalized? ______________________________

____

What do you consider your most important future goal? ____________________

____

VITA

L. Jayne White

Candidate for the Degree of

Doctor of Education

Thesis: THE ADJUSTMENT PROCESS OF THE SPINAL CORD INJURED: CASE STUDY REPORTS

Major Field: Higher Education

Minor Field: Health, Physical Education and Recreation

Biographical:

Personal Data: Born in Tahlequah, Oklahoma, June 23, 1949, the daughter of Mr. and Mrs. Jay F. Dudley. Married to Ron W. White on May 31, 1970.

Education: Graduated from Nickerson High School, Nickerson, Kansas, in May, 1967; received Bachelor of Arts degree in Health and Physical Education from Southwest Baptist College, Bolivar, Missouri, in 1971; received Master of Education degree in Adaptive Physical Education from the University of Missouri, Columbia, Missouri, in 1976; completed requirements for the Doctor of Education degree at Oklahoma State University in May, 1983.

Professional Experience: Fourth grade instructor, Iberia Elementary School, Iberia, Missouri, 1972-73; instructor of health, physical education, and recreation and women's basketball and tennis coach, Southwest Baptist College, 1973-77; third grade instructor, Leonard Elementary School, Bolivar, Missouri, 1977-78; graduate research assistant, Oklahoma State University, 1978-80.