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Status of activities of daily living for aging persons with spinal cord injury

Diane Foti
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**Status of activities of daily living for aging persons with spinal
cord injury**

Foti, Diane Rae, M.S.

San Jose State University, 1991

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STATUS OF ACTIVITIES OF DAILY LIVING FOR AGING
PERSONS WITH SPINAL CORD INJURY

A Thesis

Presented to

The Faculty of the Occupational Therapy Department

San Jose State University

In Partial Fulfillment

of the Requirements for the Degree

Master of Science

By

Diane Foti, O.T.R.

May, 1991

APPROVED FOR THE DEPARTMENT OF OCCUPATIONAL
THERAPY

Amy Killingsworth, M.A., O.T.R.

Gordon Burton, Ph.D., O.T.R.

Michael Dunn, Ph.D.

APPROVED FOR THE UNIVERSITY

Abstract

Status of Activities of Daily Living for Aging Persons with a Spinal Cord Injury

By Diane Foti, O.T.R.

This study includes 13 individual case studies to determine the age-related problems that aging persons with spinal cord injury experience. The sample was comprised of male veterans age 40 and older who had had a spinal cord injury with a complete paraplegia for at least 20 years. Subjects participated in in-depth interviews regarding age-related changes and resulting functional deficits in activities of daily living.

The subjects reported age-related problems of hand and shoulder pain and weakness, increased weight, decreased strength and endurance, and lower extremity fractures, beginning about age 50 and about 23 years post-injury. Fifty-four percent of the subjects reported that self-care activities required increased effort or modifications to maintain independence. Only 23% of the subjects required assistance with some aspect of self-care and none of the subjects required 24 hour care. The need for assistance did not occur until the about age 60 and about 35 years post-injury. Self-care activities which required assistance were dressing and getting in and out of the bathtub, and on and off household furniture and a toilet.

The implications for occupational therapy practice are the need for periodic re-evaluations of aging persons with spinal cord injury regarding their ability to participate in self-care, work, and leisure activities and more in-depth study of the aging population with a spinal cord injury.

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CHAPTER 1

INTRODUCTION

Purpose

The purpose of this study was twofold: a) to determine which activities of daily living become more difficult as the person with a spinal cord injury ages and b) to describe a role for occupational therapy in the care of the aging person with a spinal cord injury.

Statement of the Problem

As medical care and long-term follow-up of persons with spinal cord injuries have improved, the life expectancy of these persons has also increased. Aging for all people results in changes in bodily systems, and can mean changes in mobility status and in the ability to carry out simple tasks of daily living. Since persons with spinal cord injuries have had to previously adapt methods for using their bodies, they may be affected differently than the able-bodied population by normal aging processes.

As a practicing occupational therapist in a spinal cord injury service, the researcher began providing services for patients with paraplegia who had an onset of spinal cord injury of over twenty years and were being admitted for surgical repair of carpal tunnel syndrome. These patients with paraplegia had been performing transfer techniques for mobility with their upper extremities since injury, an activity which would not have been performed by these persons had they been able-bodied and capable of bearing their body weight on their legs. The complication of carpal tunnel syndrome

evident in these persons, required that they learn a new style of transfer, sometimes required the use of an electric wheelchair temporarily, and often resulted in disruptions to normal daily activities, including work, during the hospitalization and recovery period. Although this is only one example of the potential long term effects of spinal cord injury on activities of daily living, it raised the question of whether there are other functional problems encountered by the aging person with a spinal cord injury.

Questions

This study was designed to answer the following questions:

1. What are the age-related problems that affect activities of daily living which the person with complete paraplegia due to spinal cord injury experiences after a minimum of twenty years since onset?
2. How long after the initial spinal cord injury does the person with paraplegia due to spinal cord injury develop age-related problems in activities of daily living?
3. What is the role of occupational therapy in the treatment of the aging spinal cord injured population?

Definitions

Activities of daily living: Routine tasks of everyday life which include self-care, work, leisure/play activities. Self-care includes but is not limited to: grooming, hygiene, eating, dressing, functional mobility, and communication as measured in this study by the activities of daily living assessment (Appendix A).

Age-related problems: Physical changes due to either genetic predisposition such as, diabetes or as a result of factors such as, stress, disease, or poor nutrition (Wantz, 1981).

Aging: Growing old, maturing. Progressive changes related to the passage of time (Thomas, 1973). The aging process is characterized and influenced by each of the following components: physical, mental, and social dimensions (Wantz, 1981).

Carpal tunnel syndrome: Pressure on the median nerve at the point at which it goes through the carpal tunnel of the wrist. Causes soreness, tenderness, and weakness of the muscles of the thumb (Thomas, 1973).

Occupational therapy: The art and science of directing man's participation in selected tasks to restore, reinforce and enhance performance, facilitate learning of those skills and functions essential for adaptation and productivity, diminish or correct pathology, and to promote and maintain health. Its fundamental concern is the capacity, throughout the life span, to perform with satisfaction to self and others those tasks and roles essential to productive living and to the mastery of self and the environment (Hopkins, 1988).

Paraplegia: Paralysis of the lower portion of the body and of both legs (Thomas, 1973). Damage involving the spinal cord below the thoracic level of T-1 may cause paralysis to the trunk and the legs. Complete lesions result in total dysfunction of the spinal cord below the level of injury (Spenser, 1988).

Spinal cord injury: Damage to the spinal cord resulting in neurological impairment. Injuries are diagnostically labelled in

terms of the region of the spinal cord in which the damage has occurred and the numerical order of the neurological segment (Adler, 1990).

Assumptions

In this study the researcher has made several assumptions. The first assumption is that the person with a spinal cord injury is living longer due to increased quality and quantity of long-term medical care. There are no data which accurately document this population's longevity. Most references in the literature reflect clinical observation.

The second assumption was that the researcher would discover difficulties with activities of daily living due to aging processes other than the example of carpal tunnel syndrome described in the statement problem. The researcher also assumed that adults with spinal cord injury, who live in the community would be willing to discuss how they perceive their ability to perform activities of daily living in relation to the length of their injuries and age. Jointly was the assumption held that the subjects would accurately report their actual levels of functioning throughout their lives.

It was further assumed that since persons with a spinal cord injury have already adapted to the change in their physical functioning and that this adaptation was made on an individual basis, it is necessary to establish a baseline of what has been the maximum functional level since injury. For example, there are guidelines for the potential for independence of a person who has spinal cord damage at specific thoracic levels in terms of self-care. However, each person's rehabilitation outcome differs, with some individuals exceeding the guidelines and others not meeting the expectations established by the guidelines.

Limitations

Since there is little information or research on the population of aging persons with a spinal cord injury, this was a preliminary, descriptive study. Conclusions from this study cannot be generalized since the sample size was small (13 subjects) and all of the subjects were male veterans. Because the subjects participating in the study are not representative of the general paraplegic population, additional research investigating a larger segment of this population is needed to generalize results.

Since the subjects were selected from an outpatient clinic there may be some bias. The subjects are likely to have good medical care as opposed to persons with spinal cord injuries who may not have medical care by personal choice or possibly lack of medical insurance. Good medical care may eliminate medical complications that would restrict a person's ability to perform self-care, work, and leisure activities.

Further limitations include: the data collected were from the participant's viewpoint and recall of at least 20 years previous and were interpreted by the researcher as the subjects' perceptions which may be distorted by the passage of time.

Subjects were chosen from a 200 mile radius of the Palo Alto Veterans Administration Medical Center in California. This restriction may have somewhat limited the choice of subjects, although participants included persons with a variety of occupations and lifestyles.

Significance of the Study

The health care professions have recognized both a need for specialized knowledge and care for the aging person and a need for specialized knowledge and care for the person with a spinal cord injury. It is the researcher's belief that there is now a need to merge the two knowledge bases to understand the changes an aging person with a spinal cord injury experiences so that programs can be developed to assist this person in maintaining maximal independence. Since occupational therapists are concerned with "occupation" which includes activities of daily living, work, and leisure, the functional difficulties that the aging person with a spinal cord injury experiences is important to treatment planning.

This study has highlighted activities of daily living which require reassessment and treatment which have otherwise been overlooked due to lack of knowledge that there might be difficulties in these areas. The results could be used by occupational therapists, who provide initial rehabilitation, to reevaluate the compensatory techniques which may in the future cause more functional difficulties for the aging person with a spinal cord injury. Since rehabilitation and follow-up of the person with a spinal cord injury is a multidisciplinary team function, the results of the study could also have implications for patient education and treatment by other disciplines.

CHAPTER 2

LITERATURE REVIEW

Introduction

The current research encompassed both aging and spinal cord injury from biological and functional perspectives. The following literature was reviewed to provide a thorough overview of the research regarding aging and spinal cord injury:

- biological age-related changes experienced by the majority of the population
- types of activities in which the aging person participates
- physical changes experienced by a person with a spinal cord injury and a baseline for expected level of independence
- studies that specifically focus on the aging person with spinal cord injury.

Frame of Reference

Adaptation as described by King (1978) and Model of Human Occupation as described by Kielhofner (1985) provide the frames of reference on which the current study was based.

Successful management of activities of daily living, work, and/or leisure activities can build toward attainment of volitional control in one's life. Competence or incompetence in handling everyday activities contribute to one's concept of personal causation or in other words, the control the individual has over his or her life experiences. Successful interactions contribute to one's sense of control and positive self-esteem (Kielhofner, 1985).

The primary tasks with which children involve themselves are play and activities of daily living, such as getting dressed or taking the bus to school. As children mature to adulthood play tasks are replaced by work and leisure, while activities of daily living remain constant throughout life. Disruption can occur with a physical or mental disability, removing the ability to successfully complete some self-care, work and/or leisure activities. This disruption can create a loss of one's volitional control and require adaptation either through environmental changes or emotional reassessment of values and interests leading to a sense of personal causation.

For example, the inability to get in and out of bed independently may make a person feel dependent. Some methods to increase independence may be to modify the environment or teach the person compensatory techniques to get in and out of bed without assistance. If it is physically impossible for the individual to independently transfer from bed, the focus may be on good management skills for supervising attendants and increasing the ability of the individual to verbally instruct someone to assist with transfers. Ultimately the goal is for the individual to be in control of his or her activity, if not on a physical level, on a psychological and cognitive level. This transition requires new skill development and realignment of valued goals which contribute to a sense of competence and maintenance of self-esteem. The inability of the individual to develop new skills and therefore enter into some purposeful activity creates a maladaptive state.

The occupational therapists' role is to assist the client with maintaining or developing a sense of competence in some purposeful activity by eliciting adaptive responses (King, 1978). It may begin with developing a subskill, such as hand dexterity to write a letter. However, the result may serve to increase the client's sense of competency which affects achievement motivation. The occupational therapist must be able to determine the interests and valued goals of

the client to assess which skills need to be developed to allow the client to participate in these preferred occupations (Rogers, 1983).

Since life expectancy has increased for the persons with a spinal cord injury, they are experiencing changes due to aging which may be complicated, in part, by spinal cord injury. The aging person must adapt to biological, social, and psychological changes (Wantz, 1981) in order to maintain independence, either through learning new or compensatory techniques (skill development) or through modifying the environment. In order to facilitate adaptation, it is important to know the aspects of activities of daily living, work, and leisure that the aging spinal cord injured person may expect to make.

Aging

Eleven per cent of the population in the United States is over 65 years of age. Eighty-five per cent of this population suffers from at least one chronic disease (Cadieux, 1985). Aging is a normal phenomenon--it is inevitable regardless of optimal genetic and environmental factors (Kohn, 1985). According to Kohn, "every physiological process can be shown to function less effectively with increasing age when studied under appropriate conditions" (p. 7). Although some processes appear adequate under resting conditions, when placed under stress, deficits begin to appear (Kohn, 1985). Multiple changes occur in all systems of the body including: visual, musculature, skeletal, cardiovascular, and pulmonary. These changes can often affect mobility and self-care status in the older adult.

Adequate visual function is needed for the maintenance of skills as well as for learning new skills in order to accomplish the tasks of daily living (Cristarella, 1977). There is a decrease in many areas of visual functioning as an individual ages, such as, visual

acuity, depth perception, and color sensitivity (Cristarella, 1977; Verrillo, 1985). Decreased visual functioning is due to physiological changes in the eye that are age-related (Cristarella, 1977) and may also be due to age-related diseases such as, presbyopia, glaucoma, cataracts or macular degeneration (Verrillo, 1985). Visual impairment, no matter what the cause, may contribute to a loss of mobility and decrease in activity (Whitbourne, 1985). Although visual acuity was not specifically evaluated in this study, the researcher was aware that visual changes may affect the subject's ability to perform activities of daily living.

Movement involves several biomechanical components, which are muscles, joints and bones. Each of these components change in some respect as one ages. There is approximately a 10% to 20% decrease in muscle strength from the 40 to 50 year age group to the 60 to 70 year age group (Whitbourne, 1985). Seventy to eighty year olds have lost 30% to 40% of their total muscle strength (Asmussen, 1981) with greater loss in the legs than in the arms or hands (Shephard, 1981). Meanwhile, osteoporosis occurs as bones age. Osteoporosis results in loss of bone strength and decreases the ability of the bone to withstand mechanical pressure (Whitbourne, 1985). Due to bone weakening, fractures occur more easily and mobility may become impaired.

All structures of joints become involved due to aging (Whitbourne, 1985). Arterial cartilage becomes thinner, less resilient and pitted, eventually allowing the ends of bones to erode. Tendons and ligaments become fibrous and less flexible, and synovial fluid is less viscous therefore providing less cushion (Whitbourne, 1985). These destructive changes may contribute to pain, decreased mobility, and decreased activity.

Other areas which must be examined since they contribute to our ability to move are the cardiovascular and pulmonary systems and weight gain. In the cardiovascular system there are generally

four important changes that occur as one ages. These include, a decrease in maximum oxygen consumption, a decrease in maximum exercise heart rate, a decrease in exercise stroke volume, and a decrease in cardiac output (Wenger, 1984). Together these decreases in cardiac function create a loss of efficiency as a pumping device. Functionally, the results are a diminished capacity for work and a decreased ability to tolerate a variety of stresses (Kolata, 1977).

The pulmonary system also changes with age, becoming less efficient with gas exchange (Whitbourne, 1985). Keltz (1984) stated that although pulmonary function decreases with age, the loss is one of the reserve necessary during stress. Therefore the loss does not interfere with ordinary activity, unless there is cardiovascular and/or neuromuscular impairment (Keltz, 1984).

During mid-life, ages 35-59 there is often an increase in weight. The weight especially increases between the ages of 40 and 45 (Stevens-Long, 1979). Increased weight may affect flexibility and impair movement.

Literature on aging supported the idea that as one ages the body is progressively changing and tends to function less effectively. Despite age-related changes, function or activity may not be affected. Since the current study is concerned with the ongoing function of activities of daily living, work and leisure, one needs to understand the aging population's level of activity.

Activity and Aging

In order to understand changes that an aging individual or group might have with activities of daily living, it is helpful to have a baseline of "normal" expectations for specific age groups. There are a large number of studies that evaluate the use of assessment tools to measure functional abilities but none that have specifically applied

those tools to collecting data. Due to the lack of specific data on activities of daily living and aging, the literature was reviewed in terms of general activity and aging.

Jette and Branch (1985) collected data to determine if there was a correlation between physical impairment, physical disability, and social disability for people over 65 years old. This study found that with increased age there was increased physical disability, more for persons living alone than for those living with other people. The study also found that persons with increased musculoskeletal and visual problems also tended to have increased physical disabilities. Champlin (1987) attempted to correlate general lifestyle to changes in functional status for people over 65. He found that the greatest decline of functional status occurred in the 70-80 age group. Also that groups with more frequent alcohol and cigarette consumption have greater impairment with functional status than groups with less use of alcohol and cigarettes.

Three other groups of researchers have studied the type of activity in which people of different ages participate (Herzog, Kahn, Morgan, Jackson, & Antonucci, 1989; Kelly, Steinkamp, & Kelly, 1986; McGuire, Dottavio, & O'Leary, 1986). McGuire et al. (1986) and Kelly et al. (1986) specifically looked at leisure activity while Herzog et al. (1989) studied all types of productive activities. McGuire et al. found that as age increased (over 38) health reasons were increasingly given as a reason why individuals limited their participation in outdoor recreation. After age 45, McGuire et al. found that health reasons were the number one prohibitor of activity until over age 75 when safety became the number one prohibitor. Kelly et al. expanded the areas of leisure activity to include cultural, travel, exercise and sport, family leisure, outdoor recreation, social activities, community organizations and home based activities. Overall there was a decline in leisure activity as age increased. But if the data are observed more closely, it is evident that there is a shift

away from strenuous physical activity toward social engagement as persons age. Significant restriction in the majority of areas of leisure did not occur until age 75.

Herzog et al. (1989) included individuals age 25 and older to determine the number of hours spent in productive work. Productive work was defined as paid work, unpaid work, housework, childcare, helping others and volunteer work. Overall the study found there was decreased participation in all areas of productive work as age increased. Average hours of paid work remained steady from age 25-51. Average volunteer work remained steady until over age 75. Hours involved in housework remained consistent throughout all ages.

The literature on aging and activity is rather scant and although interesting data have been gathered it cannot necessarily be generalized. It does appear evident from all of these studies that there is a decrease in activity with age especially after age 75. Before age 75 it seems there is a shift in the type of activity involvement versus a withdrawal or abstinence from activity.

Spinal Cord Injury

Spinal cord damage may result in temporary or permanent paralysis. Paralysis is usually described at or below the vertebral level of injury. A spinal cord injury may be caused by trauma such as in motor vehicle accidents, gunshot wounds, sports accidents, or stab wounds. Motor vehicle accidents are the most common method of injury (Spenser, 1988).

Damage to the cervical spinal cord may result in quadriplegia with sustained sensory and motor deficits to the upper extremities, trunk, and lower extremities. Paraplegia results from damage to the thoracic, lumbar, or sacral areas with sustained sensory and muscular deficits of the trunk and lower extremities. All levels of

complete spinal cord injury also result in some loss of bowel, bladder and sexual functioning.

The location of the spinal cord injury will allow for a functional estimate to be made regarding the individual's level of independence. For example, a person with a C7 spinal cord injury level could be expected to be independent with dressing and transfer activities due to the innervation of the triceps muscles at that level. Complications secondary to medical problems and social and psychological factors may affect progression to the expected functional level.

A paraplegic can be expected to be independent with self-care, transfer and household activities, to drive with hand controls, and be employed with use of a wheelchair for mobility. Some medical complications which could impair the person with paraplegia from attaining the expected level of independence are decubitus ulcers and spasticity.

A person with spinal cord injury can also be involved in a variety of leisure activities. These include wheelchair sports such as basketball, tennis, and racing. Adaptive equipment and environmental access has provided greater opportunity for the person with a spinal cord injury to participate in leisure activities. For example, there is an attachment that will convert a wheelchair into a hand-pumped bicycle and there is also snow sledding equipment available for skiing. Community access including ramps and wheelchair accessible bathrooms has also made it easier for the person in a wheelchair to participate in leisure activities. There is also information available about accessible facilities in national parks and campgrounds and travel agencies that arrange travel for the wheelchair user.

The treatment of the person with a spinal cord injury has developed into a specialty area of its own. Bedbrook (1987) reviewed the progress of the specialty area as providing comprehensive care.

Briefly Bedbrook (1987) stated there is a need to develop programs that include extended care beyond rehabilitation.

Spinal Cord Injury and Aging

Although there are 177,000 persons with spinal cord injury in the United States (Joe, 1990) there is no specific data available from the United States Census Bureau, the National Center for Health Statistics or the National Spinal Cord Injury Statistical Center pertaining to the aged person with a spinal cord injury. As initial treatment and medical care have improved over the last 40 years the life expectancy for the spinal cord injured person has improved. In World War I, 80% of the servicemen with spinal cord trauma died within one week after injury (Gokbudak, 1985). A study by Grundy (1986) examined the life expectancy of the spinal cord injured population ages 20 - 50 at time of injury and by the level of injury. The study found that the person with incomplete quadriplegia had a life expectancy from mid to late sixties; with complete quadriplegia the range was from 50-59 years of age; with incomplete paraplegia, late sixties; and with complete paraplegia life expectancy was in the early sixties. Bedbrook (1981) stated that with adequate care and follow-up it can now be said that a young person with paraplegia has a life expectancy of normal minus 5 years and with quadriplegia a life expectancy of normal minus 10 years. The Grundy information is probably a more accurate depiction of the population as it is cited from a research study and not clinical observation as is Bedbrook's information.

It was not until the early 1980's that the literature began reflecting clinical observations by several health professionals and personal experience regarding accelerated aging in persons with spinal cord injury. Bedbrook (1981) stated that the aging process for

the person with a spinal cord injury over a 20 year period is greater than for the person in the general community. He further explained that a man of 55 years who has had paraplegia for 20 years is physiologically 10 years older than his chronological age (Bedbrook, 1981). Ohry, Shemesh, and Rozin (1983) agreed that the person with a chronic spinal cord injury is prone to premature aging. Dr. Menter ("Getting Older," 1990) stated that the more severe the disability the more accelerated the aging process. He and his colleagues are currently conducting a study to determine patterns of the aging process among people who have sustained injuries in the last few decades ("Craig Experts," 1990). Becker (1990) discussed her personal experiences with aging with paraplegia and how she has had to change her activities of daily living due to her changing physical conditions. Another article in Accent on Living reflected that long-term survivors of spinal cord injury may have been encouraged to push themselves too much and that they now need to be more moderate with activity to avoid symptoms of overuse ("Aging What's," 1990).

The literature is abundant with information on medical complications in long term care of the person with a spinal cord injury (Bedbrook, 1981; Guttman, 1976; Ohry, 1983; Pierce, 1977). Guttman (1976) described complications that the person with chronic spinal cord injury may experience, some of which are: osteoporosis, heterotopic ossification, postural hypotension, thermoregulation difficulties, pressure sores, bowel and bladder complications, sexual dysfunction and spasticity. Alijore (1985) reports that there is a high incidence of carpal tunnel syndrome in paraplegic patients and that the incidence increases with age and length of time from injury. These studies reflected medical problems but did not necessarily reflect any change in the level of functioning with activities of daily living.

There are several studies that look at functional outcomes of rehabilitation and at the spinal cord injured persons progress following rehabilitation (DeVivo, 1987; McGowan, 1987; Rogers, 1980; Yarkony, 1988) but the majority provide only short-term follow-up. Rogers (1980) and Yarkony (1988) both studied the carry over of skills learned in rehabilitation after discharge but the length of time following discharge was 1 to 4 years for Rogers' subjects and 3 years for the subjects of Yarkony's study. DeVivo (1987) reported a retrospective study regarding employment of persons with spinal cord injury seven years post-injury. This study may reflect relatively early adjustment post-rehabilitation but may not necessarily reflect changes that occur many years post-injury with an aging person. McGowan and Roth (1987) studied family adjustment with subjects who were between less than 2 years post-injury and over 5 years post-injury. This study assessed the subjects' functional level of independence, measured family functioning, and then both were categorized according to the subjects' duration of disability to determine if perceptions of family process and observed levels of functional ability varied with time. Although this study observed some post-injury aspects of spinal cord injury the length of time post-injury is not long enough to reflect aging changes with a disability.

The Eisenberg and Saltz (1989) study included veterans whose initial injury occurred at least five years prior to the interview. Some data were examined according to the subjects' ages also. The primary purpose of the study was to determine the veterans' perception of services and which groups typically use these services. Although the Eisenberg and Saltz (1989) study does not directly relate to the current study, it includes some data which give a baseline about activities of daily living with a spinal cord injured population who have been injured for at least 5 years. The difficulty with the data is that it is not analyzed according to both the age of the spinal cord injury and the chronological age of the subject. This study also

neglected to divide the subjects into those with paraplegia and those with quadriplegia. The need for this division of data is evident as a person with paraplegia generally should be more independent and therefore possibly use fewer services.

The occupational therapy literature has reported two articles recognizing the older spinal cord injured population. Sepowitz (1984) presented a case study about an aging man with quadriplegia and how his chronic medical problems affected his function. Decker (1985) studied life satisfaction and depression in the older spinal cord injured person. Neither of these studies is directly related to functional changes with the aging person with paraplegia but are the first studies regarding the older spinal cord injured person in the occupational therapy literature.

Trieschmann (1987) studied 8 people who had disabilities and were aging. The subjects had several different disabilities including quadriplegia and paraplegia from a spinal cord injury, multiple sclerosis, and post-polio. The investigation did not result in data regarding specific functional changes but instead analyzed the current medical model of health care in terms of the individual's need for psychosocial, organic, and environmental supports and presented a need for a functional model of health care.

Menter (1990) investigated the differences between individuals with various neurological levels of injury, chronological ages, and duration of injury to determine if the degrees of functional independence and handicap differed. The data also examined differences in medical expenditures during the aging process. The results showed that medical costs increase inconsistently with age but increase significantly when age and duration of injury are examined together. Menter's analysis also showed that there is an increase in the level of handicap with individuals whose age plus years post-injury totaled 50 or more years, although the functional independence scores did not show a change with age. Observations

from this study reflected that it may require greater effort for persons with spinal cord injury to maintain independence with age.

Dew, Lynch, Ernst, and Rosenthal (1983) collected data from hospitalized spinal cord injured persons regarding the level of assistance needed with self-care, employment, physical and leisure activities, and rehabilitation experiences. The difficulty with this descriptive study is that the responses were not delineated between persons with paraplegia and quadriplegia, age, or duration of injury thus making the data collected too general. The subjects' responses may also not be representative of the spinal cord injured population at large as only people who were hospitalized were questioned. Since the subjects represented sicker persons, responses may have been skewed.

The most extensive study regarding function of persons with spinal cord injury was done by Nakajima and Honda (1988). The data included physical condition, method of urination, morbidity, occurrence of decubitus ulcers, activities of daily living, use of crutch walking, environmental modifications, activity outside of the house and employment status. The subjects responses were divided by level of injury and age. The study found several changes for the aging persons with paraplegia including a decrease in activity outside of the house and decrease in sitting time in a wheelchair. The data could have been more specific if not only the subjects' ages had been separated but also the duration of disability as was done in the Menter study (1990). Cultural differences also need to be considered before these data are compared with other studies as it was done in Japan.

As life expectancy of persons with spinal cord injuries has increased the literature has reflected more interest in long-term functioning, cost of medical care and utilization of services. Until the 1980's most studies which collected data about the post-rehabilitation phase were a reflection of adjustment to the spinal cord injury and

did not necessarily represent changes that occurred due to aging in conjunction with long-term spinal cord injury. The earliest literature about aging with a spinal cord injury are not studies but articles discussing clinical observations. Dew, et al. (1983), Nakajima and Honda (1988), and Menter (1990) have reported the most comprehensive studies regarding aging spinal cord injured persons.

There is still a need to jointly study chronological age, duration of disability, level of disability, and status of activities of daily living to determine what changes occur with the aging spinal cord injured person.

Summary of Literature Review

The literature review encompassed: the researcher's frames of reference, studies regarding aging, aging and activity, spinal cord injury, and spinal cord injury and aging. The frames of reference on which the current study is based are Adaptation as described by King (1978) and Model of Human Occupation as described by Kielhofner (1985). Together these frames of reference support the current research, regarding how the person with a spinal cord injury is adapting to aging changes.

The literature on aging supported the idea that as one ages the body is progressively changing and tends to function less effectively. Despite age-related changes, function or activity may not be affected. The literature on aging and activity is rather scant and although interesting data have been gathered it cannot necessarily be generalized. It does appear evident from all of the studies that there is a decrease in activity with age especially after age 75. Before age 75 it seems there is a shift in the type of activity involvement versus a withdrawal or abstinence from activity.

The literature on treatment of the person with a spinal cord injury is abundant but not until the 1980's has research been completed about the aging person with a spinal cord injury. Much of the literature about the aging person with a spinal cord injury is based on clinical observation. Only three studies have been completed which describe the aging person with a spinal cord injury. There is a lack of research regarding the status of activities of daily living for aging persons with spinal cord injury.

CHAPTER 3

DESIGN AND METHODOLOGY

Purpose

The purpose of this study was twofold: a.) to determine which activities of daily living become more difficult as the person with a spinal cord injury ages and b.) to describe a role for occupational therapy in the care of the aging person with a spinal cord injury.

Questions

This study was designed to answer the following questions:

1. What are the age-related problems that affect activities of daily living which the person with complete paraplegia due to spinal cord injury experiences after a minimum of twenty years since onset?
2. How long after the initial spinal cord injury does the person with paraplegia due to spinal cord injury develop age-related problems in activities of daily living?
3. What is the role of occupational therapy in the treatment of the aging spinal cord injured population?

Design and Sample

This study used case study methodology. It is a preliminary, exploratory study.

The sample included 13 adults with paraplegia due to a spinal cord injury aged 40 or above with 20 years or more post onset of the

spinal cord injury. The participants were found through the Palo Alto Veterans Administration Medical Center Spinal Cord Injury Outpatient Clinic.

The participants sustained spinal cord injuries at least 20 years before and were at least 40 years old with a diagnosis of complete paraplegia, resulting in the inability to move the lower extremities and to walk. The participants are wheelchair bound. The participants live in the community in private residences and not in a convalescent hospital. The participants were assumed to be mentally competent with no history of head injury or dementia. The participants signed a consent form (Appendix B).

Subjects were initially chosen according to age as listed on a copy of their medical cards kept at the Palo Alto Veterans Administration Medical Center Spinal Cord Injury Outpatient Clinic. The subjects' medical charts were then pulled from the files to determine each candidate's level of injury and date of initial injury. Subject's medical files that were not immediately available during initial sampling were eliminated from the pool of potential subjects. Also eliminated from the pool of subjects were those living more than 200 miles from Palo Alto Veterans Administration Medical Center. The medical charts were not reviewed for medical background other than pertinent data on age, level of injury, and year the spinal cord injury occurred.

Forty-three potential participants were originally found with the procedure described above. Only 34 of those met the 200 mile radius criterion, so those 34 were contacted by letter (Appendix C). Two letters were returned with the incorrect address and no forwarding address. This left a possibility of 32 subjects to respond to the request for an interview. Twenty-one responses were received (66%). Eleven (34%) of those initially contacted did not respond. Three of the responses indicated that the person was now deceased and two people who responded declined to be interviewed (11% of the

18 potential participants). Of the sixteen persons (89% of the 18 potential participants) who agreed to be interviewed, one additional person was eliminated since he no longer lived within the 200 mile radius of the medical center. This provided 15 subjects who met the study criteria and who were subsequently interviewed; however, one subject who was interviewed was eliminated from the data since he was ambulatory with short-leg braces until the last few years. Another subject's response was lost due to a poor tape recording. This left a total of 13 subjects included in the study.

Subjects were contacted by letter in which the requirements of their involvement in the study was described (Appendix C). They were requested to return a response form (Appendix D). Individual interviews were arranged once a positive response was received. Confirmation letters regarding specific time and place of the interview were sent to the participants (Appendix E) along with the human subjects consent form (Appendix B).

Procedure and Instrument

The data were collected through indepth interviews using an activities of daily living functional evaluation (Appendix A) and a questionnaire (Appendix F) which provided inquiries about instrumental activities of daily living, work, leisure, and the participant's physical environment. The checklist is a modified version of the occupational therapy evaluation that has been used by the occupational therapists at Palo Alto Veterans Administration Medical Center for the last thirteen years. The evaluation instrument was used with the permission of the Occupational Therapy Department at Palo Alto Veterans Administration Medical Center (Appendix G). The participants were asked to describe their post-rehabilitation activities of daily living status and present status

of activities of daily living. The researcher also explored when changes in self-care, work, and leisure occurred and how the participant adapted to those changes. The interviews were tape recorded with the participants' consent (Appendix B). The data collected during the interviews will be presented with graphic displays of statistics, such as, bar graphs, pie charts, and tables.

CHAPTER 4

DATA AND RESULTS

Data analysis included examination of the demography, physical problems, and functional limitations reported in self-care, work, and leisure activities.

Overall grouping of reported incidences with physical problems and the specific data on each physical problem were examined. Impairment with activities of daily living were described generally, with a review of self-care, work, and leisure activities. The data were then examined as to when physical problems and functional limitations began to occur and the relationship between the two.

Demography of the Study Group

The demographics of the group studied were examined and then demographics of the spinal cord injury population were discussed as a comparison. Table 1 presents the subjects' age, number of years post-injury, level of spinal cord injury, marital status, education, employment status, living arrangements, and whether the subject was service connected or non-service connected.

The subjects studied were all male veterans. One subject was Black; the others were white. The age range was 40 to 71. Six subjects were in their 40's, four were in their 50's, one was age 60, and two subjects were in their 70's.

Table 1
Demography of the Study Group

Subject	Age	#Years Post- Injury	Level of ¹ SCI	Marital ² Status	Educa- ³ tion	Employ- ⁴ ment Status	Living Arrange- ment	SC ⁵ NSC
A	41	20	T 8-9	M X 2	H.S.	UNEMP	WIFE	SC
B	51	22	T 11	D	H.S. / College	UNEMP	Room- mates	NSC
C	71	46	T 12	M X 2	H.S. / College	RETIRE	WIFE	SC
D	43	24	T 5	M X 2	H.S.	EMPL	WIFE	SC
E	42	20	T 12	S	B.S.	EMPL	ALONE	NSC
F	43	22	T 4	D	M.A.	EMPL	ALONE	NSC
G	70	46	T 4	M X 2	H.S.	RETIRE	WIFE	SC
H	60	35	T 6	M	H.S.	EMPL	WIFE	NSC
I	57	37	L 3	S	H.S. / College	EMPL	ALONE	SC
J	50	25	T 9	M X 2	H.S. / Voc. Ed.	UNEMP	WIFE	NSC
K	40	20	L 1-2	D	H.S.	EMPL	ALONE	SC
L	40	19+	T 5-6	D	H.S.	UNEMP	ALONE	NSC
M	59	36	T 10	M X 2	Ph.D.	EMPL	WIFE	SC

¹Level of Spinal Cord Injury, T = Thoracic, L = Lumbar.

²S = Single, M = Married, M x 2 = Married twice, D = Divorced.

³H.S. = High School, Voc. Ed. = Vocational Education, B.S. = Bachelor of Science, M.A. = Master of Arts, Ph.D. = Doctor of Philosophy.

⁴UNEMP = Unemployed, EMPL = Employed, RETIRE = Retired

⁵SC = Service connected injury, NSC = Non-service connected injury

The average age when initially spinal cord injured was 24 years. At the time of the study, the number of years post-injury ranged from just under 20 to 46. The subject who was just under 20 years post-injury was included in the study because the nature of the information being reported would not be affected by two months. This subject has been included in the subject grouping, 20 years post-injury. There were eight subjects with 20-29 years since their spinal cord injury. Three subjects have had a spinal cord injury from 30-39 years. Two subjects have had a spinal cord injury 40-46 years. All of the subjects had a complete paraplegia from thoracic level four to lumbar level three.

Two subjects were single and had never been married. Seven subjects were married. Six of this group had been previously married. Four subjects were divorced and not married at the time of the study.

All of the subjects had a least a high school education. Six of the subjects had only a high school education. Four of the subjects have taken some college or vocational education but did not complete a degree. Three of the subjects completed college receiving a degree, with two completing a master's degree and one completing a doctoral degree.

Employment status was listed as employed, unemployed or retired. Seven subjects were employed, four subjects were unemployed, and two subjects were retired. The employed subjects were examined more closely in the work analysis section of the data analysis.

Living arrangements were listed as either alone, with a wife, or with roommates. The seven married subjects live with their wives. Five subjects live alone and one lives with roommates.

Seven subjects have service connected injuries and six subjects have non-service connected injuries. Service connected and non-service connected defines the subjects' status within the Veterans

Administration. The veterans' service or non-service connected status is important in terms of income, medical care resources, and resources for adaptive equipment. Service connected veterans were injured while in the service and receive some financial compensation and full use of the Veterans Administration Medical Centers. Financial compensation includes a guaranteed monthly income and a house and car grant. Non-service connected veterans were not in the service when injured. Non-service connected veterans do not receive financial reimbursement for their injuries but are able to benefit from use of the Veterans Administration Medical Centers. Both service connected and non-service connected veterans have the benefit of receiving adaptive equipment through the Veterans Administration Medical Centers.

Only three subjects reported secondary medical conditions other than the spinal cord injury. Subject B reported having diabetes that was not insulin dependent. Subject G reported having a history of congestive heart failure. Subject L had a kidney removed and went in for frequent medical appointments to monitor kidney function. All subjects reported episodes of bladder infections.

Demographics of the Spinal Cord Injury Population

The Paralysis Society of America (1990) has recently completed a nationwide survey to establish a demographic picture of the spinal cord injury population. The Paralysis Society of America's survey of the spinal cord injury population reported that: over 70% were male; there were nearly twice as many divorced persons as the general population; over half have had some college; the median age at the time of the spinal cord injury was 27 years; those surveyed had been injured on the average for 14 years with more than half being injured before 1980; 56% reported paraplegia; incomplete injuries were more prevalent than complete injuries; and veterans accounted

for about 25% of the total spinal cord injury population in the United States.

Comparison of Demography

The results of the Paralysis Society of America's survey have been used as the "typical" picture of the spinal cord injury population and will be compared to the study group.

In terms of age at injury, sex, marital status, and level of injury the study group was much like the general spinal cord injury population. In terms of current age, number of years post-injury, veteran status, race, and extent of injury there are some differences.

The average age at the time of the spinal cord injury for the group studied was 24. The general spinal cord injury population was reported with the average age at injury before age 30.

The study subjects were all male while the general spinal cord injury population was 70% male.

When marital status of the study group was compared to the general population, they were found to be similar. The typical person with a spinal cord injury was married and over half (54%) of the study subjects were married. The Paralysis Society (1990) also reported a divorce rate nearly twice the general population. The study group also had a very high divorce rate with 77% of the group divorced.

The educational level for the two groups was similar. The study group and the general population have over half having had some college education.

When level of injury of the study group was compared to the general population they were similar. Over half of the spinal cord injury population has paraplegia, while 100% of the study subjects had paraplegia. The study group intentionally included only subjects with paraplegia as the age-related problems for the person with

paraplegia might be different than those of the person with quadriplegia.

The extent of the injury was not similar between the two groups. In the general spinal cord injury population four of five injuries were reported as incomplete, while all of the subjects studied reported complete injuries and were specifically chosen with complete injuries for the study.

The age of the study group was not typical of the general spinal cord injury population. The age range of the study group was 40 to 71 while the age range for the general spinal cord injury population was between 25 to 44.

The average number of years post-injury for the study group and the general spinal cord injury population were not similar. The median number of years post-injury for the study group was 29, with a wide range from 20 to 46 years post-injury. The typical post-injury span for the person with spinal cord injury was 10 to 20 years.

Representation of race was imbalanced when comparing the study group and the general spinal cord injury population. The study group had 92% white subjects, while the general population was 88% white.

All of the study subjects were veterans while only 25% of the general spinal cord injury population was veterans.

The demography of the two groups was compared to determine if during the analysis some generalizations might be made. As discussed there were some similarities but also some differences in the two groups. Generalizations would be difficult to make about even the aging spinal cord injury veteran population since the subject group was so small. The age-related problems reported, along with functional deficits will be presented in terms of trends but not in terms of generalizing to the general spinal cord injury population.

Data on Age-Related Physical Problems

Six physical problems were reported by the study group. These problems included hand dysfunction, shoulder impairment, increased body weight, fractures, decreased strength and endurance, and impaired skin integrity. Wrist and hand dysfunction included pain, loss of sensation, decreased strength and / or incoordination. Shoulder impairments included pain and decreased strength. Skin integrity was reported as incidences of pressure areas and / or decubitus ulcers. All of the problems were given by subject report and were not verified with medical charts.

As can be seen in Table 2 the reported incidences of physical problems varied from three subjects having fractures to 10 subjects experiencing problems with skin integrity. When the combined responses of the group were examined there were 12 of the 13 subjects (92%) whom reported one or more physical problem.

Table 3 shows the individual subjects reporting hand problems by number of years post-injury and age of onset. Five subjects (38%) reported problems involving hand function. The average age of onset for reported problems involving hand function was 50.4 and the average number of years post-injury was 26.8.

Five subjects (38%) reported problems of shoulder dysfunction as can be seen in Table 4. The problems included pain and decreased strength. The average age of onset was 53.6 and the average years post-injury of onset of shoulder problems was 30.

Table 2

Age Related Physical Problems of the Aging Person with Spinal Cord Injury

<u>Physical Problems</u>	<u>Number of Subjects</u>
Skin integrity	10
Strength / Endurance	7
Shoulder	5
Hand	5
Weight	4
Fractures	3

Note. n = 13.

Table 3

Subjects Reporting Problems with Hand Pain & Weakness

<u>SUBJECT</u>	<u>ONSET BY YEARS POST-INJURY OF NEW PROBLEM</u>	<u>ONSET BY AGE OF NEW PROBLEM</u>
B	22	51
C	36	61
E	20	42
F	19	41
I	37	57
Average	26.8	50.4
% Reporting Hand Pain and Weakness	38%	

Note. n = 13.

Table 4

Subjects Reporting Problems with Shoulder Pain & Weakness

SUBJECT	ONSET BY YEARS POST-INJURY OF NEW PROBLEM	ONSET BY AGE OF NEW PROBLEM
C	36	61
E	20	42
H	32	57
I	37	57
J	25	51
Average	30	53.6
% Reporting shoulder pain and weakness		38%

Note. n = 13.

Table 5 shows that four subjects (30%) reported increased body weight. The average age of onset was 46.5 and the average number years post-injury was 23 for problems with increased weight .

Table 6 shows the incidence of fractures in the study group. Three subjects (23%) reported one incidence of lower extremity fracture. All fractures reported occurred in the lower extremities. The average age of onset with the fractures was 59 and average number of years post-injury for onset was 34 years.

Table 7 shows the number of subjects who have reported difficulty with decreased strength and endurance. Seven subjects (54%) reported decreased strength and endurance. The average number of years post-injury when problems began to occur was 29 and the average age was 53.

Table 8 shows the reported incidences of problems with skin integrity. The category of skin integrity includes both incidences of pressure areas and decubitus ulcers. Eleven subjects, 85%, reported problems with skin integrity. Seven subjects (54%) reported several incidences. Six of the eleven subjects had their first incidence of skin breakdown within the first year following injury. Five of the eleven had a later onset of initial skin breakdown with the average being 18 years post-injury and average age of 37. The average number of years post-injury for onset of skin breakdown was six and age 29, although the mode was one year post-injury. The averages were established for the first incident of problems with skin integrity only. One subject was left out of these averages as he was unable to recall when his incidence of skin breakdown occurred. It is clear that skin integrity problems are ongoing for the person with a spinal cord injury and not necessarily related to age.

Table 5

Subjects Reporting Problems with Increased Body Weight

SUBJECT	ONSET BY YEARS POST-INJURY OF NEW PROBLEM	ONSET BY AGE OF NEW PROBLEM
B	19	48
D	24	43
H	30	55
K	20	40
Average	23.25	46.5
% Reporting problems with increased body weight		31%

Note. n = 13.

Table 6

Subjects Reporting Problems with Lower Extremity Fractures

SUBJECT	ONSET BY YEARS POST-INJURY OF NEW PROBLEM	ONSET BY AGE OF NEW PROBLEM
C	36	62
G	43	67
H	23	48
Average	34	59
% Reporting problems with lower extremity fractures		23%

Note. n = 13.

Table 7

Subjects Reporting Problems with Decreased Strength & Endurance

SUBJECT	ONSET BY YEARS POST-INJURY OF NEW PROBLEM	ONSET BY AGE OF NEW PROBLEM
B	11	41
C	42	67
D	24	43
E	20	42
G	37	61
H	35	60
M	37	57
Average	29.4	53
% Reporting problems with strength & endurance		
	54%	

Note. n =13.

Table 8

Subjects Reporting Problems with Impaired Skin Integrity

SUBJECT	ONSET BY YEARS POST- INJURY OF NEW PROBLEM	ONSET BY AGE OF NEW PROBLEM	APPROXIMATE OCCURRENCES
B	22	51	Multiple
C	1	26	Multiple
C	2	28	Multiple
C	46	71	Multiple
D	1	19	Multiple
D	18	37	Multiple
E	12	30	1
F	1	22	1
G	1	24	Multiple
G	39	63	Multiple
H	1	25	1
I	13	33	Multiple
I	33	53	Multiple
J	1	27	Multiple
L	7	35	1
M	-	-	Multiple
Average	6.0	29.2	
% Reported skin integrity problems	11 / 85%		
% Repeated skin integrity problems	7 / 54%		

Note. n = 13.

Data on Age-Related Problems with Self-Care Activities

Although subjects report physical problems the subjects did not necessarily require assistance with self-care, work, or leisure activities as a result of the reported physical problems. In order to determine how the reported physical problems affected activities of daily living, self-care, work, and leisure activities need to be examined.

The areas of self-care included in the study were dressing, grooming, bathing, transfer performance to and from all surfaces, wheelchair mobility, bowel and bladder care, and driving. Subject responses were divided into three categories; independent, independent with increased effort or modification, and requires assistance. The first category, independent or no change in status means the subject did not require any assistance but may be using some adaptive equipment which has been used since initially having spinal cord injury. The second category is independent with increased effort or modification. Modifications include both environmental and activity modifications. Environmental modifications included use of adaptive equipment such as, a tub bench or trapeze over the bed. Activity modifications are those that require learning a new technique to complete a task or modifying the task, such as taking a tub bath every other day because it requires too much effort to take one every day. The third category includes those subjects requiring minimal, moderate, or maximum assistance from another person to complete a task. The second category of independent with increased effort and / or modification was included because it could indicate a transitional stage for the aging person with spinal cord injury.

Table 9 shows the status of self-care by individual self-care activities and the number of subjects that reported in each category.

Table 9

Status of Self-Care Activities

SELF-CARE ACTIVITIES	INDEPENDENT / NO CHANGE	INCREASED EFFORT	ASSISTANCE REQUIRED
Bathing	13	0	0
Bladder Care	13	0	0
Bowel Care	13	0	0
Driving	13	0	0
Grooming	13	0	0
Household Maintenance	13	0	0
Meal Preparation	13	0	0
Yard work	12	0	1
Dressing	10	0	3
Toilet Transfers	10	1	2
Car Transfer	8	5	0
Tub/Shower Transfer	7	4	2
Wheelchair Mobility	7	6	0
Furniture Transfer	6	6	1
Sitting Time	7	6	--

Note. n = 13.

The areas of self-care in which all of the subjects reported being independent or no change included grooming, bathing (not including the transfer), driving, bowel and bladder care, meal preparation, and household maintenance. The self-care activities which required assistance or increased effort to perform included dressing, transfer performance to all surfaces, and wheelchair mobility. The self-care analysis will include individual analysis of each reported activity which required increased effort or required assistance.

Ten subjects (77%) reported independence or no change in their ability to dress themselves. Three subjects (23%) required assistance to get dressed each day. Table 10 shows the average number of years post-injury and age at onset of this problem.

The average number of years post-injury when difficulty with dressing occurred was 33 and the average age was 57. Subject G is listed twice because he had two specific episodes which required a change in his ability to dress himself. The first was the onset of congestive heart failure and the second was a lower extremity fracture. The date of the initial onset of difficulty with dressing was only included in the averages. All three of the subjects required assistance with pulling their pants over their hips. Only one subject (C) required assistance with upper extremity dressing and that was with buttoning due to fine motor difficulties.

Twelve subjects reported independence or no change in their ability to perform yard work. Only one subject (C) reported a change which occurred at age 67, 42 years post-injury.

Table 10

Subjects Reporting Problems with Dressing

SUBJECT	YEARS POST- INJURY OF NEW PROBLEM	AGE AT ONSET OF NEW PROBLEM
E	36	61
G	37	61
G	43	67
H	25	50
Average	32.6	57.3
% Reporting Problems with Dressing	23%	

Note. n = 13.

Table 11 shows the subjects reporting problems with wheelchair mobility and the average number of years post-injury and age with onset. Seven subjects (54%) reported independence or no change in their status with wheelchair mobility. Six subjects (46%) reported independence with increased effort or modifications. None of the subjects reported needing assistance with their daily wheelchair mobility. Wheelchair mobility included ability to handle a wheelchair on varied terrain and also handling curbs. The average number of years post-injury for onset of difficulty with wheelchair mobility was 35 and the average age was 59.

All but one subject (G) continues to use a manual wheelchair. Subject G began using an electric wheelchair with the onset of congestive heart failure when he was 37 years post-injury, age 66. The ability to handle curbs was the most frequently reported difficulty with wheelchair mobility. Many of the subjects stated that they would go a block out of their way to avoid a curb.

Transfer performance was divided into toilet, tub / shower, car, and furniture transfers. Table 12 shows the subjects who reported a change with their ability to perform chair to toilet transfers.

Ten subjects (77%) reported being independent with toilet transfers or had no change in their status. Two of the subjects (C, G) required assistance and one subject (B) was independent but required increased effort to perform the task. The averages were established using only the first incidence of reported difficulty. The average years post-injury for onset of difficulty with toilet transfers is 31 and the average age is 57.

It is important to note that although these three subjects had a change in their ability to perform chair to toilet transfers there has been no change in the status of their bowel and bladder care. Subject G has always had assistance with bowel care.

Table 11

Subjects Reporting Problems with Wheelchair Mobility

SUBJECT	ONSET BY YEARS POST-INJURY OF NEW PROBLEM	ONSET BY AGE OF NEW PROBLEM
B	19	48
C	46	71
G	37	61
H	35	60
I	37	57
M	33	56
Average	34.5	58.8
% Reporting Problems with Wheelchair Mobility	46%	
<u>Note. n = 13</u>		

Table 12

Subjects Reporting Problems with Chair to Toilet Transfer Performance

SUBJECT	ONSET BY YEARS POST-INJURY OF NEW PROBLEM	ONSET BY AGE OF NEW PROBLEM
B	19	48
C	36	61
C	36	62
G	37	61
G	43	67
Average	31	57
% Reporting Problems with Chair to Toilet Transfer Performance	23%	

Note. n = 13.

Table 13 shows the subjects who had changes in chair to tub / shower transfer performance. Seven subjects (54%) reported independence or no change in their ability to perform chair to tub / shower transfers. Four subjects (30%) reported being independent with increased effort or a need for modifications. The average number of years post-injury when there was a change with chair to tub / shower transfer performance was 26. The average age of the subjects with onset of difficulty with chair to tub / shower transfer performance was 51.

Two subjects (16%) reported a need for assistance with chair to tub / shower transfers. As with toilet transfers these two subjects (C and G) reported two different times when there were changes with their ability to transfer.

Several different modifications were made by subjects to accommodate changes in their ability to transfer from chair to tub or shower. One type of activity modification included taking only sink baths and the other was to take a tub bath every other day, instead of daily. Environmental modifications included a roll-in shower and use of transfer tub benches.

Eight subjects (61%) reported independence or no change in status with their ability to perform chair to car transfers. Five subjects (38%) reported increased effort or need a modification with car transfers. Table 14 shows the subjects reporting a change in their chair to car transfer performance. The average number of years post-injury when difficulty with chair to car transfer performance was reported was 31 and the average age was 57.

Only two subjects actually made environmental modifications due to difficulty with car transfers. The modifications included use of a van with an electric wheelchair lift. The other three subjects continue to perform chair to car transfers independently but with increased effort.

Table 13

Subjects Reporting Problems with Chair to Tub / Shower Transfer Performance

SUBJECT	ONSET BY YEARS POST-INJURY OF NEW PROBLEM	ONSET BY AGE OF NEW PROBLEM
B	19	48
C	40	65
C	42	67
E	20	42
G	37	61
G	43	67
H	25	50
J	13	38
Average	25.6	50.6
% Reporting Problems with Chair to Tub / Shower Transfer Performance		
	46%	

Note. n = 13.

Table 14

Subjects Reporting Problems with Chair to Car Transfer Performance

SUBJECT	ONSET BY YEARS POST-INJURY OF NEW PROBLEM	ONSET BY AGE OF NEW PROBLEM
B	12	41
C	36	62
G	37	61
H	35	60
J	25	51
Average	29	55
% Reporting Problems with Chair to Car Transfer Performance		38%

Note. n = 13.

Six subjects (46%) reported independence or no change in their ability to transfer from chair to furniture other than the wheelchair, tub, toilet, or car. Six subjects (46%) reported independence with increased effort or modifications. Only one subject reported a need for assistance. Table 15 shows the subjects who reported a change. The average number of years post-injury of reported changes in transfer performance to other furniture was 27 and the average age was 50.

Changes in sitting time in a wheelchair were examined as it can disrupt activities of daily living. Table 16 shows the reported changes with sitting time in a wheelchair. Six (46%) subjects required a change in the amount of time up in a wheelchair. Of this group three subjects (D, J, B) required extended bed rest, while the other three (I, C, G,) required more frequent rest periods out of the wheelchair on a daily basis. The average number of years post-injury of reported changes in sitting time in a wheelchair was 26 and the average age was 50.

Table 15

Subjects Reporting Problems with Wheelchair to Furniture Transfer Performance

SUBJECT	ONSET BY YEARS POST-INJURY OF NEW PROBLEM	ONSET BY AGE OF NEW PROBLEM
B	19	48
C	42	67
D	24	43
E	20	42
G	37	61
H	30	55
K	17	37
Average	27	50.4
% Reporting problems with wheelchair to furniture transfer performance		
	54%	

Note. n = 13.

Table 16

Subjects Reporting Changes with Sitting Time in a Wheelchair

SUBJECT	ONSET BY YEARS POST-INJURY OF NEW PROBLEM	ONSET BY AGE OF NEW PROBLEM
B	22	51
C	46	71
D	18	37
G	37	61
I	33	53
J	1	27
Average	26.1	50
% Reporting Changes with Sitting Time in a Wheelchair		
	46%	

Note. n = 13.

Data on Age-Related Problems with Work Activities

In order to determine how reported physical problems affect employment the subjects' employment history was gathered. Employment history was taken for each subject from immediately post-rehabilitation to the present to determine why and when subjects transition into employment, reasons for unemployment and retirement, and physical changes that have effected work. The subjects can be divided into three groups when examining work: unemployed, retired, and employed. At the time of the interviews four subjects (31%) were unemployed, seven subjects (54%) were employed, and two subjects (15%) were retired. The employed subjects were further examined in terms of being self-employed or employed by others. Three subjects (23%) were self-employed and four subjects (31%) were employed by others. Figure 1 shows the distribution of retired, self-employed, employed by others, and unemployed.

Of the four subjects who were employed by others none had difficulty maintaining their employment due to increased physical changes or limitations. Two of the part-time self-employed (D and I) chose their work because it gave them more flexibility with sitting time in the wheelchair and allowed them to take breaks during the day. One subject (I) required more frequent rests from sitting due to cysts in his hips since he was 33 years post-injury, age 53, but was still able to manage his ranch work. One of the self-employed subjects (L) chose to limit how much he worked to allow more time for socialization. Subject D also experienced reoccurring skin breakdown which appeared to be more related to his increased social activity during extended holidays as this was when it occurred; however, it required him to curtail his work activities to those that could be accomplished from in bed, or the one hour he allows himself up in the wheelchair each day when recovering.

Figure 1. Employment Status.

Data on Age-Related Problems with Leisure Activities

Changes in leisure activities were examined in terms of the number of incidences reported and the type of leisure activities. The changes that are considered in the analysis are ones that were reportedly due to new physical problems, not due to a change in personal interest.

Nine subjects, 69%, reported they had no change in their ability to participate in their preferred leisure activities. Three subjects reported decreased endurance in their participation of leisure activities but continued to pursue them. One subject (G) reported changes in leisure activities due to physical problems. Subject G discontinued several hobbies at the time he developed congestive heart failure and also became quite dependent with self-care. When his problems resolved he never resumed those hobbies but instead developed an interest in volunteering in the community and continued to do so on a half-time basis.

Results and Discussion

The results are presented as answers to each research question. The results and discussion include: the physical problems which affect activities of daily living; the age-related problems as they affect self-care, work, and leisure activities; and the onset of age-related problems by age and number of years post-injury. Given the findings from the first two questions the role of occupational therapy in treating the aging person with a spinal cord injury is discussed.

Question One: What are the age-related problems that affect activities of daily living which the person with complete paraplegia due to spinal cord injury experiences after a minimum of twenty years since onset?

The study group reported the following five physical problems as changes that affect activities of daily living: hand and shoulder problems (38%), increased body weight (31%), lower extremity fractures (23%), and decreased strength and endurance (54%).

The physical problems that were reported by the study group were identified in the aging literature as changes which are to be expected in the aging process. Fractures due to osteoporosis, loss of skin turgor and elasticity, gradual decrease in muscle strength, increased body weight, and biomechanical changes which occur in the joint structures are all described in the aging literature.

In the spinal cord injury literature, fractures and loss of skin integrity were reported. One study reported impaired hand function and another mentioned impaired shoulder function. Decreased strength and increased body weight have not been described in the spinal cord injury literature as a result of long-term injury or aging with a spinal cord injury. This does not mean the problems do not exist but possibly the lack of research in the subject area can account for the lack of information. Menter (1990) did report anecdotally on

the greater effort required for the aging spinal cord injured person to maintain independence.

Age-Related Problems Affecting Self-Care

Although some physical problems were reported, not all of the subjects reported impairment with activities of daily living as a result of the physical problems. To determine the importance of the reported physical problems, their impact on activities of daily living was examined.

Only one subject, 8% of the total sample, reported hand function as impairing activities of daily living. He had difficulty with fine motor control activities, such as buttoning and hand writing and also reported poor grip strength. The other four subjects perceived their symptoms of numbness, tingling, and/or pain as not affecting their activities of daily living.

Of the five subjects reporting shoulder problems three, (23%), reported that the shoulder problems impaired activities of daily living. The areas of self-care affected by the shoulder limitations were primarily transfers, with car transfers being the most difficult. One subject (C) also reported increased difficulty with wheelchair mobility and difficulty reaching which affected his leisure activities as well. Two subjects (I, E) reported pain in their shoulders but did not perceive it as limiting their participation in activities of daily living.

All four of the subjects with increased body weight (31%) reported that it impacted their ability to perform activities of daily living. Increased body weight was identified by subjects as causing difficulty with floor transfers, transfers to furniture, and bed mobility. There appears to be some occurrence of increased weight for some subjects that influences ability to perform activities of daily living but not for a large portion of the subjects studied.

Of the three subjects with lower extremity fractures, two (C and G) described significant changes in ability to transfer from chair to toilet and chair to shower / tub following the fractures. Since the literature is already clear that the underlying etiology for some fractures, osteoporosis, is present in both the spinal cord injured population and the aging population, it is important to acknowledge functional problems resulting from lower extremity fractures. Although the person with a complete spinal cord injury is nonambulatory, the study results show that functional deficits do result from the lower extremity fractures.

Over one-half of the study group reported problems with decreased strength and endurance. Decreased strength and endurance were associated with limiting transfer performance to all surfaces and wheelchair mobility. Three subjects reported that decreased strength and endurance affected their participation in leisure activities.

The areas of self-care reported as requiring increased effort, modifications, or assistance were dressing, yard work, wheelchair mobility, transfers from chair to toilet, tub, car, and furniture, and sitting time in a wheelchair.

There is some incidence of dependency with dressing but only three subjects reported difficulty. It is notable that the three oldest subjects reported this difficulty, although subject H was only 50 when he required assistance. It does not seem that one would expect a progression of needing assistance with dressing at such an early age as there were four other subjects in their middle to late 50's who had yet to develop a need for assistance with dressing.

Only one subject reported a change in ability to do yard work. As with leisure and work activities, it may be that the subjects had already adapted to their abilities and therefore as they aged the task of yard work was already modified or delegated to others. In general,

yard work was not an activity of daily living where much change occurred with the study group.

The six subjects who reported problems with wheelchair mobility reported being independent with increased effort or modifications. None of the subjects reported needing assistance with their daily wheelchair mobility. All but one subject used a manual wheelchair for mobility. Subject G began using an electric wheelchair with the onset of congestive heart failure.

Transfer performance to all surfaces was affected by age-related problems. Five subjects reported being independent but required increased effort to perform chair to car transfers. No subjects reported a need for assistance with car transfers. Two subjects reported that assistance was required to perform chair to toilet and chair to tub / shower transfers. One subject required assistance to perform chair to furniture transfers. With each type of transfer there were between three to six subjects whom reported that the transfer performance required increased effort or modification.

The study group made several modifications to maintain independence with transfer performance. Furniture transfers were modified by the subjects sitting in their wheelchairs instead of transferring to other furniture because it required less effort. Two of the subjects had eliminated the activity of chair to car transfers by getting a van with an electric wheelchair lift. For chair to tub / shower transfers some subjects began using tub benches and shower / commode chairs. Other subjects modified their activity by taking a tub bath every other day instead of daily and one subject took sink baths instead of transferring to the shower or tub.

Changes in sitting time in a wheelchair were reported by 46% of the study group. Six (46%) out of the seven subjects with multiple incidences of pressure sores required a change in the amount of time up in a wheelchair. One study in the literature supports this finding

(Nakajima & Honda, 1988). Nakajima & Honda reported a decrease in sitting time for the aging person with a spinal cord injury (1988).

Of those reporting changes in sitting time, three subjects (D, J, B) required extended bed rest, while the other three (I, C, G,) required more frequent rest periods out of the wheelchair on a daily basis. Of significance is that three of subjects are the greatest number of years post-injury for the subject group and two of the subjects (C, G) are the oldest. The difference in the group which modifies sitting on a daily basis versus requiring lengthy periods of bed rest is that one group is working on preventing skin breakdown, before a decubitus develops and the other goes to bed once a decubitus develops. The data do not clarify that incidences occur more frequently with those who are older although, in the group studied the more experienced person with a spinal cord injury worked on prevention of skin breakdown by modifying sitting time when pressure areas appeared.

Table 17 shows the functional level of the study group. Although 92% of the subjects reported physical symptoms, 77% of the subjects were independent or had no change in their ability to perform self-care activities and only 23% of the subjects actually reported a limitation in self-care requiring assistance from another person. It is significant that another 54% required modifications or required increased effort to perform some aspect of self-care. The importance is that these subjects are at risk for requiring assistance in the future if physical problems progress. The two oldest subjects (C, G) reflected the progression of assistance that can be required. Both have gradually required first environmental modifications and / or task modification and more recently physical assistance for chair to toilet and tub transfers. Menter (1990) and Becker (1990) both support the results that the aging person with a spinal cord injury may require increased effort to maintain independence.

Table 17

Functional Level Reported by Subject Group

<u>FUNCTIONAL LEVEL</u>	<u>NO. OF SUBJECTS / PER CENT</u>
INDEPENDENT / NO CHANGE	3 / 23%
INDEPENDENT W/ INCREASED EFFORT OR MODIFICATION	7 / 54%
REQUIRES ASSISTANCE	3 / 23%

Note. n = 13.

It is not possible to generalize the study results of problems in self-care to the spinal cord injury population since the sample size was small. The areas of self-care at risk for dependence with the aging person with a spinal cord injury in the study group were dressing, wheelchair mobility, transfer performance to all surfaces, and decreased sitting time. All of the reported physical problems contributed to difficulties with self-care although not large percentages of subjects reported some physical problems. It is evident that problems with skin integrity are not limited by age or number of years post-injury but an ongoing problem from the onset of the spinal cord injury.

Age-Related Problems Affecting Work

Retired and unemployed subjects were analyzed together to determine if the reasons for unemployment were related to the reported age-related problems. Table 18 shows the reasons why subjects are unemployed. Of the unemployed subjects, two subjects (50%) had not been employed since they were injured, one subject (25%) had not worked since he was four years post-injury and one subject (25%) had been out of work only six months prior to the interview and was actively applying for work. In the unemployed group only one subject (L) discontinued work due to a physical limitation which was his concern over developing skin breakdown due to required sitting time in his wheelchair while at work. This occurred four years post-injury.

Table 18

Reasons for Unemployment

	Unemployed due to injury	Unemployed due to physical problems	Unemployed due to other reasons	Total
Unemployed	2	1a	1	4
Retired	N/A	1b	1c	2
Total	2	2	2	6

Note. n = 13.

- a. Subject's perception of potential pressure sores if he worked full-time.
- b. Subject C had chronic ulcer sores.
- c. Subject G had congestive heart failure.

Two subjects (G, C) retired due to medical problems. One at approximately age 61, 37 years post-injury, due to congestive heart failure . The other subject retired at age 52, 26 years post-injury, due to chronic ankle decubiti which his physician felt was the result of trauma while at work. Although both were retired, subject C has volunteered full time at his church since he was 59 years old, 33 years post injury, and G volunteers approximately 20 hours a week in the community. Any changes these two subjects have experienced with their volunteer work will be considered in the leisure section.

Of the currently unemployed and retired subjects 1/3 was due to complicating conditions of the spinal cord injury, with both occurring relatively early post-injury (two years post and four years post). The subject who discontinued work four years post-injury chose to discontinue work to prevent decubiti while the other subject continued to work until he was 26 years post-injury despite his chronic ankle ulcers.

An element that may contribute to the effect that reported physical problems have on employment is how physically demanding or sedentary the work. Three of subjects had sedentary jobs, three had semi-physical jobs and one had a physically demanding job. Semi-physical was defined as requiring more mobility than being in the same office all day. Of seven subjects, only one (I) had a highly demanding physical job. This subject is also one who described the beginning symptoms of carpal tunnel syndrome, which he felt at the time of the interview did not limit his ability to work on his ranch.

Self-employment allowed subjects to modify their work schedules to accommodate physical problems. Although two of the subjects had problems with skin integrity and required variable periods in bed, they were both able to continue with work as they were self-employed.

The data showed that most of the changes made in work occurred within the first ten years post-injury. It seems the subjects

chose work that would accommodate their physical needs and abilities, therefore as they have aged the onset of new physical problems has not made a great impact on their work.

Age-related changes can be expected to affect work in some, but not all aging persons with spinal cord injury. Two of the subjects retired due to age-related changes, at ages 52 (C) and 61(G), while three other subjects in the same age range were continuing to work (M, H, I). The results seem to agree with the results of the Herzog et al. (1989) study that paid work remained steady until age 51.

Age-Related Problems Affecting Leisure Activities

There was very little change reported in participation in leisure activities. Only one subject reported an inability to pursue leisure activities and it was due to the onset of congestive heart failure. Once this subject recovered he developed new interests in volunteer work in the community. Three subjects reported decreased endurance while participating in leisure activities but continued to pursue them. Subject C reported decreased endurance but continued to do volunteer work on a full-time basis. Nine of the subjects, 69%, had no change in their ability to participate in leisure activities.

To determine if the type of activity might be more affected by reported physical problems types of leisure activities were divided into sedentary, semi-physical, and physical. Activities such as reading, watching television, and socializing were listed as sedentary. Semi-physical activities included light manual hobbies. Activities such as sports, camping, and woodworking were listed as physical. The leisure activities the subjects described as of greatest interest and that were participated in on a regular basis were then categorized.

Seven subjects (H, I, D, E, G, L, K) were primarily involved in sedentary leisure activities, one (C) reported participation in semi-

physical activities, and five (F, M, A, B, J) reported participation in physical leisure activities. Subject G as described in the work analysis, changed his leisure activities due to physical limitations from physical to sedentary. Many subjects had at one time tried more physical activities but generally sedentary activities were the most frequently participated in over the length of their spinal cord injury.

The results show there is very little change in leisure activities for the person with complete paraplegia due to spinal cord injury after a minimum of twenty years since onset. The results are congruous with the Kelly et al. (1986) study which reported that as one ages there is a shift from strenuous activities to more social activities. It could also be explained as the study group having adapted to their abilities by choosing more sedentary activities and therefore as they aged, leisure activities were already modified to suit the subjects' physical abilities.

Question Two: How long after the initial spinal cord injury does the person with paraplegia due to spinal cord injury develop age-related problems in activities of daily living?

In order to determine when age-related problems occur with the aging person with a spinal cord injury, onset of individual problems were examined as well as the results as a whole.

The average age of onset for reported problems involving hand function was 50.4 and the average number of years post-injury when problems began was 26.8. Subject C, who reported impaired function with activities of daily living, had a later onset than the overall average of the subjects' reporting hand problems. It is possible that there was a disease process of which the subject was unaware or did not reveal, as the researcher observed during the interview that the subject had hand tremors.

The average age of onset for shoulder problems was 53.6 and the average number of years post-injury was 30. The range of when

onset occurred both by years post-injury and age was wide with a 17 year spread for years post-injury and a 19 year spread by age. If only the subjects are examined who reported that the shoulder symptoms affected activities of daily living (H, C, J), the spread is smaller with 11 and 10 years, respectively.

The average age of onset for increased body weight problems was 46.5 and the average number of years post-injury was 23. The range of when onset occurred by years post-injury was 11 and the range of onset by age was 15.

The average age of onset with fractures was 59 and the average number of years post-injury for onset was 34. Two of the subjects with lower extremity fractures had significant limitations with transfers following the fractures. These two subjects were also the oldest and had the greatest number of years post-injury.

The average number of years post-injury when problems with decreased strength and endurance began to occur was 29 and the average age was 53. The age range was 41 to 67. The literature supports this finding of decreased strength (Whitbourne, 1985). Whitbourne reported that there is a decrease in strength from the 40 to 50 year age group to the 60 to 70 year age group (1985). There was also a wide range from 11 to 42 years post-injury.

Subjects B and G both had medical conditions which may have contributed to changes in strength and endurance. Subject B had diabetes which may have accounted for an early occurrence of decreased strength and endurance post-injury. Subject G had congestive heart failure which clearly affected strength and endurance.

Of those subjects with a work history only two, Subjects C and G reported discontinuing work due to age-related problems. Subject C retired secondary to chronic ankle ulcers at age 52, 26 years post-injury. Subject G retired at approximately age 61, 37 years post-injury due to congestive heart failure. It cannot be generalized that

at a given age or number of years post-injury that the aging person with a spinal cord injury may have difficulty with work. There were 3 subjects in their late 50's who continued to work without difficulty.

It is important to note that Subjects C and G, although not working at paid employment both did volunteer work. Subject C volunteered on a full-time basis and Subject G volunteered approximately 20 hours a week in the community. Herzog et al. (1989) supported this same finding. They found that volunteer work continued until about age 75 although paid employment only remained steady until age 51.

When the subjects were examined in terms of age and years post-injury as to choice of sedentary versus physical leisure activities there was very little difference. The average number of years post-injury for the subjects participating in sedentary leisure activities was 29 and the average age was 51. The average number of years post-injury for the subjects participating in physical leisure activities was 25 and the average age was 48. The category of semi-physical only had one subject, therefore will not be included in this comparison. In the study group, the subjects involved in physical leisure activities were just slightly younger than the average age of the person involved in sedentary activities and also had not had a spinal cord injury quite as long. It is clear that the two oldest subjects by age and number of years post-injury were not involved in physical leisure activities.

General landmark ages can be established for when physical problems occurred with the study group. The data can be examined in terms of average age of onset and average number of years post-injury for both physical problems and self-care activities. Figure 2 shows the average age of onset by age and years post-injury of age-related problems.

In examining the data in Figure 2, skin integrity was eliminated since it seems to be an ongoing problem from early onset of a spinal cord injury.

Overall, the data show that the physical problems began occurring about 23 years post-injury, with all but fractures beginning between 20 and 30 years post-injury for the study group. Average age at onset of the reported physical problems seems to be mid 40's with fractures not occurring until the late 50's.

To determine if there were functional limitations associated with the reported physical problems, onset of changes in self-care was examined. The data in Figure 3 include the subjects who are independent but for whom activities require greater effort or modification and those who require assistance. The average onset of the new problem by age and years post-injury was indicated in each area of self-care. Some of the subjects reported that there was no change in their level of performing certain activities therefore, these areas have been deleted from the chart.

Figure 2. Average onset by age and number of years post-injury of reported physical problems.

Figure 3. Status of self-care activities requiring increased effort or assistance by average age & years post-injury. Chair transfers refer to chair to furniture transfers. W/C = wheelchair.

For the study group, average years post-injury for onset of difficulties with self-care began about 26 years post-injury with changes occurring up to over 40 years post-injury. Average age at which onset of difficulties by age with self-care began was the fifties. Change in ability to perform toilet transfers did not occur until the early sixties. Although yard work is shown in Figure 3 it will not be considered in the final analysis as only one subject reported a change.

When the data from Figures 2 and 3 are compared it appears that there is an onset of functional impairment which follows the report of age-related problems. When comparing onset by years post-injury of age-related problems and self-care activities, there is a change in sitting time in a wheelchair and most transfers soon after the onset of physical problems. If age of onset of both age-related problems and self-care are compared the majority of changes occurred between age 50 and 60.

Figure 4 shows the average onset by age and post-injury for assisted self-care activities only. The results show that the average years post-injury when assistance is required is 35 and the average age of onset when assistance is required is 60. This indicated that physical problems began earlier than the actual need for assistance.

When Figures 2 and 4 are compared it is clear that age-related problems began prior to actual need for assistance with self-care. The age-related problems began about 23 years post-injury and the need for assistance with self-care began about 35 years post-injury. When examined by age, the age-related problems began in the middle 40's and the need for assistance with self-care began about age 60. The comparison of these two charts shows that there was a span of approximately 10 to 17 years when subjects were experiencing increased difficulty with self-care activities.

Figure 4. Status of assisted self-care activities by average age and years post-injury. Chair transfers refer to chair to furniture transfers.

Question Three: What is the role of occupational therapy in treating the aging person with a spinal cord injury?

Given the findings in the answer to questions one and two, the occupational therapist and other multidisciplinary professionals need to be aware of the changing status of the aging person with spinal cord injury. The results of the study show that in the first twenty years post-injury the aging person with spinal cord injury has relatively few new physical or functional deficits. But after the first 20 years, age-related problems begin to cause increasing difficulty with self-care. This indicates a need for periodic reassessment of physical status and functional status. The person with a spinal cord injury who is over age 50 and over 30 years post-injury appears to be at the greatest risk for having increasing difficulty with self-care.

The aging person with spinal cord injury may require education to adapt to new methods of self-care to maintain independence. Activity modifications may also be needed so that techniques for self-care that contribute to age-related problems can be changed. Intervention may be needed to evaluate the need for new adaptive equipment such as, use of a transfer tub bench instead of transferring to the bottom of the bathtub.

Energy conservation and work simplification techniques may need to be reassessed since over 50% of the subjects reported that increased effort was required to perform some aspects of self-care. For example, the occupational therapist could assess the number of transfers made throughout the day and help the client determine how to decrease the number of transfers without limiting activity. Patterns of self-care, work and leisure activities could be assessed to determine those which could be modified or eliminated.

Although the results of this study did not reflect a significant problem with hand function there was some incidence of shoulder weakness and pain which impaired transfer ability. Because of this,

energy conservation and work simplification techniques should also be considered during the rehabilitation phase to prevent problems that may be due to overuse.

The results of the study indicated that the person with a spinal cord injury requires periodic reassessment of the wheelchair cushion used to prevent skin breakdown. Several different findings of this in the study suggest this need. The subjects had ongoing problems with skin integrity and six subjects required a change in their sitting time in the wheelchair. Other subjects indicated that transfers from their wheelchair onto other furniture were fewer as they aged. Because of this, the subjects were spending more time in their wheelchairs, therefore they required a wheelchair cushion which would prevent skin breakdown.

Over half of the subjects reported decreased strength and endurance as a problem and that self-care activities were requiring increased effort to maintain independence. Thirty-percent of the subjects reported that increased weight was affecting transfer ability. The occupational therapist needs to be aware of clients who are overweight and the effect this may have on mobility. There is a need for exercise programs for the aging person with a spinal cord injury to help maintain or lose weight and also to maintain strength and endurance. Nutritional education by a dietitian is also indicated.

The occupational therapist can serve as a resource person for the client interested in expanding leisure interests. During the interviews several subjects reported not being aware of new devices that are available to make participation in sports more accessible for the person with a spinal cord injury. When reassessing for self-care status, the occupational therapist will need to include questions regarding the client's status with leisure activities.

In the area of work, there are several roles for the occupational therapist. The first is to help the client develop skills required for self-employment. Self-employment was an option many of the

subjects chose but often did not settle into until 10 -15 years post-injury. It may be that if subjects were taught the skills needed for self-employment as part of the rehabilitation process, employment would have begun earlier.

It would appear that some of the subjects could have benefitted from a work hardening program following rehabilitation. It took many of the subjects several years to realize that they could not return to work their previous work. Other subjects were unsure how much they could accomplish physically and so did not return to work. Use of a work tolerance screening and a work hardening program could have helped the subjects to evaluate their capabilities in a controlled environment.

The occupational therapist can be an advocate for the client who would like to work for others and is not interested in being self-employed. The study showed that many subjects were self-employed. This raised the question of whether this was due to social barriers which may make work inaccessible for the person with a spinal cord injury. The occupational therapist should be available to do work-site evaluations to eliminate as many barriers as possible when a person is returning to work or starting a new job.

It took as many as ten years for most of the subjects to adjust to their spinal cord injury. Some of the problems subjects' reported during the first 10 years following spinal cord injury were unemployment or unsteady work, alcohol abuse, and divorce. The implication as occupational therapists is that when a client is seen either in the hospital or on an outpatient basis, even though they are not "newly injured" we must be aware that there are many changes to which the individual is adjusting and therapists need to be sensitive to these ongoing changes. Support groups aimed at serving the person with spinal cord injury who has been injured for several years may help with adjustment.

Conclusions

It is not possible to generalize the study results due to small sample size although there are some similarities between the study group and the spinal cord injury population

Twelve of the 13 subjects reported one or more physical problems. The age-related physical problems included hand and shoulder impairment, increased body weight, lower extremity fractures, and decreased strength and endurance. Problems with skin integrity were a continuous problem from the onset of spinal cord injury therefore not considered age-related.

Although physical problems were reported there was not always a resulting functional deficit. Hand problems impaired only one subject (8%); shoulder problems impaired three subjects (23%); increased body weight impaired four subjects (31%); fractures impaired two subjects (15%); and skin integrity impaired 77% of the subjects but more specifically five subjects (38%), had ongoing limitations with sitting time in a wheelchair.

Overall the study results showed that the person with complete paraplegia due to spinal cord injury after a minimum of twenty years since onset was generally independent but: required increased effort with transfer performance to all surfaces and wheelchair mobility; required increased effort for leisure activities; and has had little change in work. More specifically the areas of self-care which required physical assistance from another person were dressing and transfer performance from chair to the furniture, tub / shower, and toilet. Sitting time in a wheelchair was also limited with almost one-half of the subjects.

There was no conclusive evidence that the physical problems reported can be expected to affect the aging person with spinal cord injury in their work ability. Although two subjects (C, G)

discontinued work due to physical problems there were three subjects (M, H, I) in the same age range and years post-injury, who had not discontinued work.

The study results showed there was only a slight change with the study group's participation in leisure activities. Four subjects reported problems with leisure activities. Only one subject discontinued his activities and the other three found it required increased effort to participate in their usual leisure activities due to decreased strength and endurance. There was some evidence to indicate that those involved in more physical leisure activities were slightly younger than those participating in more sedentary activities. Since the data show that most of the changes made in work and leisure occurred within the first ten years post-injury it may be that the study group chose work and leisure activities which would accommodate their physical needs and abilities and therefore did not experience limitations as physical changes occurred with the aging process.

The study results showed that the person with paraplegia due to spinal cord injury developed age-related problems about 23 years post-injury but activities of daily living were not affected until 26 - 40 years post-injury. It is clear that age-related problems began prior to actual need for assistance with self-care. The age-related problems began about 23 years post-injury and the need for assistance with self-care began about 35 years post-injury. When examined by age, the age-related problems began in the middle 40's and the need for assistance with self-care began about age 60. There was a span of approximately 10 to 17 years when subjects were experiencing increased difficulty with self-care activities.

Overall 77% of the group studied were independent with self-care and only three subjects (23%), required assistance with self-care. These three subjects required assistance with specific tasks

throughout the day. Their wives were able to assist them and none of the subjects' level of care had yet to result in a need for full-time care.

Over 50% of the subjects reported that activities of daily living required increased effort or modification to maintain independence. Although it cannot be generalized to the aging spinal cord injury population because the sample size is small, these results provide direction for further study. Both clinical and personal observations were made in the literature review that the aging person with a spinal cord injury may be requiring increased effort to maintain independence. If this is a pattern for the aging person with a spinal cord injury there are implications for periodic reassessment of activities of daily living and strategic interventions to maintain independence.

The study results indicate that there is a role for the occupational therapist beyond the initial rehabilitation phase in providing services for the aging person with a spinal cord injury. Periodic reassessment of the physical and functional status of the aging person with a spinal cord injury is needed. Reassessments may indicate problem areas in self-care, work, and leisure which require further client education. Education regarding activity modifications, energy conservation and work simplification techniques may be indicated. Reassessments may also indicate the need for new adaptive equipment to improve ability to perform self-care and leisure activities. The need for periodic wheelchair cushion evaluations is also needed as the study results show that problems with skin integrity is an ongoing problem.

The occupational therapist should also be aware of the potential areas related to work that need addressing. In order to facilitate the client's ability to return to work, work tolerance screenings, work hardening programs, and job site evaluations may be indicated. Exercise programs to maintain strength and endurance and manage body weight are also needed. When treating

the aging person with a spinal cord injury the occupational therapist must be aware that there are many adjustments the individual is making not just during rehabilitation but for many years following the onset of spinal cord injury.

In conclusion, the group studied appeared to have some physical problems and had some areas of self-care affected by aging. The group in general was remarkably independent with work, self-care, and leisure activities and able to make environmental and activity modifications as needed to maintain independence.

CHAPTER 5

PROFESSIONAL IMPLICATIONS, RECOMMENDATIONS AND SUMMARY

Implications for the Practice of Occupational Therapy

The study results indicate that there is a need for occupational therapists and other multidisciplinary professionals to be aware of the changing status of the aging person with spinal cord injury. The study shows that in the first twenty years post-injury the aging person with spinal cord injury has relatively few new physical or functional deficits. But after the first 20 years, age-related problems begin to cause increasing difficulty with self-care. This indicates a need for periodic reassessment of physical status and functional status. The person with a spinal cord injury who is over age 50 and over 30 years post-injury appears to be at the greatest risk for having increasing difficulty with self-care.

There is a role for the occupational therapist beyond the initial rehabilitation phase in providing services for the aging person with a spinal cord injury. Periodic reassessment of the physical and functional status of the aging person with a spinal cord injury may indicate problem areas in self-care, work, and leisure which require further client education. Education regarding activity modifications, energy conservation and work simplification techniques may be indicated. Reassessments may also indicate the need for new adaptive equipment to improve ability to perform self-care and leisure activities. The need for periodic wheelchair cushion

evaluations is also needed as the study results show that problems with skin integrity is an ongoing problem.

The occupational therapist needs to also be aware of the potential areas related to work that need to be addressed. In order to facilitate the client's ability to return to work, work tolerance screenings, work hardening programs, and job site evaluations may be indicated. Exercise programs to maintain strength and endurance and manage body weight are also needed to maintain independence with self-care, work, and leisure activities.

When treating the aging person with a spinal cord injury, the occupational therapist needs to be aware that there are many adjustments the individual is making not just during rehabilitation but for many years following the onset of spinal cord injury. It took as many as ten years for most of the subjects to adjust to their spinal cord injury. Some of the problems that subjects' reported during the first 10 years following spinal cord injury were unemployment or unsteady work, alcohol abuse and divorce. The implication for occupational therapists and for other health care professionals is to be aware that there are many changes to which the individual is adjusting and to be sensitive to these ongoing changes even though the client is not "newly injured."

Implications for Further Research

Overall, there were more questions generated from the study than answered by the study. One of the most obvious needs for further research is to study a larger sample of aging persons with a spinal cord injury and to include persons with quadriplegia. This would allow for more generalization with the results.

There is a need to look at work patterns in terms of the nonservice connected veteran and the service connected veteran. The

researcher was surprised to find that more service connected veterans worked than nonservice connected veterans in the study group. This may not be an accurate depiction of the veteran population with spinal cord injury as the sample size was small. But several questions arise: Who tends to be employed, the nonservice connected veteran or the service connected veteran?; How does service connected status contribute to employment versus unemployment?; Are more service connected veterans self-employed?; and what type of skills are needed for self-employment since this seems to fit many people's lifestyle?

A question that arose throughout the study was whether age-related problems can be separated from problems resulting from overuse. Overuse syndrome is a term used to describe a variety of physical symptoms which result from repetitive activities. A study that would separate the problems of overuse versus aging would be helpful in terms of prevention and treatment.

Many questions and potential areas of research regarding adjustment to disability arose from the study. The first is to examine the factors that contribute to "adjustment" and to study how long "adjustment" takes. Of course, the term adjustment would need to be clearly defined. The researcher was surprised to find that most of the subjects took at least 10 years after injury before they were settled into a job or their life style settled down. Most of the subjects reported 5 to 10 years of heavy drinking following their spinal cord injury. This raises the question of whether heavy drinking is a trend for the spinal cord injury population in general, only trend of the study group, or a trend of veterans only? Research regarding the type of support needed and available for the person with spinal cord injury who is still adjusting to his / her disability is also needed.

There were many positive changes that occurred with the subjects studied but because the study was problem oriented they were not reported. A study focusing on the positive changes that

occur with the aging / maturing person with spinal cord injury would be interesting. Most of the subjects had a positive attitude and felt that their lives had improved over the first 20 years post-injury. A positive view of aging and living with a spinal cord injury is important for health care workers and for persons with spinal cord injury.

A study that examines aging as a maturation process is needed. The physical, social and mental changes that occur with aging would present a more holistic process the aging person with spinal cord injury is experiencing.

Recommendations for Improving this Study

There were several problems with the design of this study. The results cannot be generalized, the researcher held certain biases, and the term age-related did not allow for distinction between age-related and overuse symptoms.

Small Sample

The small size of the study group and the fact that the subjects were all male veterans makes it impossible to generalize the results. It is possible that because the subjects all have readily available health care through the Veterans Administration Medical Centers they are healthier than the general population of aging persons with spinal cord injury. But since 25% of the spinal cord injury population are veterans the results of the study may be suggestive for that group.

As the knowledge base for care of the spinal cord injured person has expanded since the 1960's it may be that the oldest subjects' experiences are not comparable to those of people who are now newly injured and will be aging. The post-injury experiences that the subjects discussed were not the typical acute care or rehabilitation experience which the average person with spinal cord

injury has now. The length of hospital stay was often over a year and a half and many of the subjects had decubitus ulcers from their initial care. Now the stay for rehabilitation is usually less than 6 months and prevention of decubiti begins immediately. The change in emphasis on prevention of decubiti is critical as the Nakajima (1988) study showed that the initial area of skin breakdown is the one that often reoccurs as the person with spinal cord injury ages. The subjects in this study also seemed to reflect that the area of skin breakdown that occurred early after injury also caused reoccurring problems. As care of the person with spinal cord injury has advanced, today's aging person with spinal cord injury may report different age-related problems than the person with a recent spinal cord injury will report when he/she ages.

Researcher Bias

The researcher held a bias toward a more in-depth activity analysis of self-care activities than of work or leisure. If a subject reported a self-care activity as being more difficult, the researcher would ask detailed questions regarding how and why the activity was more difficult but did this less often with discussions of work and leisure. If a more in-depth activity analysis had been done on work and leisure the researcher expects more subjects would have fallen into the the category of independent with increased effort or a need for modification.

Definition of Age-Related

The broadness of the definiton for age-related was a constant concern of the researcher. Age-related changes were defined as the physical changes due to either genetic predisposition such as, diabetes or as a result of factors such as, stress, disease, or poor nutrition (Wantz, 1981). The definition is so broad and general that

all of the physical problems reported by the subjects were defined as age-related. In hind sight, the researcher was more specifically looking for problems due to overuse but the definition of age-related and the design of the study did not allow for this distinction.

In order to allow for a distinction between what could be aging problems versus overuse problems, the study would need to be designed differently. If the study had been designed with 2 groups, one injured in their 20's and one over 40 or children with spinal cord injury, it would have helped to determine the problems related to overuse and those which were the result of aging.

Design of the Study

The researcher's bias also contributed to some difficulty with the design of the study. The primary emphasis of the study was to identify problems with the expectation that there would be a decrease in activity over time. The study did not allow for exposure of information on improvement the subjects had experienced, especially during the first 20 years post-injury. The study examined aging only in a physical sense which is a narrow perspective, as opposed to looking at aging as a maturation process which includes physical, social, and mental processes. The researcher had assumed that most of the changes experienced would be a result of new physical problems. More often changes in work, leisure and self-care occurred due to mental, emotional, or social changes. Because of this, much of the information the subjects shared regarding changes they had experienced was not included.

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APPENDICES

APPENDIX A
ACTIVITIES OF DAILY FUNCTIONAL ASSESSMENT

BED MOBILITY	Date	Date
1. Trigger call bell		
2. Operate bed controls		
3. Reach trapeze, loops, headboard		
4. Rolls left w/wo bed rails		
5. Rolls right w/wo bed rails		
6. Turns self w/wo covers		
7. Rolls supine		
8. Rolls prone		
9. Moves up in bed		
10. Comes to straight leg sitting		
11. Maintains straight leg sitting		
12. Assumes crossed leg sitting		
13. Positions Pillows		
14. Moves legs to edge of bed		
15. Brings legs to bed		
16. Maintains sitting on edge of bed		
17. Performs push-up on edge of bed		
18. Can push-up/slide on edge of bed		
19. Places/removes sliding board		
SKIN CARE		
20. Recites basic anatomy/phys. of skin		
21. Names all boney prominences		
22. Uses stand/hand/quad mirror		
23. Inspects anterior surfaces		
24. Inspects lateral surfaces		
25. Inspects posterior surfaces		
26. Uses blanch technique		
27. Instructs others in skin care		
DRESSING		
28. Put on socks/hose		
29. Remove socks/hose		
30. Put on trousers/skirt/dress		
30a Dress/undress in w/c		
31. Remove trousers/skirt/dress		
32. Put on pullover garment		
33. Remove pullover garment		
34. Put on front-opening garment		

35. Remove front-opening garment		
36. Button/unbutton		
37. Zip/unzip		
38. Snap/unsnap		
39. Buckle/unbuckle		
40. Put on shoes/remove shoes		
HYGIENE		
41. Turn faucet on/off, lever/knob		
42. Hold, wring-out washcloth, adapted		
43. Handle soap, rope		
44. Bathe ant. UE/torso in bed/sink/tub		
45. Bathe post, UE/torso in bed/sink/tub		
46. Bathe LE in bed/sink/tub		
47. Shampoo hair		
48. Pick up toothbrush/toothpaste		
49. Remove/replace toothpaste cap		
50. Squeeze toothpaste		
51. Brush teeth/dentures w regular/elec.		
52. Pick up razor, adapted		
53. Shave safety/electric razor		
54. Pick up comb/ brush		
55. Comb/brush hair		
56. Apply deodorant		
57. Trim/clean fingernails		
58. Trim/clean toenails		
59. Apply make-up		
BLADDER MANAGEMENT		
60. Handle urinal		
60a Clean leg/drainage bag		
61. Apply skin cement		
62. Apply condom		
63. Cut/apply tape		
64. Connect/disconnect drainage bags		
65. Put on/remove leg bag		
66. Drain leg bag w/wo devices		
67. Tap bladder, knowledge/physiology		
BOWEL MANAGEMENT		
68. Remove clothing, w/c to toilet		
69. Transfer to/fr. toilet seat w/o clothing		

70. Locate anal opening		
71. Put on gloves		
72. Insert suppository		
73. Apply lubricant to gloves		
74. Manual stimulation		
75. Cleanse self		
76. Don clothing, w/c to toilet		
TRANSFERS		
77. To/fr. bed via lift/ovrhd/bd/manual		
78. To/from toilet seat via board/manual		
79. To/from com. chair via board/manual		
80. To/from tub bench via lift/bd/manual		
81. To/from bottom of tub via lift/manual		
82. To/from shower via bd/manual/lift		
83. To/from car/van via board/manual/lift		
84. To/from low surface via lift/bd/manual		
WHEELCHAIR MOBILITY		
85. Remove/replace armrest		
86. Remove/replace footrest/leg rest		
87. Push up/weight shift		
88. Manual w/c rims: std, plastic, proj.		
89. Elec. w/c: hand, chin, pneumatic drive		
90. Propel on flat level surface		
91. Propel up/down 10" incline		
92. Propels w/c on grass/gravel		
93. Manages curbs/cutouts		
94. Manage door sill/open doors		
95. Manage elevator		
96. Fold/unfold w/c		
97. Load/unload w/c to/from car/van		
98. Community mobility on public bus		

Note: Used by permission of Department of Occupational Therapy,
Palo Alto Veterans Administration Medical Center.

APPENDIX B

SUBJECT CONSENT FORM

SUBJECT CONSENT FORM

You are invited to participate in a study about adults with spinal cord injury. I hope to learn about any problems the aging person with a spinal cord injury may have with activities of daily living. You were selected as a possible participant in the study because you have had a spinal cord injury for at least 20 years, are over 40 years of age, and have complete paraplegia.

If you decide to participate, I will meet you at a mutually agreeable time and location, and will be asking you questions about your ability to perform activities of daily living in the past and in the present. Interviews will be tape recorded so that I will be able to more accurately record all that you have to tell me, therefore making the study more accurate. Interviews will last between 2 1/2 to 5 hours and may be completed in one or more meeting times.

I CANNOT AND DO NOT GUARANTEE OR PROMISE THAT YOU WILL RECEIVE ANY BENEFITS FROM THIS STUDY. Other than the time you give to complete the interview, there will be no cost to you. You will not receive payment for your participation.

Persons who participate in a medical experiment are entitled to certain rights. These rights include but are not limited to the subject's right to : be informed of the nature and purpose of the experiment; be given an explanation of the procedures to be followed in the medical experiment, and any drug or device to be utilized; be given a description of any attendant discomforts and risks reasonably to be expected, if applicable; be given a disclosure of any appropriate alternatives, drugs or devices that might be advantageous to the subject, their relative risks and benefits; be informed of the avenues of medical treatment, if any available to the subject after the

experiment if complications should arise; be given an opportunity to ask questions concerning the experiment or the procedures involved; be instructed that consent to participate in the medical experiment may be withdrawn at any time and the subject may discontinue participation without prejudice; be given a copy of the signed and dated consent form; and be given the opportunity to decide to consent or not to consent to a medical experiment without the intervention of any element of force, fraud, deceit, duress, coercion or undue influence on the subject's decision.

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. If you give your permission by signing this document, I plan to disclose information you have given me regarding your experience with a spinal cord injury. However, no names will be mentioned, and I do not anticipate that it will be possible for anyone to identify you as distinguished from others participating in the study. In the interest of public safety, patient information will be provided to Federal and regulating agencies as required.

My study will be presented to the Department of Occupational Therapy at San Jose State University, and will be submitted for publication in a professional journal. Any data that may be published in scientific journals will not reveal the identity of the subjects.

Your decision whether or not to participate will not prejudice your future relations with the Palo Alto Veterans Administration Medical Center or San Jose State University. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without prejudice.

All forms of medical diagnosis and treatment--whether routine or experimental--involve some risk of further injury. In spite of all precautions, you might develop medical complications from participating in this study. If such complications arise, the researchers will assist you in obtaining appropriate medical treatment but this study does not provide financial assistance for additional medical or other costs. Additionally, Stanford University Medical Center is not responsible for research and medical care by other institutions or personnel participating in this study. You do not waive any legal rights by signing this form. For further information, please call (415) 723-5244 or write the Medical Center for the Protection of Human Subjects at Medical School Office Building, Room C-05IJ, Stanford, California 94305. In addition, if you are not satisfied with the manner in which this study is being conducted, you may report any complaints to the same telephone number and address.

In the unlikely event you are injured as a result of participation in this study, Palo Alto Veterans Administration Medical Center will furnish humanitarian emergency medical care (for non-veteran participants) or medical care (for veteran participants) as provided by federal statute. Compensation for such injury may be available to you under the provisions of the Federal Tort Claims Act (for non-veteran and veteran participants) and/or 38 U.S.C. (for veteran participants). For further information, contact the Veterans Administration District Counsel at (415) 556-4656.

If you have any questions, please ask me directly. If you have additional questions later I will be happy to answer them and can be reached at 415-651-9728. If you would like a copy of this form, please ask me.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION, THAT YOU HAVE DISCUSSED THIS STUDY WITH THE PRINCIPAL INVESTIGATOR AND HIS OR HER STAFF, AND THAT YOU HAVE DECIDED TO PARTICIPATE BASED ON THE INFORMATION PROVIDED. A copy of this form is available to you upon request.

Signature of Participant

Date

Signature of Investigator

Date

Signature of Witness

Date

APPENDIX C
LETTER TO SUBJECTS

October 19, 1988
43528 Southerland Way
Fremont, CA 94539

«name»
«street»
«city», «state», «zip»

Dear Mr. or Ms. «lastname»,

I am an occupational therapist currently working on research regarding the spinal cord injured person and aging. I am interested in learning how the person who has had a long term spinal cord injury (paraplegia) for over 20 years and is at least 40 years old is managing daily activities including self-care, work and leisure. I am contacting people who potentially meet the above criteria to arrange an interview. Through in-depth interviews I hope to learn what, if any, are the problems the aging spinal cord injured person is experiencing so that I as a health professional can provide the appropriate services.

This area of research has been of interest to me since I worked at the Palo Alto Veterans Administration Medical Center (PAVAMC) several years ago. Since then I have gone on to get my Master's Degree and have decided to research this area for my thesis. The research plan has been approved by the Palo Alto Veterans Administration Medical Center, Stanford University Human Subjects Committee, and San Jose State University Occupational Therapy Department and Human Subjects Committee.

You were selected after a review of the PAVAMC Spinal Cord Injury Center outpatient clinic records as a person who is at least 40 years

old and has paraplegia due to a spinal cord injury for a minimum of 20 years. I would appreciate your participation in this research in the form of an interview with me. The interview will take a couple of hours and can be arranged at your convenience either on a week day or weekend at a location that is convenient for you. I have included a response form and return envelope. Please return the completed response form whether or not you are interested in participating in this research. If you agree to meet with me I will contact you in November to arrange a meeting time.

If you have any questions please call me at home at 415-651-9728. If I do not answer please leave a message on the answering machine and I will return your call. I would appreciate your response as soon as possible. Thank you.

Sincerely,

A handwritten signature in cursive script that reads "Diane Foti, O.T.R.".

Diane Foti, O.T.R.

APPENDIX D
RESPONSE FORM FROM SUBJECTS

PLEASE RETURN THIS FORM WHETHER OR NOT YOU ARE WILLING TO PARTICIPATE IN THE RESEARCH DESCRIBED IN THE ATTACHED LETTER. THANK YOU.

PLEASE CHECK THE APPROPRIATE BOX BELOW TO INDICATE YOUR RESPONSE.

☐

I AM INTERESTED IN BEING INTERVIEWED.

☐

I AM NOT INTERESTED IN BEING INTERVIEWED.

IF YOU ARE WILLING TO BE INTERVIEWED PLEASE FILL IN THE FOLLOWING INFORMATION TO ASSIST ME IN CONTACTING YOU.

THE FOLLOWING ADDRESS AND PHONE NUMBER IS CORRECT:

☐

YES

☐

NO

«name»

«street»

«city», «state» «zip»

«phone»

CORRECT ADDRESS AND PHONE NUMBER IF THE ABOVE IS INCORRECT:

IN ORDER TO CONFIRM THAT YOU MEET THE CRITERIA
NEEDED FOR THE STUDY PLEASE CHECK THE APPROPRIATE
BOX BELOW.

I am over 40 years old ☐ YES ☐ NO

I have had a spinal cord injury for at least 20 years ☐ YES
☐ NO

My spinal cord injury resulted in paraplegia ☐ YES ☐
NO

THANK YOU,

DLANE FOTI, O.T.R.

APPENDIX E
CONFIRMATION LETTER TO SUBJECTS

February 5, 1989
43528 Southerland Way
Fremont, CA 94539

«name»
«street»
«city», «state», «zip»

Dear Mr. or Mrs. «lastname»,

This letter is to confirm our interview time and to give you a copy of the Human Subject's consent form. The time and date we agreed to meet will be «day», «date» at «time». If you need to change this please let me know. My home phone number is 415-651-9728.

I hope you will take the time to read the consent form required for this research project before we meet. All research involving people requires each participant to sign a consent form. Since this study is connected to the Veterans Administration and Stanford it is quite lengthy. Please don't let this discourage you from participation in the study as we will only be talking and not doing anything that could harm you.

I also wanted to let you know I would appreciate tape recording our conversation. Since I will be meeting many people a tape recording will make the final summary of all of the interviews more accurate. All information gathered in the interview will remain confidential and the tapes will be erased when the study is completed.

If you have any questions prior to our meeting please call me. Thank you.

Sincerely,

Diane Foti, O.T.R.

Diane Foti, O.T.R.

APPENDIX F
QUESTIONNAIRE

Demographic Information

Name_____

Address_____

Age_____ Date of Birth_____

Date of spinal cord injury _____

Other medical problems
_____How old were you when you had your initial spinal cord injury?
_____Did you go through a rehabilitation program following your spinal
cord injury? _____yes _____no

Marital status ___Married ___Divorced ___Single ___Widow

Living Situation ___Alone ___Spouse ___Relative ___Friend
___Other (explain)_____

Do you have attendant care? ___yes ___no

If yes, how many hours a week? _____

How many years have you had attendant care? _____

Questionnaire

1. Do your responsibilities at home include any of the following?

yes no

---- ____ cooking

---- ---- meal clean-up

---- ---- laundry

---- ---- shopping

---- ---- cleaning house

---- ---- other

2. If you are responsible of any of the above tasks has there been
any change in your ability to complete the tasks?

yes no

---- ____ cooking

---- ---- meal clean-up

---- ---- laundry

---- ---- shopping

---- ---- cleaning house

---- ---- other -----

3. Do you drive? ☐yes ☐no

4. If yes, have you had to modify your driving equipment or seat to
accommodate to any physical limitations you are having?
☐yes ☐no

What type of driving modifications have you made? _____

5. Has your endurance while driving changed? ☐yes ☐no
If so, how?

6. Do you use public transportation? ☐yes ☐no

7. If so, do you have any physical difficulties using public
transportation? ☐yes ☐no
If yes, what are the difficulties? _____

8. Do you work (either volunteer or paid position? ☐yes ☐no

9. If so, do you work outside of the house or in your home? _____
Job/ Position _____

10. Have you had to change your work habits or surroundings due to
any new physical limitations? ☐yes ☐no
If yes, in what way? _____

11. How many hour a day do you work? _____

12. How many hours are you able to sit up in your wheelchair? ____
Has this amount of time changed? ☐yes ☐no

In what way? _____

13. What do you do for fun? _____

14. Has the type of recreation or hobbies you participate in changed
due to any new physical limitations? ____yes ____no

If yes, in what way? _____

15. Have you modified your home or work to assist you with self-care
activities, work, or hobbies? ____yes ____no

If yes, in what way? _____

16. Have you changed the way you do other activities that we have not
talked about? ____yes ____no

What activities? _____

What type of changes have occurred? _____

APPENDIX G
APPROVAL FOR USE OF ACTIVITIES OF DAILY FUNCTIONAL
ASSESSMENT

3431 Middlefield Road
Menlo Park, CA 84025
January 26, 1987

Mrs. Eugenia Martino
Occupational Therapy Supervisor
Palo Alto Veterans Administration Medical Center
3801 Miranda Avenue
Palo Alto, CA 94304

Dear Mrs. Martino,

I am currently writing my thesis proposal for the Master of Science degree in occupational therapy. I plan to study the aging spinal cord injured population and would like to use the Palo Alto Veterans Administration Occupational Therapy Activities of Daily Living Functional Assessment that is used in the Spinal Cord Injury Service. I have enclosed a form that will indicate whether the Activities of Daily Living Functional Assessment can be used in my thesis study. Please return the enclosed form indicating whether I may use the assessment. If you have any questions my phone number is 415-365-2541. Thank you.

Sincerely,

Diane Foti, O.T.R.

Diane Foti, O.T.R.

X Diane Fotl, O.T.R. has permission to use the Activities of Daily Living Functional Assessment used at Palo Alto Veterans Administration, Spinal Cord Injury Service for her thesis.

 Diane Fotl, O.T.R. does not have permission to use the Activities of Daily Living Functional Assessment used at Palo Alto Veterans Administration, Spinal Cord Injury Service for her thesis.

Eugenia I. Martino, DPH, OTR

Eugenia Martino, Occupational Therapy Supervisor
Palo Alto Veterans Administration Medical Center

APPENDIX H
RESEARCH & DEVELOPMENT APPROVAL

SCHOOL OF MEDICINE
STANFORD UNIVERSITY, STANFORD, CALIFORNIA 94305

INDER PERKASH, M.D.
PARALYZED VETERANS OF AMERICA
PROFESSOR OF SPINAL CORD INJURY
MEDICINE

May 11, 1987

Diane Foti, O.T.R.
3431 Middlefield Road
Menlo Park, California 94025

Dear Diane:

In response to your letter dated March 30, 1987, that you are going to work on your masters thesis at San Jose State University on the status of activities of daily living secondary to spinal cord injury in aging persons, we would be delighted to have you study on this service.

However, even for an unfunded project you will need to submit a written proposal to RRand (Rehabilitation Research and Development) Committee at this medical facility. For additional information on the format you may want to contact RRand Center at (415) 493-5000, Extension 5465.

Thanks and wishing you the best.

Sincerely,

INDER PERKASH, M.D.
Professor of Surgery
Chief, Spinal Cord Injury Center (128)
Veterans Administration Medical Center
3801 Miranda Avenue
Palo Alto, California 94304

Memorandum

Date : February 3, 1988
To : Inder Perakash, M.D. (128)
Diane Foti, O.T.R.
From : Research Administration (151A)
Subject : Results of R & D Committee Meeting

1. Your research proposal, entitled
STATUS OF ACTIVITIES OF DAILY LIVING WITH THE AGING SPINAL CORD-INJURED PATIENT

was approved at the Research and Development (R&D) Committee meeting of
January 21, 1988

2. The Committee made the following comments:

None

3. Please notify this office when this project is initiated and/or funded.

BARBARA GLEASON
Administrative Officer

cc: Service Chief ()

NOTE: Application is pending funding by N/A