

CONCERNS OF SPINAL CORD INJURED AND
THEIR PARTNERS REGARDING
SEXUAL ACTIVITY AND FUNCTION

A THESIS
SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF MASTER OF SCIENCE
IN THE GRADUATE SCHOOL OF THE
TEXAS WOMAN'S UNIVERSITY

COLLEGE OF NURSING

BY
CYNTHIA C. CONNOR, R.N., B.S.

DENTON, TEXAS

AUGUST 1979

The Graduate School
Texas Woman's University

Denton, Texas

July 10, 1979

We hereby recommend that the thesis prepared under
our supervision by Cynthia C. Connor, R.N., B.S.
entitled CONCERNS OF SPINAL CORD INJURED AND
THEIR PARTNERS REGARDING
SEXUAL ACTIVITY AND FUNCTION

be accepted as fulfilling this part of the requirements for the Degree of
Master of Science.

Committee:

Shirley M. Jones

Chairman

Accepted:

Margaret J. Ferrell

Dean of The Graduate School

TABLE OF CONTENTS

LIST OF TABLES	iv
ACKNOWLEDGEMENTS	v
Chapter	
I. INTRODUCTION	1
Statement of the Problem	2
Purposes	2
Background and Significance	3
Hypothesis	8
Definition of Terms	8
Limitations	9
Delimitations	9
Assumptions	10
Summary	11
II. REVIEW OF LITERATURE	13
Historical Implications of Spinal	
Cord Injury	14
Identity and the Personality Structure	18
The identity self	19
Gender identity	20
Body image	22
Sexual Response Cycle	24
Male sexual response cycle	25
Female sexual response cycle	26
Erection and ejaculation	27
Orgasmic experience	29
Male and Female Fertility	30
Marital Status	31
Facilitating Sexual Adaptation	33
III. PROCEDURE FOR COLLECTION AND	
TREATMENT OF DATA	40
Setting	40
Target Population	41
Sample	42
Ethical Considerations	43

Tool	44
Data Collection	46
Treatment of the Data	48
Individual subject responses	48
Disagreement and agreement between partners	48
Selected descriptive factors	49
Summary	49
IV. ANALYSIS OF DATA	52
Description of the Sample	52
Analysis of Data	55
Psychosexual elements	59
Sexual behavior patterns	62
Feelings about sexual relationships	65
Relationship of Three Selected Disability Factors to Spinal Cord Injured Subject Responses	69
Summary of Findings	69
V. SUMMARY, CONCLUSIONS, IMPLICATIONS, AND RECOMMENDATIONS	72
Summary of the Study	72
Conclusions	77
Implications	79
Recommendations for Future Study	81
APPENDIXES	83
REFERENCES CITED	100
SELECTED BIBLIOGRAPHY	107

LIST OF TABLES

1.	Characteristics of Spinal Cord Injured Subjects	53
2.	Individual Subject Responses to Index of Sexual Adjustment Questions	57
3.	Comparison of Couple's Interest in Sex	59
4.	Comparison of Couple's Feelings about the Importance of Discussing Sex Function with Spinal Cord Injured Individuals	60
5.	Comparison of Couple's Feelings about Desirability as Sexual Partners	61
6.	Couple's Attempts to Engage in Sex Relations After Injury	62
7.	Comparison of Couple's Perceptions about the Regularity of Sexual Contact	63
8.	Comparison of Couple's Feelings about Physical Problems During Sex Relations	64
9.	Comparison of Couple's Pre-Injury Sexual Satisfaction	65
10.	Comparison of Couple's Feelings about Sex Relations Since Injury	66
11.	Comparison of Partner Satisfaction	68

ACKNOWLEDGEMENTS

The following people made valuable contributions to the completion of this project. My gratitude goes to all of them.

To the members of my thesis committee,
Beth Vaughan-Wrobel and Betty Wade;

To the chairman of my thesis committee,
Geraldine Goosen;

To G. F. Biesel, Ph. D. and Rick Clary
who assisted with the statistical analysis;

To Sara E. Allison, R.N., Ed. D., a special
thanks for her critical guidance throughout
the writing of the paper;

And finally, to my parents and friends who
offered support in ways too numerous to list.

CHAPTER I

INTRODUCTION

In an age of the "new sexual freedom" and the "sexual revolution," Western Society is turning toward the issue of acknowledgment and acceptance of sexual expression. Sexual wholeness has come to encompass both feelings and behavior as inseparable.

Sexual wholeness has also been associated with full physical function while altered degrees of physical function have been designated as incomplete. Able-bodied individuals have this sexual wholeness, while disabled individuals have had the stigma of "incomplete" applied to all facets of their lives. Spinal cord injured individuals are very characteristic of this group. Instead of emphasis being placed on the remaining physical capabilities, emphasis has largely been placed on the physical limitations.

Nursing management of sexual concerns has only recently been recognized as a necessary part of nursing education. Nursing education has offered little on the physiology and psychology of sexual expression. Now that the consumers of health care are demanding that their sex-

uality be acknowledged, nursing can move toward an active role. Instead of the haphazard counseling approach of trial and error, a direct approach can be utilized, particularly with spinal cord injured individuals. Only when the sexual dysfunctions of spinal cord injured individuals are viewed in the context of their psychosocial adjustment, can these areas of sexuality be communicated to the health team as well as to the partners of spinal cord injured individuals.

Statement of the Problem

The problem of this study was to compare the concerns of spinal cord injured individuals and their partners regarding sexual activity and function.

Purposes

The purposes of this study were:

1. To determine similarities and differences between the concerns of spinal cord injured individuals and their partners regarding sexual activity and function
2. To identify areas of concern for spinal cord injured individuals and their partners regarding sexual activity and function.

Background and Significance

Sexual dysfunction of the severely disabled has necessitated the formation of a new perspective on this human condition; the new perspective being the duality of mind and body on a continuum. Psyche and soma have been linked for centuries, but the contemporary version has joined with human sexuality. The major emphasis of this link has been a concern for the whole person in his natural life situation, which in the context of sexual life means the relationship between fantasies, emotions, and overt actions. These three elements have been called the trilogy of human sexuality. The basic human right presented by this trilogy is the right to produce congruence between internal and external reality and to do only acts that are consistent with fantasy and feeling (Stephens 1970).

For the spinal cord injured individual, the ability to connect internal and external reality has often been denied when these realities are presented as incompatible. Often the technical or physical barrier is less significant for the spinal cord injured individual than the attitudinal one (Smith and Bullough 1975). These patients with traumatic injuries to the spine are faced with a more complex situation because the damage affects the four

phases of the sexual cycle. The four phases of the sexual cycle are excitation, plateau, orgasm, and resolution (Masters and Johnson 1966). Tumescence during excitation and the detumescence of the resolution phase are controlled by the autonomic nervous system with the innervation coming primarily from the sacral portion of the cauda equina and possibly through an ancillary pathway of innervation from the mid-thoracic region. Innervation for the plateau phase and consequent orgasm comes primarily from the lumbar area (Smith and Bullough 1975).

Research conducted with patients who have spinal cord injuries reveals a hopeful picture. In a study of 529 men who suffered damage to the spinal cord, Comarr found that 70 percent of men with complete lesions can consummate coitus, whereas the percentage is higher--80 percent or more--for those with incomplete lesions. Successful coitus implies not only intromission, but that the woman reaches orgasm (Bors and Comarr 1960). Guttman (1973) indicated that there is a general agreement in the literature that between 42 and 94 percent of men with spinal injuries can have erections, and 3 to 19.7 percent can experience orgasm. It has also been reported that the most significant satisfaction is probably not the physiological one, but the satisfaction of participating in what is often

considered to be the most significant social experience (Smith and Bullough 1975).

A major obstacle to the spinal cord injured individual is the fear of sexual inadequacy. Instead of concentrating on establishing meaningful human relationships that could lead to sexual relationships, the fear of inadequacy completely distracts the individual from his or her natural responsivity to sexual stimuli, created by or reflected from the sexual partner (Masters and Johnson 1970).

Sexuality has many components. First, sexuality is a massive build-up of autonomic and striated muscle activity culminating in orgasm and ejaculation. It is a method of procreation. Sometimes it is a means of bolstering a faltering ego and the attainment of self esteem. Sometimes and hopefully often, it is a means of merging two people in tenderness, respect, and concern for each other.

While orgasm, ejaculation, and procreation may not be possible for the spinal cord injured individual, the aspects of a sharing relationship offer endless possibilities (Hohmann 1972). Masters and Johnson (1966) stated that the genitalia have been overemphasized in sex. They stated that the important aspect is the giving and re-

ceiving of pleasure, or as the coined phrase suggests, "Give to get".

Sexual counseling has gone from benign neglect to a beginning recognition that the disabled individual deserves information about his ability to express sexuality. The University of Cincinnati conducted a survey in which 160 rehabilitation facilities were surveyed as to their offering of instruction in sexuality. With a 95 percent response rate, 46 percent of the institutions surveyed reported making some attempt to offer sexual counseling or sexual re-education for spinal cord injured individuals. What was offered was not an established program in the facility. The survey indicated that in 33 percent of the cases it was the attending physician who was the most prominent figure in sexual counseling. The clinical psychologist discussed sexual problems with the spinal cord injured patients in 16 percent of the cases. This was followed by the neurologist in 9 percent of the cases, the social worker in 8 percent, the psychiatrist in 7 percent, and the nurse in 4 percent (Tomko 1973). These figures indicate that counseling was done by a wide variety of people from different fields.

The first step in counseling is to learn about the patient before the accident. What kind of sex life was

he leading? What did sexuality mean to him? What abilities has paralysis cost him which he considers important to the requisites of manhood: physical abilities, occupational abilities, as well as sexual abilities (Hanlon 1975)? While these questions often deal with what is gone, the emphasis should be placed on the human relationship necessary for participation in an active sexual role. The University of Minnesota has emphasized in workshops that the psycho-sexual factors, particularly those of effective communication patterns between partners are of prime importance (Griffith, Tomko, and Timms 1973). The attraction between the patient and his mate, whether disabled or able-bodied, must depend on what each does to please the other as a symbol of affection (Hanlon 1975). Masters and Johnson (1970) indicated that this approach will only be enhanced if there is routine evaluation of both sexual partners. Another aspect that must take priority is the realistic determination of the patient's spinal lesion so that both the patient and the partner can achieve a satisfactory sexual adjustment (Comarr and Gunderson 1975).

Sexual function for the spinal cord injured individual is the joining of realistic expectation and imagination to produce a sexual role that is acceptable for both the spinal cord injured individual and his partner. The

realization of this approach by the health team can be a valuable reinforcer of this very basic premise.

Hypothesis

The hypothesis for this study was:

There will be no differences in the concerns of spinal cord injured individuals and their partners regarding sexual activity and function.

Definition of Terms

The definitions for this study were:

1. Sexual function-the joining of neuromuscular activity and behavioral patterns to express sexuality
2. Sexual activity-those activities which comprise the sum of sexuality
3. Partner-a significant "other" who participates in a sexual relationship
4. Sexuality-the joining of mind and body, formed in the context of needs and desires to express feelings of self worth
5. Concerns-disagreement between partners on items in a structured questionnaire dealing with sensitive subject matter in the area of sexual activity and function
6. Spinal cord injured-quadriplegic and paraplegic individuals so designated by medical diagnosis.

Limitations

The limitations of this study were:

1. The availability of couples willing to be interviewed
2. The availability of partners of unmarried spinal cord injured individuals in the out-patient clinic setting
3. Lack of a previous history of sexual experience of the spinal cord injured individuals and their partners
4. Variations in the knowledge base of the subjects concerning sexual activity and function which was not ascertained prior to participation in the study
5. Use of a nine item pre-structured questionnaire which limited responses
6. Potential differences in subject responses to questions that were administered with the assistance of the interviewer as compared to the responses of those individuals who were able to complete the questionnaire independently.

Delimitations

The delimitations of this study were:

1. The spinal cord injured individuals were at least 18 years of age

2. The spinal cord injured individuals had indentified sexual partners

3. The spinal cord injured individuals were followed medically on an out-patient basis.

Assumptions

The assumptions for this study were:

1. Man is a sexual being whose sexuality is dependent on the duality of mind and body along a continuum

2. Sexual activity is a matter of conscious personal choice based upon the individual's needs and desires

3. Each spinal cord injured individual has a unique sexual script determined by such diverse elements as the stage in the life cycle the injury occurred and the antecedent personality structure

4. Despite the damage to his biological system, the disabled individual continues to be a sexual human being from a hormonal, psychological, and biological view

5. Sexual counseling of the spinal cord injured individual is based on the premise found in the general literature that the "patient" (client) is the couple.

Summary

Spinal cord injury effects not only physical elements of sexual expression but also psychological elements. In addressing the area of sexuality and the spinal cord injured individual, emphasis has generally been placed on genital responses. Only within the last eight to ten years has the literature on rehabilitation begun to address the psycho-dynamics of altered sexual function in the spinal cord injured individual.

Sexuality when viewed in the context of psychosocial adjustment is an obvious area where disturbances may occur. In addressing this subject, the general literature on sexuality has supported many concepts. One concept that is very important is the evaluation and counseling necessary with both partners when sexual dysfunction occurs. In the following chapters, the area of sexuality and the spinal cord injured individual will be discussed in the context of this concept.

Chapter II presents a survey of the literature which describes the physiologic and psychologic disruptions which contribute to sexual dysfunction in the spinal cord injured individual. Sexual dysfunction is discussed in the context of how this disruption of the sexual cycle affects

both the spinal cord injured individual as well as the sexual partner.

Chapter III discusses the methodology utilized to ascertain areas of partner concern or disagreement in the area of sexual activity and function. Various modalities that were utilized in obtaining this information will be presented.

Chapter IV presents the results and interpretations of the statistical methods used in analyzing the data.

Chapter V presents all possible conclusions that can be derived from the study and their implications for nursing as well as other rehabilitation personnel. Recommendations for future study are then postulated on the basis of the conclusions and implications.

CHAPTER II

REVIEW OF LITERATURE

Human sexuality has as its genesis a process based on physiological, psychological, social, behavioral, and cultural components. These components are involved in a dynamic process interfacing with all aspects of the developmental learning experience. An interruption of this dynamic process may occur with the disruption of the interaction between organic and psychic factors (Kaplan 1974). This occurrence is common with physical disability or illness and has many behavioral consequences.

Sexual dysfunction can be caused by medication as frequently happens in the treatment of high blood pressure and psychiatric disorders. Changes in sexual activity are often prescribed following cardiac disease. Even in the absence of a physiologic interruption of the sexual cycle, complications of disease can make sexual performance change. Problems such as spasticity, amputation, pain, stress, and fatigue contribute to a process that may necessitate a changed approach to sexual behavior (Berkman 1975).

Historical Implications of Spinal Cord Injury

While the identification of problems occurring in sexual function is not new, it is an area that has been shrouded in misconceptions and centuries of cultural and religious confusion. Freud's efforts in the nineteenth century to bring the "problems of the bedroom" into the scientific arena were met with skepticism and embarrassment (Marmor 1971). Even into the twentieth century when pioneers such as Kinsey and Masters and Johnson attempted to describe and document sexual behavior, their efforts were met with resistance (Marmor 1971).

The area of sexuality and the disabled has lagged even farther behind in this developing area. Until recently, it was considered quite extraordinary for the disabled to express their sexual needs. Concrete actions such as pursuing vocational endeavors, increasing independent function, and pursuing a useful place in society were considered to be accepted and expected functions of the disabled individual. Addressing the sexual needs of the disabled became a problem and a somewhat ridiculous proposition (Romano and O'Connor 1978).

The advent of World War II brought with it the beginning information on sexual function in spinal cord injured individuals. Before World War II, the survival

prospect for this group was limited. Therefore, little attention was given to the sexual needs of a group which had little hope of successfully dealing with the physical implications of their spinal cord injury, much less the sexual concerns that are now recognized to be of great importance to this group (Pierce and Nickel 1977). Even though there is a definite organic sexual dysfunction in this population, studies of spinal cord injured persons show that the libido is intact and active (Berkman 1975). Perhaps the questioning of an intact or functioning libido came into play when health professionals began to deal with the multiplicity of physical complications occurring with spinal cord injury. In the face of devastating physical losses and psychological losses, the asexual nature often attributed to the disabled seems logical in a culture that equates physical attractiveness and function to sex and romance (Nigro 1975).

The evolution of sexual awareness in rehabilitation literature is clearly illustrated in the work of Talbot. In a pioneering study on the sexual function of paraplegics in 1949, Talbot reported some of the initial information obtained on the genital sexual response. An interesting observation was made concerning the

apparent satisfaction in performing the sexual act, even in the absence of voluptuous sensation... the patient is less distressed by the loss of pleasurable sensation than by the accompanying sense of inadequacy (Talbot 1949, p. 207).

Twenty-two years later, the same author addressed not only the physical aspects of sexuality, but also directly addressed the psychosocial aspects of sexuality of the spinal cord injured (Talbot 1971). In a review of eight professional journals in the field of rehabilitation medicine, Cole and Glass (1977) found that all articles written prior to 1971 dealt exclusively with the medical and reproductive aspects of sexuality. This trend was also reflected in the number and types of papers presented at the American Congress and American Academies of Physical Medicine and Rehabilitation annual meetings. These professional organizations are two of the primary information-sharing organizations for rehabilitation personnel.

The apparent significance of sexuality to the spinal cord injured as opposed to the other problems these individuals face after injury has been a matter of some concern. In 1975, Hanson and Franklin conducted a study in which paraplegics and quadriplegics were asked to rank order functional losses associated with their injuries. Also, staff members of the rehabilitation team

were asked to predict the importance of the functional losses as perceived by the spinal cord injured patients. In a sample of seventy-four quadriplegics and fifty-four paraplegics the majority of the spinal cord injured men ranked sex as being the least important of the major functional losses. The functional categories included: (1) normal use of the legs, (2) normal control of bowel and bladder functions, (3) normal feeling and use of sexual organs, and (4) normal use of arms and hands. In a further delineation of the results, more than 80 percent of the paraplegics ranked use of their legs as more important, and 70 percent ranked control of bowel and bladder as more important than sexual function. Conversely, of the 102 staff members surveyed, 50 percent predicted sex would be either first or second choice of the patients. In a similar study on the relative importance of sexuality and other concerns during the rehabilitation hospitalization, sex was again reported as least important when compared to areas such as ambulation, activities of daily living, muscle strengthening, pain relief and transfer ability (Spergel, Rosenthal, and Albert 1976). It is not abnormal then for the sexual concerns of the spinal cord injured individual to be sublimated until other areas are dealt with. The problem arises when this area of concern

is not addressed as an area to be dealt with in the total context of adjustment to disability.

Identity and the Personality Structure

Disability, with its accompanying anxiety, disruption of self-concept, and feelings of unacceptability, can cause a disruption in the normal progression through the grief process, which if viewed in a situational context, is a natural occurrence (Romano and O'Connor 1978). The specific factors that join together to make each individual's reaction pattern unique have been stated by Stewart and Rossier (1978). The first of these factors is the point in the life cycle that the paralysis or injury occurs. Each stage of the life cycle from birth to death has its own unique characteristics. An injury or defect sustained at birth does not allow the individual to compare normal function and the paralyzed condition. Therefore, the individual does not know the experience of intact physical functioning and grief is then directed toward an unknown entity. In adolescence, paralysis at a time of conflict and personality reconfirmation, diverts the stabilization of this process and forces the individual to deal with other things. Finally, paralysis at middle age occurs at a time when physical and psychological losses

are beginning to occur. The paralysis may only reconfirm this trend of loss (Stewart and Rossier 1978). Losses occurring at whatever stage of the life cycle threaten the patient's concept of self and severely impinge on body integrity and identity (Crigler 1975). What then is the meaning of paralyzed parts (Stewart and Rossier 1978)?

Identity Self

Theorists have attempted to describe those elements in an individual's personality that allow the individual to express his true reason for existence. Cooley's theory of the "Looking Glass Self" identifies basic elements which focus on what the self imagines a perception of itself to be in the mind of another person. This imagined perception is a behavior moderator. Mead focuses on self-concept from the view that an individual will think of himself as he believes significant others think of him; he will therefore tend to act the way that others view him (Singh and Magner 1975).

The self is not an isolated entity but a combination of the identity self, the behavioral self, and the judging self (Singh and Magner 1975). The identity self is the strongest and most unifying element in self-concept. How a person feels about himself as a sexual being is the

organizing force in developing a sense of identity (Berkman 1975).

Gender Identity

Sexual identity involves not only an individual's sense of maleness or femaleness but also a combination of biological, behavioral, and developmental components (Crigler 1974). It has been generally accepted that the masculine identity problems in disability are more severe than those of the female (Teal and Athelston 1975). In part, the very obvious loss of normal function of external sexual organs is viewed as demasculating. Strength, muscular ability, and genital functioning are usually identified as pivotal elements in maintaining a masculine identity (Crigler 1974). The interruption of these elements is even more significant when the importance most spinal cord injured men place on physical activity as opposed to intellectual activity is considered (Romano and Lassiter 1972). In a study by Weiss and Diamond (1966) on sexual adjustment of patients with myelopathy, sex role function and identification was more impaired after disability in men than in women. It was also found that men and women with myelopathy were significantly different from a normative group on masculinity-femininity measures both on the

Wechsler Work Interest Inventory and the Weiss Sex Role Association Nouns Test.

The conflict of the feminine sexual identity with paralysis has had little investigative work done. Spinal cord injury has statistically involved the male population. The obvious physical dysfunction for the female with paralysis has been perceived as less severe (Crigler 1974). Woman's traditionally less active and passive role in the sexual relationship has been a prime offender in generating this premise. The physical losses have also taken a secondary role to the importance of a sexual relationship which combines both love and respect before the sexual act (Griffith and Trieschmann 1975). The emphasis on a complete sexual relationship often aids in the adjustment period for the spinal cord injured woman.

In a relationship, role ambiguity becomes a complex issue when viewed in the light of cultural expectations. In a study of thirty-six disabled women between the ages of twenty-one and sixty, one of the major goals was to explore the relationship between the physical mobility of the disabled woman and the satisfaction of her everyday needs and the needs of her spouse. The study indicated that the disabled female may perceive the disability differently than the family members, and the differences

in perception are not usually adequately communicated. Also, greater mobility does not automatically assure greater need satisfaction of the family or spouse when viewed in the context of physical disability (Skipper, Fink, and Hallenbeck 1968).

Body Image

Not only is sexual identity threatened with spinal cord injury, but the individual's perception of his body or body image is changed. Because the body image provides the base for identity, almost any change in body structure or function is viewed as a distortion (Luckman and Sorenson 1974). Body image is a combination of conscious and unconscious elements (Schonfield 1963). It is a relationship of body size, postural relationships, and somatic movement and sensation that affects how an individual sees his body in space apart from others (Conomy 1973). Weber and Wessman (1971) have noted that individuals with a spinal cord injury often perceive a discrepancy between what appears to be a physically intact functioning body and the reality of paralyzed body parts. The visual perception of a whole body often perpetuates an unrealistic body image.

Berger (1952) hypothesized that the long period of withdrawal, depression, and lack of interest following a

spinal cord injury is due to the large psychic energy expenditure necessary to integrate the injury into the body image. The image has to be reorganized to allow the useless part or parts of the body to be integrated into the individual's image of himself (Grayson 1952). The formation of body image is a complex psycho-physical process of sorting out sensory input as it comes to the body. This process goes unnoticed until a disruption in the body data occurs.

The role that the spinal cord itself plays in the mediation of body data is unclear. The role of the central nervous system and the peripheral nervous system in mediating body image has been addressed more frequently by such men as Head and Holmes (Conomy 1973). In a study of eighteen patients with spinal cord injury, specific questions and neurologic data was gathered concerning body image. Although the reported data varied from patient to patient, three common areas occurred: (1) disordered perception of the body in space, (2) disordered perception of posture and movement, and (3) disordered perception of bulk, size, and continuity (Conomy 1973). While Conomy's study emphasized the physical perceptions, the mind-body dichotomy may be losing some of its separate elements. The role of neural biology in mental imagery is being

explored as a function of the cerebral hemispheres (Stephens 1978).

Sexual Response Cycle

Normal sexual function is a complex physiologic process which involves three components of the peripheral nervous system: the parasympathetic, the sympathetic, and the somatic systems (Crigler 1974). Spinal cord disorders regardless of the cause affect sexual functioning directly proportional to the severity of the sensorimotor interruption. While the sensorimotor components are altered, the cognitive and affective components are left intact (Horenstein 1976). If the four stages of the sexual response cycle are considered, sexual response consists of an orderly sequence from the excitement phase, plateau phase, orgasm phase, and the resolution stage. It has been suggested that the sexual response is not a singular event but a biphasic event. It consists of two separate and independent components: (1) a genital vasocongestive reaction which produces penile erection in the male and vaginal lubrication in the female; and (2) the reflexic muscular contraction which is the orgasm for both sexes (Kaplan 1974).

Male Sexual Response Cycle

In the male, erection, ejaculation, and orgasm are the three main elements involved in the male sexual response. Erection, which is a local vasocongestive response, is regulated by involuntary nervous system reflexes. Autonomic (parasympathetic) fibers in the sacral cord from S₂, S₃, and S₄ are connected to the penile blood vessels which produce the erection (Guyton 1971).

Erection can be the result of both psychogenic or reflexic stimuli. Psychogenic erections are dependent on functioning pathways from the spinal cord and parasympathetic system. The stimulus originates in the brain where a sight or thought sends an impulse to the psychogenic erection center in the thoracic cord (T₁₂ - L₂) and then to the sacral cord segments. Reflex erection requires intact nerve roots at S₂, S₃, and S₄. The reflex arc which originates from these sacral segments conducts impulses which travel from the penis to the sacral segments and back to the penis. Reflex erections may be elicited by light touch or friction to the genital area. Damage to the sacral cord or its nerve roots will impair reflexogenic erections (Crigler 1974).

The period of excitement and erection is followed by ejaculation. Ejaculation consists of two phases: seminal emission and true ejaculation (Pierce and Nickel 1977). Emission begins with peristaltic contractions which cause sperm to be propelled into the internal urethra. These contractions cause the seminal fluid and prostatic fluid to mix with the sperm. The combination of these fluids is semen which is now at the posterior urethra. At this point, rhythmic nerve impulses are sent through the somatic center in which the pudendal nerve originates. The propulsion of the semen from the urethra to the exterior is the true ejaculation (Guyton 1971). Orgasm occurs at the time of seminal emission and true ejaculation, both of which depend on autonomic and somatic nerves (Pierce and Nickel 1977).

Female Sexual Response Cycle

The female sexual response is composed of a local vasocongestive response which is similar to erection, and orgasm which is similar to the male emission and ejaculation. While the physiologic response cycle of the male and female is similar, some gender differences are present. For the female, tactile stimuli is usually more erotic than visual stimuli. Also, the quality of the relationship with

the sexual partner has a strong influence on the nature of the response. While the neurophysiologic and neuro-anatomic basis of the female orgasm have not been determined, the pathways must be similar to the male. Both the male and the female libido are dependent on androgen as well as psychic determinants. In both of these sexual response cycles, the biological and experiential responses cannot be separated, even in the light of a physical disability such as spinal cord injury (Kaplan 1974). Orgasm in the spinal cord injured man or woman is altered from the experience of an individual with intact neural pathways.

The orgasmic experience may be normal in those individuals with incomplete lesions particularly if the spinothalamic pathways are intact. The individual with a complete spinal cord injury may experience a new type of orgasm that is predicated on fantasy and not on actual pelvic or lower limb involvement (Horenstein 1976).

Erection and Ejaculation

Various studies have been done to determine the physical performance capabilities of the spinal cord injured male. Erection and ejaculation have received the greatest amount of attention in the literature. General

estimates of the ability of spinal cord injured males to obtain erection vary from 83 to 99 percent (Eisenberg and Rustad 1974). One of the earliest studies in this area by Talbot (1949) indicated that in a male population of two hundred, 36 percent were unable to have erections, 42 percent were able to have reflex erections and 21 percent were able to have psychogenic erections. In the early study by Bors and Comarr (1960) 80 percent of the males, both paraplegic and quadriplegic were capable of erections. In a 1970 study by Comarr of 156 paraplegics and quadriplegics, he found that 82 percent could obtain at least one type of erection. In a similar study by Tarabulcy (1972), 77 percent of the spinal cord injured males were able to obtain erections. Tarabulcy also postulated some conclusions which have been supported by various investigators. Patients with a partial cord lesion have more success in achieving coitus. Patients with high cord lesions are more likely to retain erection than those with low lesions though the reverse is true of ejaculation. Therefore, if the two cord centers for erection are considered, the reflex activated thoraco-lumbar center, erection capabilities are more easily determined. In individuals with a supra-sacral lesion, reflex stimulation produces the erection. While those individuals with a sacral

lesion indicate the cranial-nerve stimulation (Tarabulcy 1972).

Ejaculation appears to be more susceptible to disturbance because of the disturbed thoraco-lumbar sympathetic outflow (Crigler 1974). Statistics vary widely on the matter of ejaculation. Tarabulcy (1972) found that only 18 percent of the individuals with complete lower motor neuron lesions were able to ejaculate while 70 percent of those individuals with incomplete lesions were able to ejaculate. Of the patients with complete upper motor neuron lesions only 5 percent were able to ejaculate whereas when the lesion was incomplete 32 percent were able to ejaculate (Tarabulcy 1972). While the percentage of ejaculation in males with complete upper motor neuron lesions is small, ejaculation is much more frequent in those with incomplete lower motor neuron lesions. Problems which affect ejaculation capabilities range from retrograde ejaculation to testicular atrophy and impaired spermatogenesis (Weber and Wessman 1971).

Orgasmic Experience

While the orgasmic experience is severely interrupted, individuals with spinal cord injury report a variety of sensations ranging from anesthesia to nearly

normal orgasm (Woods 1975). Fantasied orgasms have been reported by both males and females with spinal cord injury. Even though there may have been complete denervation of the pelvic structures, the reported orgasm indicates a resolution similar to those who are neurologically intact (Cole 1975). Some individuals reported the occurrence of heightened feeling or intense tactile stimulation above the sensory level (Griffith and Trieschmann 1975). Orgasm has been reported to relieve the severe flexor and extensor spasms that are often associated with higher lesions (Bors and Comarr 1960). Even though the response cycle is altered, sexual responses for both sexes have the potential to provide for satisfaction even if they are altered from the neurologically intact state (Cole 1975).

Male and Female Fertility

Fertility in men with spinal cord injuries is low. The consensus is that from 5 to 7 percent can be expected to produce offspring (Weber and Wessman 1971). Bors (1950) studied fertility levels of thirty-four paraplegic males. Microscopic examination of testicular biopsies revealed that tubular pathology was present. While low sperm count is often present, the ability to father children is not directly related to fertility, as in the case of retro-

grade ejaculation (Jackson 1972).

The main thrust of research dealing with fertility has primarily involved male populations. Changes in female fertility are primarily in the menstrual cycle which may be changed for up to six months but will return in almost all women in one year (Cole 1975). With the return of the menstrual cycle, fertility is restored. In a study conducted in 1966, twenty-five women between the ages of eighteen and fifty years were interviewed regarding their menstrual periods. Nearly 50 percent of the women did not miss a single menstrual period following their injury. The level of completeness or incompleteness as well as the presence or absence of reflex arcs appeared to have no effect on their cycle. Therefore, the prospects of pregnancy are open to the spinal cord injured female (Comarr 1966).

Marital Status

The altered sexual function of the spinal cord injured individual affects both the biologic and psychosocial, particularly in the context of the marital relationship (Woods 1975). It is often supposed that the divorce rate for the spinal cord injured population is greater than the divorce rate of the general population. An early

study by Guttman (1964) indicated that quadriplegia or paraplegia is not necessarily a hindrance to married life. In a study conducted by Deyoe (1972), he found that in a population of 219 veterans, 72 percent of the paraplegics and 55 percent of the quadriplegics were married. All of the patients had been outside the rehabilitation center from periods of two to thirty years. Statistics indicated that divorce rates of this population may be lower than that of the general population.

In two similar studies, outcomes of marriages existing at the time of injury and marriage and divorce patterns after spinal cord injury were studied. The outcome of 333 marriages in which the husband sustained a spinal cord injury was examined. Of this group, 26.7 percent of these marriages ended in divorce and 1.8 percent were separated at the time of the survey. This divorce rate did not differ from that of the general population and was considerably lower than that found in the state of California where the majority of respondents resided (El Ghatit and Hanson 1975). In another California study with a population of 1,4000 patients, marriage that occurred after the spinal cord injury was studied. Those individuals whose first marriage occurred after their injury had a divorce rate of 24.4 percent. Of those who were married

prior to their injury and then remarried following injury, 16.4 percent were divorced. If all of the post-injury marriages are considered, the divorce rate is 23.1 percent. With the United States divorce rate in 1965 at 27 percent and the 1970 divorce rate at 33 percent, the chances of divorce are no different between pre-injury and post-injury marriages (El Ghatit and Hanson 1976).

Facilitating Sexual Adaptation

When both the health professional and the spinal cord injured individual address the area of sexuality, the understanding that sexual functioning is a joining of knowledge, comfort, and choice is an important concept.

To choose to ask questions and learn the truth about sex is a personal choice. To evaluate answers is a personal necessity. To be comfortable with what one learns and to utilize what one knows in the establishment of an enduring sexual relationship is a lifelong quest (Masters and Johnson 1976, p. xii).

Past perspectives on sexual function have tended to polarize around the following misconceptions: (1) all sexual malfunction is caused by deep psychological problems, (2) problems of sexual performance are primarily technical in nature, and (3) great sex follows naturally if a couple is compatible or well-matched (Burchell 1975). Sexual therapy as proposed by Masters and Johnson (1976)

looks at the problem from the perspective of partners expressing their natural feelings in a nurturing environment. Blame is placed on neither partner, and the emphasis is placed on those behaviors that the couple can change together. Approaching sex therapy from this viewpoint is entirely appropriate when dealing with the spinal cord injured individual. Both public and private sexuality must be addressed. Public sexuality is composed of sexual patterns and roles and they are the outer demonstration of socially recognized sexual expression. Private sexuality centers around the genital sexual response. In a professional setting, not only is public and private sexuality addressed, but the actors in the situation and their perspectives must be considered (Diamond 1974).

In order for therapeutic intervention to be undertaken with the spinal cord injured, assessment of physiologic, psychologic, and sociologic variables must occur (Woods 1975). To assess the physiologic component, Comarr (1978) suggested that two diagnoses are needed: a neurological diagnosis and a sex diagnosis. Elements of the diagnosis include: (1) careful evaluation of the sacral segments to determine whether pin prick or light touch is present at the genitals, (2) whether reflex tone

is present in the external sphincter, and (3) whether there is volitional control of the external sphincter.

While these important physical factors are considered, the psychological aspects of sexuality become extremely important. In a series of semistructured interviews with thirty-one women with a spinal cord injury, the subjects stressed the sexual compensatory methods that they enjoyed. They also stated that as they began to feel like themselves again, their social relationships began to improve and so did their sexual relationships. The readiness to explore new sexual frontiers includes confrontation with the self as well as the partner (Bregman and Hadley 1976).

In terms of sexual counseling, the patient is the couple. As each partner begins to accept his own individuality, whatever his physical limitations, guilt is excluded as a factor in an environment predicated on neutrality and not guilt (Hoch 1977).

The establishment of a sexual relationship after spinal cord injury involves risk-taking which must be fostered in the context of high self-esteem (Blanchard 1976). Adequate self-esteem enables the individual to perform several essential functions in developing a sexual relationship. The ability to receive pleasure and

communicate how it may be best achieved from the partner is an element that requires high self-esteem. Seeking pleasure is an active and risk-taking proposition. Also, self-esteem allows the individual to acknowledge his own sexual tastes and pleasures. When individual preferences are accepted, the individual is then able to actively search for how best to express these needs. High self-esteem then gives the individual the freedom to be able to ask another to help satisfy his individual tastes and preferences. Each step in the risk-taking process leads to an open environment, an environment that will be necessary when altered modes of sexual expression are required (Burchell 1975).

Offering the individual with a spinal cord injury an environment suitable for sexual exploration is very important. Oftentimes medical personnel are unable to create this type of environment due to personal sexual conflict and misunderstanding of the sexual needs of this population. While libidinal drives may be somewhat diminished in the male population, oftentimes the woman's sexual drive is accentuated (Weber and Wessman 1971). While the libidinal changes may be true at times, elements such as availability of partners and lack of opportunity may be factors in this dilemma (Paradowski 1977). If the

health professionals who surround the individual lack the important skills necessary for sexual assessment and counseling the permission the individual may need to explore unknown areas could limit sexual experimentation (Krozy 1978). Even though our society offers a "right" and a "wrong" scale for sexual performance, the professional has only to look at both performance expectations and performance capabilities. When these two areas are considered and realigned with each other, intervention can then be directed toward what the individuals prefer within their abilities (Diamond 1974).

In an attempt to allow for experimentation and testing of abilities, the rehabilitation department at the University of Cincinnati maintained a room for just that purpose. The availability of this room offered a means of restoring and reaffirming the bonds between the couple during a time of stress (Griffith and Trieschmann 1977). Such progressive thinking allows for constructive work in an area that can cause conflict in both the rehabilitation personnel and the patient (Frankel 1967).

One of the most innovative tools developed to aid in desensitization and resensitization have been the Sexual Attitude Readjustment Workshops (SAR). The SAR

format was first developed in San Francisco by the National Sex Forum in 1968. This format was later modified by Cole and Associates to include material on sex and the disabled (Eisenberg and Rustad 1976). Utilizing the sharing process of common problems in a group format has been the general approach (Manley 1973). One of the first programs was started at the University of Michigan Hospital in 1969. The major focus of this program was on sexual and nonsexual problems that might be faced as the disabled individual reentered the community. The Rehabilitation Institute of Chicago has used a group approach to sex education since 1972. Several major Veterans Administration Hospitals have utilized group approaches designed for patients and their partners (Eisenberg and Rustad 1976).

In a study of fifteen such SAR Workshops at the Texas Institute of Research and Rehabilitation, comparison of pre- and post-workshop responses to sexual attitude scales were studied. While the study population consisted of 650 participants, 552 or 85 percent were able-bodied and 98 or 15 percent were disabled. Seventy-five percent of the disabled population were spinal cord injured. The composition of the group reaffirms the primary objectives of these workshops which is reassessment of personal sexual attitudes. Not only have these workshops provided for

evaluation of personal attitudes of health professionals, but they have provided evaluation of the sexual satisfaction and problem areas of participants with physical disabilities (Halstead et al. 1978). Even a recent article in Playboy magazine has addressed the successful modalities of the SAR Workshops (Medelman 1975).

While the SAR Workshop format is not designed to fulfill the needs of all participants, it is a beginning. From group counseling to one-on-one interaction, sexual counseling for the disabled individual and his partner must go on. Creative sexuality is often a fear-provoking concept particularly if past performance is always the predicator of future performance. Grasping new concepts of pleasuring from oral-genital sex to development of secondary errogenous zones is not an easy task. Spinal cord injury is a stress provoking disability in terms of the life script. The complexity of a physical interruption which alters the bio-psycho-social elements of being is not easily dealt with. Therefore, the integration of knowledge must be put into a framework of theory and practice that ties sexual and psychological adjustment together.

CHAPTER III

PROCEDURE FOR COLLECTION AND TREATMENT OF DATA

This chapter is a presentation of the research methodology used in the study. The design chosen for this study was a descriptive survey as described by Polit and Hungler (1978). The modalities addressed in this chapter include: (1) the setting chosen for the study, (2) description of the target population and study sample, (3) ethical considerations in the study, (4) the tool utilized, (5) the sequence of data collection, and (6) the methods chosen for data analysis.

Setting

The setting for this study was a sixty bed, private non-profit hospital and rehabilitation facility, located in the major metropolitan area of a predominately rural southern state. Permission to conduct the study was submitted to a Research Committee for review.

The rehabilitation facility was selected because of the availability of spinal cord injured individuals. The catchment area for the facility is primarily the state itself with some referrals coming from the surrounding

states. The rehabilitation center serves approximately 120 spinal cord injured individuals yearly. Services at the rehabilitation center are offered on both an inpatient and outpatient basis. The spinal injury service is the largest with a bed allocation of twenty-four to twenty-eight beds. Other major disability categories serviced by the center include Stroke/Head injury, Arthritis, Problem Fracture/Amputee, Cardiac, Pulmonary and Hand services. The rehabilitation center offers services centered around comprehensive rehabilitation which utilizes the multidisciplinary team approach.

Target Population

In 1975, the National Spinal Cord Injury (SCI) Data Research Center in Phoenix, Arizona, was established as a central collection source for data from the eleven Model SCI Systems. Both the Data Research Center and the Model SCI Systems are funded by the Rehabilitation Services Administration (RSA). Data that were included from these sources were from cases of traumatic spinal cord injury. The data banks of the Research Center contain information on nearly 3,000 SCI patients (Young 1978).

In considering the sample selected for the study,

data from the eleven Model SCI Systems provided significant similarities to the study population. In a survey of over 700 patients at the Texas Institute for Rehabilitation and Research, the average age at onset of injury was twenty-five years. When data from all eleven systems were considered, the average age at onset was twenty-eight years. Research done by the RSA indicated that 80 percent of spinal cord injuries occurred in the fifteen to thirty year age range. Also, during the last decade, the ratio of new quadriplegics and paraplegics had shifted from 65 percent and 35 percent respectively, to 50 percent for each category. Other demographic data obtained by the Data Research Center between 1973 and 1977 indicated that of 2,854 spinal cord injured, 58.2 percent were single and 32.9 percent were married. In a somewhat smaller sample of the same group, the majority of subjects had completed high school. The data available on sex category indicated that 82.0 percent of the population were male and that 18.0 percent were female.

Sample

While the data from the Research Data Center does not fully represent the general spinal cord injury population, it does provide a useful picture of trends in the

larger group. The sample chosen for the purposes of this study was limited to that portion of the general population of spinal cord injured individuals that had partners. The sample was further delimited by an arbitrary age limit of eighteen years of age and above. All individuals selected for the study were obtained through the outpatient facility of the rehabilitation center. The partner of the spinal cord injured individual had to be the identified sexual partner. The total number of subjects in the sample included twenty spinal cord injured individuals and their sexual partners for a total of forty subjects or twenty couples.

Ethical Considerations

In order to protect the rights and the confidentiality of the study subjects, guidelines were established to accomplish this requirement. At the inception of the study, the initial prospectus and protocols were submitted to the Human Research Review Committee of Texas Woman's University in Dallas, Texas (Appendix A). After approval was received from the Committee, the prospectus and protocols were submitted to and approved by the Research Review Committee at the institution chosen as the setting for the study (Appendix B).

All subjects willing to participate in the study received a verbal description of the study with all purposes, risks, and possible benefits explained. When verbal consent was obtained, each individual was required to sign a standardized oral consent form (Appendix C). If physical limitations prevented the subject from signing the consent form, consent was witnessed and noted by a mark. To assure the anonymity of each subject, numbers and letters were assigned to the corresponding questionnaires. In the event that either subject was unable to complete the questionnaire without verbal assistance, the subjects were moved to separate rooms. Each subject's questionnaire was kept confidential from the partner's questionnaire (Appendix D).

The final measure undertaken to protect the subjects was the deletion of the institutional name from any documents used in the publication of the study.

Tool

The tool used for this study was adapted from a tool called the Index of Sexual Adjustment (ISA) which was developed by Berkman, Weissman, and Frielich (1978). The tool was originally developed to ascertain current attitudes and behaviors in the area of sexuality and to measure the extent that respondents were actively engaged

in some source of sexual gratification. The Index was based on such factors as adaptation to sexual limitations, partner satisfaction, sexual self-concept, and regularity of sexual contact. The tool was first used with 145 male veterans of the spinal cord injury outpatient clinic of the Veterans Administration Hospital, Bronx, New York. The sample was characterized as middle aged, working class males who were injured while in the military service (Berkman, Weissman, and Frielich 1978).

Of the ten original items in the tool, one was not used because a delimitation on the study would have made the question not applicable. The tool used in this study elicited information in the following areas: (1) current interest in sexual activity, (2) attempts at sexual activity since injury, (3) self-concept question on feelings of desirability, (4) perception of partner satisfaction, (5) physical problems associated with sexual activity, (6) importance of sexual counseling, (7) frequency of sexual activities, (8) self rating of sexual satisfaction, and (9) comparison with pre-injury sexual satisfaction (Berkman, Weissman, Frielich 1978).

All of the questions in the tool were close-ended. Each question had two to four answer choices. This format

was chosen for this study because results were easily quantified. While this type of questionnaire limited responses, it did highlight important areas of a sensitive subject.

In this study, the tool was administered to both the spinal cord injured individuals and their partners. Questions were modified in wording to allow the tool to be administered to both subjects. The content of the questions was the same for both subjects. The length of time required to answer the questionnaire was generally ten minutes. Additional time was often required if one or both of the subjects required assistance with the questions.

The Index of Sexual Adjustment was used primarily to elicit areas of agreement and disagreement between the answers given by spinal cord injured individuals and their partners to the same questions.

Data Collection

Subjects that met the basic requirements for the study were included by simple random sampling (Treece and Treece 1973). During a time period from April 1978 through September 1978, a total of twenty couples were obtained that met the criteria for the study. The subjects

were initially contacted in the outpatient clinic. Spinal cord injury clinics were generally held two half days every week during the month. Both of these clinics were used for new patient evaluation and return patient evaluation. The availability of subjects during that time period was limited due to a decrease in spinal cord admissions during the spring and summer. With a decrease in new patient admissions, the reservoir of outpatients was largely dependent on those individuals whose rehabilitation hospitalization had occurred prior to April 1978.

Each of the twenty couples in the study received a verbal description of the study with all purposes, risks, and possible benefits explained. Each couple was informed that participation by both individuals was necessary before the questionnaire would be administered. When verbal consent was obtained, each individual was required to sign a standardized oral consent form. If physical limitations or limited writing skills were a problem, consent was noted by a mark. To assure the confidentiality and anonymity of each subject, numbers and letters were assigned to each questionnaire.

Although a couple might be in the same room, each subject answered the questionnaire separately. In the event that either subject was unable to complete the

questionnaire without assistance, the subjects were moved to separate rooms. Each subject was instructed to answer each question to the best of his ability. Completeness of the questionnaire was encouraged, but the sensitive nature of some of the items caused several subjects to omit answers.

Treatment of the Data

The following three areas were chosen for data analysis: (1) the individual responses of the spinal cord injured (SCI) subjects and their partners to questions in the ISA, (2) disagreement and agreement between partners on questions in the ISA, and (3) selected descriptive demographic factors.

Individual Subject Responses

The individual responses of the subjects were analyzed by use of raw numbers and percentage tabulations. In this manner, individual responses of the SCI subjects could be compared to those of the partners.

Disagreement and Agreement Between Partners

The numbers of couples in disagreement and agreement on questions were analyzed by use of raw numbers and percentage tabulations. The nonparametric Binomial test

as described in Siegel (1956) was applied to the nominal data. The 0.05 level of significance was chosen for the study. The Binomial test was only applied to the data which indicated that more than 50 percent of the subjects were in agreement or disagreement.

Selected Descriptive Factors

The nine questions on the ISA were cross tabulated with selected descriptive factors of the SCI subjects to determine potential areas of association. Fisher exact probability test was applied to the data by use of the Statistical Analysis System (Siegel 1956).

Summary

The research design chosen for the purposes of the study was a descriptive survey that was exploratory in nature (Polit and Hungler 1978). In order to implement the design, several modalities were utilized.

The setting of the study was a sixty bed rehabilitation facility located in a southern state. The facility was selected to ensure that the study sample would include adequate numbers of spinal cord injured individuals and their sexual partners. The sample was further delimited by the following: (1) an arbitrary age limit of eighteen,

(2) all individuals were obtained through the outpatient facility of the rehabilitation center and, (3) the partner of the spinal cord injured individual had to be the identified sexual partner. The total number of the subjects in the sample included twenty spinal cord injured individuals and their partners for a total of forty subjects.

Ethical considerations were established at the inception of the research project. Protocols were submitted to and approved by both the Research Review Committee of Texas Woman's University in Dallas, Texas and the Research Review Committee in the institution chosen for the study. The protocols established for the study are documented in the chapter and appendixes.

The tool chosen for the study was adapted from the Index of Sexual Adjustment (ISA) which was originated by Berkman, Weissman, and Frielich (1978). The three major areas addressed in the ISA were: (1) psychosexual elements of the individual, (2) feelings about sexual relationships, and (3) sexual behavior patterns. In this study, the tool was administered to both the spinal cord injured individual and their partners. The ISA was used to elicit areas of agreement and disagreement between the subject's answers.

Simple random sampling was utilized to obtain the study sample. The data collection occurred over a six month time period from April 1978 to September 1978. Data collection ended when twenty couples were obtained. In order to assure the confidentiality of each subject, partners were not allowed to view the questionnaires and numbers or letters were assigned to each questionnaire.

The three areas chosen for data analysis were: (1) the individual responses of the spinal cord injured subjects and their partners to questions in the ISA, (2) disagreement and agreement between partners on questions in the ISA, and (3) selected descriptive demographic factors. The data were analyzed by use of raw numbers and percentage tabulations. Two nonparametric tests were applied to the nominal data which addressed agreement and disagreement between partners as well as the association of three disability factors to questions in the ISA.

With these modalities established, the null hypothesis of no differences in the concerns of spinal cord injured individuals and their partners regarding sexual activity and function could be tested. The results of the hypothesis testing are reported in Chapter IV.

CHAPTER IV

ANALYSIS OF DATA

This chapter presents the description of the sample and the analysis of the data that were obtained. The data will be presented from several different perspectives. Each method of data presentation will be based on the need to explore the purposes of the study and to establish their relationship to the null hypothesis which stated that there would be no differences or disagreement between partners on a questionnaire which dealt with sexual activity and function.

Description of the Sample

Demographic data were obtained on the spinal cord injured but not the partners (see table 1). Data were computed into percentages on a total of twenty spinal cord injured. Data obtained indicated a trend similar to that of the data obtained from the Research Center in Arizona. The areas of similarity were: (1) sex distribution, (2) age at injury, and (3) educational status.

Of the twenty spinal cord injured (SCI) subjects, 70 percent were paraplegic and 30 percent were quadriplegic. Sex category data indicated that 80 percent were males and

20 percent were females which was essentially identical to the model system information.

TABLE 1
CHARACTERISTICS OF SPINAL CORD INJURED SUBJECTS

Attributes	Subjects n = 20	Subjects Percent
<u>Disability</u>		
Paraplegic	14	70.0
Quadriplegic	6	30.0
<u>Sex</u>		
Male	16	80.0
Female	4	20.0
<u>Marital Status</u>		
Single	1	5.0
Married	19	95.0
<u>Current Age, year</u>		
20-29	6	30.0
30-39	8	40.0
40-49	5	25.0
50-59	0	0
60-69	1	5.0
<u>Age at Injury, year</u>		
14-25	5	25.0
26-40	11	55.0
41-60	4	20.0
<u>Time since Injury, year</u>		
Less than 2	9	45.0
2 to 5	8	40.0
More than 5	3	15.0

TABLE 1--Continued

Attributes	Subject n = 20	Subjects Percent
<u>Index of Physical Function</u>		
Independent	9	45.0
Partially dependent	7	35.0
Dependent	4	20.0
<u>Mobility</u>		
Walks with crutches, braces, canes	3	15.0
Wheelchair, able to transfer	12	60.0
Wheelchair, unable to transfer	5	25.0
<u>Educational status*</u>		
Grades 1-6	2	10.5
Grades 7-12	13	68.4
Grades 12 and above	4	21.1
<u>Current Annual Income</u>		
Under \$6,000	6	30.0
\$6,001 to \$12,000	10	50.0
\$12,001 to \$20,000	1	5.0
More than \$20,001	3	15.0

*Item omission by one subject.

Marital status did not have a distribution similar to the model system population due to the fact that the portion of the population chosen for the study were couples. The average age at injury was between twenty-six to forty with 55 percent of the subjects in this category. Educa-

tional status indicated that the largest majority of subjects had completed some portion of a high school education as was the case with the Arizona samples.

Information regarding physical function was obtained in addition to the medical diagnosis of paraplegia and quadriplegia. Subjects were asked to describe the level of their physical function when given the categories of independent, partially dependent, and dependent. While these categories were based on the subjects' individual perceptions of physical function, concrete abilities were elicited in the mobility category. On the Index of Physical Function, 80 percent of the subjects described themselves as either independent or partially dependent which indicated they perceived their function to be at a fairly high level. Likewise, 75 percent of the subjects described themselves as fitting the criteria of the two most functional categories in mobility which were: (1) ability to walk with assistive devices, and (2) ability to complete wheelchair transfers. Both of these areas closely corresponded to the disability distribution which was obtained by medical diagnosis.

Analysis of Data

The data presented will describe four areas of

the responses given by spinal cord injured individuals and their partners on the Index of Sexual Adjustment (ISA). For descriptive purposes of the total study sample, the individual responses of the spinal cord injured subjects (SCI) and their partners to questions are presented (see table 2). The number of couples which were in disagreement on questions are presented in relation to those couples that were in agreement on questions. Analysis of the areas of disagreement and agreement on questions is presented to further describe trends in the group when presented a questionnaire dealing with sensitive subject matter. The final data presented will address the analysis of selected descriptive demographic factors which were cross-tabulated with questions in the ISA to explore possible association.

Three primary components of sexuality were addressed by the ISA. The three major areas addressed in the ISA were: (1) psychosexual elements of the individual, (2) feelings about sexual relationships, and (3) sexual behavior patterns. The nine questions in the ISA were evenly divided into these three categories. For clarity of presentation, the analysis of the questions in the ISA will follow the three major divisions of content in the ISA.

TABLE 2
INDIVIDUAL SUBJECT RESPONSES TO ISA QUESTIONS

Questions	Answer Choices	SCI No.	Partner No.	SCI %	Partner %
1. Do you have any interest in sex?	Yes	n=20 18	n=20 15	90.0	75.0
	Sometimes	2	4	10.0	20.0
	No	0	1	0	5.0
2. Have you tried sex since injury?	Yes	n=20 19	n=20 19	95.0	95.0
Have you tried sex with your partner since injury?	No	1	1	5.0	5.0
3. Do you feel you are a desirable partner?	Yes	n=20 10	n=20 16	50.0	80.0
	Sometimes	8	4	40.0	20.0
	No	2	0	10.0	0
4. Do you think your partner is satisfied?	Usually:	n=20	n=20		
	3/4 of time	13	14	65.0	70.0
	1/2 of time	5	3	25.0	15.0
	1/4 of time	2	0	10.0	0
	Never	0	3	0	15.0
5. Do you have any physical problems during sex relations with bowels, bladder, catheter or position?	None	n=20 11	n=20 9	55.0	45.0
Does your partner have any physical problems during sex, etc.?	Some Problem	9	11	45.0	55.0

TABLE 2--Continued

Questions	Answer Choices	SCI No.	Partner No.	SCI %	Partner %
6. Do you feel it is important to discuss sexual function with people who have spinal cord injury?	Yes No Not Sure	n=20 19 0 1	n=20 17 1 2	95.0 0 5.0	85.0 5.0 10.0
7. How many times would you say you had sex in the last three months?	Once weekly or more Less than once weekly but more than once monthly Once monthly or less None for 3 months	n=20 8 6 1 5	n=19 6 3 4 6	40.0 30.0 5.0 25.0	32.0 15.0 21.0 32.0
8. How do you feel about your sex relations since injury? How do you feel about your sex relations with your partner since injury?	Satisfactory Somewhat satisfactory Unsatisfactory	n=18 5 9 4	n=20 10 5 5	28.0 50.0 22.0	50.0 25.0 25.0
9. How does this compare with sex experience before injury? How does this compare with sex experience with your partner before injury?	Better now Same Better before	n=20 1 1 18	n=15 0 2 13	5.0 5.0 90.0	0 13.0 87.0

Psychosexual Elements

Of the twenty couples asked about their interest in sex, fifteen couples were in agreement about their interest in sex while only five of the couples were in disagreement (see table 3). Of the five couples in disagreement, only one couple had an answer in extreme opposition to their partner when they answered yes or no. The remaining four couples answered yes and sometimes which indicated a smaller degree of difference. While disagreement between partners on this question was minimal, the level of agreement was significant ($p=.021$). Overall, the interest in sex was high in both the SCI subjects and their partners. Of the forty subjects, only one of the partners expressed no interest in sex.

TABLE 3
COMPARISON OF COUPLE'S INTEREST IN SEX

Responses	Couples n=20	Percent
<u>Couples in agreement</u>		
Yes	14	
No	0	
Sometimes	1	
Total	15	75.0**
<u>Couples in disagreement</u>		
Yes and Sometimes	4	
Yes and No	1	
Total	5	25.0

** $p=.021$

The importance of discussing sexual function with the spinal cord injured individual was affirmed by sixteen of the twenty couples (see table 4). Disagreement between partners was again minimal with only four couples in disagreement. With this obvious distribution, agreement between couples was again the significant element ($p=.006$). Of the total forty subjects, only one partner indicated that sexual function should not be discussed with the SCI individual.

TABLE 4
COMPARISON OF COUPLE'S FEELINGS ABOUT THE
IMPORTANCE OF DISCUSSING SEX FUNCTION
WITH SPINAL CORD INJURED INDIVIDUALS

Responses	Couples n=20	Percent
<u>Couples in agreement</u>		
Yes	16	
Not Sure	0	
No	0	
Total	16	80.0**
<u>Couples in disagreement</u>		
Yes and No	1	
Yes and Not Sure	3	
Total	4	20.0

** $p=.006$

Individual feelings about desirability as a sexual partner indicated a more pronounced division between partner agreement and disagreement (see table 5). Eleven of the couples were in agreement while nine of the couples were in disagreement. Although nine of the couples were in disagreement about their feelings of desirability, seven of these couples indicated that they did feel desirable as partners by answering yes and sometimes. Of the total forty subjects, only two of the SCI subjects gave totally negative responses about feeling desirable while eight of these subjects indicated sometimes. This was compared to a response of sometimes by only four of the partners.

TABLE 5

COMPARISON OF COUPLE'S FEELINGS ABOUT
DESIRABILITY AS SEXUAL PARTNERS

Responses	Couples n=20	Percent
<u>Couples in agreement</u>		
Yes	9	
Sometimes	2	
No	0	
Total	11	55.00**
<u>Couples in disagreement</u>		
Yes and Sometimes	7	
Yes and No	1	
Sometimes and No	1	
Total	9	45.00

**p=.412

Sexual Behavior Patterns

Of the twenty couples asked whether sex had been attempted since injury, all subjects were in agreement ($p < .001$) (see table 6.) Only one couple indicated that sexual contact had not occurred after the spinal cord injury.

TABLE 6
COUPLE'S ATTEMPTS TO ENGAGE IN
SEX RELATIONS AFTER INJURY

Responses	Couples n=20	Percent
<u>Couples in agreement</u>		
Yes	19	
No	1	
Total	20	100.0**
<u>Couples in disagreement</u>		
Yes	:::	:::
No	:::	:::

** $p < .001$

Regularity of sexual contact was determined by having the twenty couples estimate the frequency of sexual contact for the three months prior to their participation in the study (see table 7). Of the twenty couples, eleven couples were in agreement while eight couples were in disagreement on the question. Despite the number of couples

in disagreement, their responses indicated that sexual contact with varying frequency was occurring though the responses did not agree on the exact frequency. Of the eleven couples in agreement, five couples indicated that no sexual contact had occurred for three months. Variations in the answers on this question may have occurred because some respondents had difficulty in deciding how to answer the question.

TABLE 7
COMPARISON OF COUPLE'S PERCEPTIONS ABOUT
THE REGULARITY OF SEXUAL CONTACT

Responses	Couples n=19*	Percent
<u>Couples in agreement</u>		
Once weekly or more	5	
Less than once weekly but more than once monthly	0	
Once monthly or less	1	
None for three months	5	
Total	<u>11</u>	58.0**
<u>Couples in disagreement</u>		
Once weekly or more and less than once weekly	4	
Less than once weekly and once monthly or less	3	
Less than once weekly and none for three months	<u>1</u>	
Total	<u>8</u>	42.0

*no response to the question by one partner

**p=.412

Physical problems that might occur during sexual relations when one partner was spinal cord injured were described in the ISA as bowel, bladder, catheter, and position problems (see table 8).

TABLE 8
COMPARISON OF COUPLE'S FEELINGS ABOUT
PHYSICAL PROBLEMS DURING
SEX RELATIONS

Responses	Couples n=20	Percent
<u>Couples in agreement</u>		
None	5	
Some problem	5	
Total	10	50.0**
<u>Couples in disagreement</u>		
None and Some Problem	10	50.0

**p=.588

Agreement and disagreement between couples was evenly divided between the twenty couples. The ten couples in disagreement had differing ideas about the presence or absence of physical problems. Of the ten couples in agreement, five couples indicated there were no problems and five couples indicated there were some problems. When these responses were compared to individual responses of the subjects, eleven of the partners responded there were

some problems during sex relations while only nine of the SCI felt there were problems. Additional comments on the questionnaires indicated that bladder, catheter, and positioning problems were present for five of the couples.

Feelings About Sexual Relationships

Pre-injury sexual satisfaction was compared to post-injury sexual satisfaction on the ISA (see table 9).

TABLE 9
COMPARISON OF COUPLE'S PRE-INJURY
SEXUAL SATISFACTION

Responses	Couples n=15*	Percent
<u>Couples in agreement</u>		
Better	0	
Same	0	
Better before	12	
Total	12	80.0*
<u>Couples in disagreement</u>		
Same and Better before	3	20.0

*Four subjects were not sexual partners with the SCI subjects prior to injury. Question also omitted by one partner.

**p=.018

Of the fifteen couples responding to this question, only three couples were in disagreement while twelve couples were in agreement ($p=.018$). The three couples in disagreement had differing ideas as to whether the sexual relationship was the same or better before injury.

Each of the couples was asked to rate their sexual satisfaction as either satisfactory, somewhat satisfactory, or unsatisfactory (see table 10).

TABLE 10
COMPARISON OF COUPLE'S FEELINGS ABOUT
SEX RELATIONS SINCE INJURY

Responses	Couples n=18*	Percent
<u>Couples in agreement</u>		
Satisfactory	4	
Unsatisfactory	4	
Somewhat satisfactory	4	
Total	12	67.0**
<u>Couples in disagreement</u>		
Satisfactory and somewhat satisfactory	6	33.0

*No response to the question by two partners

** $p=.119$

Of the eighteen couples responding to the question, only six were in disagreement while twelve couples were in agreement. Of the twelve couples in agreement, eight indicated that the sexual relationship was less than satisfactory. Of the six couples in disagreement, there was difference in couple opinion as to whether the relationship was satisfactory or somewhat satisfactory. The perceptions that satisfactory sexual relationships were maintained after injury were more predominant with the partners of the SCI subjects. Ten of the twenty partners responding to the question indicated that sexual relations were satisfactory. Of the eighteen SCI subjects responding to the question, only five indicated that sex relations were satisfactory while the remaining subjects indicated that sex relations were less than satisfactory.

Couples were asked to quantify the degree of partner satisfaction in sexual relations (see table 11). When asked to specify the amount of time their partners were satisfied in sexual relations, the distribution of disagreement and agreement was similar to that of the preceeding question, with eight couples in disagreement and twelve couples in agreement. The eight couples in disagreement responded with different answers to the

amount of time they thought their partner was satisfied. Eleven of the twelve couples in agreement indicated that their partners were satisfied at least three-fourths of the time. With the exception of three partners who indicated that their SCI partners were never satisfied, thirty-seven subjects indicated that satisfaction did occur at least one-fourth of the time up to three-fourths of the time.

TABLE 11
COMPARISON OF PARTNER SATISFACTION

Responses	Couples n=20	Percent
<u>Couples in agreement</u>		
Usually $3/4$ of time	11	
Usually $1/2$ of time	1	
Usually $1/4$ of time	. . .	
Never	. . .	
Total	<u>12</u>	60.0**
<u>Couples in disagreement</u>		
$3/4$ and $1/2$ of time	3	
$3/4$ and $1/4$ of time	1	
$1/2$ and $1/4$ of time	1	
$3/4$ and Never	1	
$1/2$ and Never	2	
Total	<u>8</u>	40.0

**p=.252

Relationship of Three Selected Disability
Factors to SCI Responses

Type of disability, physical function, and mobility were the three characteristics of the SCI subjects cross-tabulated with the nine items on the ISA. Fisher exact probability test was applied to the data. No significant differences in the responses of the SCI subjects were found when compared to the three selected factors (Appendix E).

Summary of Findings

In addressing the relationship of spinal cord injured individuals and their partners, areas of concern regarding sexual activity and function needed to be ascertained. For the purpose of the study, a concern was defined as disagreement or differences between partners on items in the Index of Sexual Adjustment. While the definition of a concern addressed only one area of potential conflict, it gave information about areas where there were disparities in perceptions about the sexual relationships.

Implicit in the null hypothesis was the assumption that there would be significant differences in the concerns of the spinal cord injured and their partners. In the study, the percent of disagreement between couples

on the nine questions did not exceed 50 percent. Only one question which dealt with physical problems during sex had 50 percent or ten of the twenty couples in disagreement. Responses on the remaining eight questions had a range of disagreement between couples from zero to 45 percent.

While disagreement between partners on questions indicated disparity in ideas, it did not necessarily indicate an unsatisfactory sexual relationship. When couples were asked about their feelings of desirability as sexual partners there was a pronounced division between partner agreement and disagreement. While nine of the twenty couples were in disagreement about feelings of desirability, seven of these couples indicated they did feel desirable at least part of the time. When couples were asked to rate their kind of sexual relationship, six of the twenty couples were in disagreement but only as to whether the relationship was satisfactory or only somewhat satisfactory. The area of physical problems during sexual relations had ten of the twenty couples in disagreement about the presence or absence of physical problems. When couples were asked to quantify the regularity of sexual contacts and the amount of time their partners were satisfied, eight couples in both cases were in

disagreement. Disagreement between couples on these two areas may have been due to a lack of understanding of the questions and their inability to place numerical values on the number of sexual contacts and the amount of time partner satisfaction occurred.

Disagreement between partners occurred on eight of the nine questions in the ISA. Disagreement went as high as 50 percent but did not exceed that level.

Agreement between partners on questions in the ISA was significant at or below the 0.05 level on four of the nine questions. Areas where there were significant agreement between partners were: (1) attempts at sex since injury, (2) interest in sex, (3) importance of discussing sexual function with the spinal cord injured, and (4) the comparison of pre-injury sex to post-injury sex relations.

With the differences noted in the responses of the SCI subjects and their partners, certain descriptive demographic factors were chosen to be cross-tabulated with the questions on the ISA. The three categories of diagnosis, physical function, and mobility did not significantly affect the answers of the SCI subjects.

CHAPTER V

SUMMARY, CONCLUSIONS, IMPLICATIONS AND RECOMMENDATIONS

This chapter will present the major conclusions and implications of the study. Areas that will be addressed include: (1) a summarization of the study, (2) conclusions of the study as related to the purposes and hypothesis, (3) implications derived from the findings, and (4) recommendations for future study.

Summary of the Study

The purpose of this study was to compare the concerns of spinal cord injured individuals and their partners regarding sexual activity and function. For the purpose of the study, a concern was defined as disagreement between partners on items in a structured questionnaire dealing with sensitive subject matter in the area of sexual activity and function. A null hypothesis was formulated which stated there would be no differences in the concerns of the spinal cord injured and their partners regarding sexual activity and function. Implicit in the null hypothesis was the assumption that there would be significant differences or disagreements between partners

on a questionnaire which dealt with sexuality.

The population for the study were spinal cord injured individuals, both quadriplegic and paraplegic, and their partners. Selection of the couples was based on the delimitations of the study which were: (1) the spinal cord injured were at least eighteen years of age, (2) the spinal cord injured had identified sexual partners, and (3) the spinal cord injured were followed medically on an outpatient basis.

Subject participation in the study was on a voluntary basis. All subjects received complete explanations about the risks and benefits of the study. Anonymity of the subjects was established by the assignment of numbers to each questionnaire.

The setting chosen for the study was a sixty bed rehabilitation facility located in the major metropolitan area of a predominantly rural southern state. The setting for the study was chosen because of the availability of spinal cord injured individuals who had undergone rehabilitation at the facility or had been referred as outpatients to the facility.

The tool used in the study was adapted from the Index of Sexual Adjustment (ISA) which was developed by Berkman, Weissman, and Frielich (1978). The tool addressed

three primary components of sexuality which were: (1) psychosexual elements of the individual (2) feelings about sexual relationships, and (3) sexual behavior patterns. The tool as utilized in the study had nine close-ended questions, each of which had two to four answer choices. The format of this questionnaire was chosen because important areas of sexuality were addressed and results were easily quantified to show agreement and disagreement between partners' answers.

With these modalities established, the study was conducted during a six month time period from April 1978 to September 1978. Data collection was ended when twenty couples were obtained that met the criteria for the study.

The methods chosen for the treatment of the data were determined by the three areas to be analyzed. The three areas were: (1) the individual responses of the spinal cord injured subjects and their partners to questions in the ISA, (2) disagreement and agreement between partners on questions in the ISA, and (3) the relationship of selected disability factors to answers on the ISA of spinal cord injured subjects. Raw numbers and percentage tabulations were done on all of the data. The nonparametric Binomial test was applied to the nominal data in

which more than 50 percent of the partners were in agreement or disagreement on questions. Fisher exact probability test was applied to the nominal data as a test of association of selected disability factors and responses of the spinal cord injured subjects to questions in the ISA. The 0.05 level of significance was used for the study.

Analysis of the findings showed that disagreement between partners did occur on eight of the nine questions in the ISA. While disagreement between partners was present, it never exceeded 50 percent on any of the questions. Only the question which dealt with physical problems during sex relations had 50 percent of the couples in disagreement. Disagreement between partners showed disparity in ideas but not necessarily unsatisfactory sexual relationships. The five areas which had disagreement between partners were: (1) physical problems during sex relations which had ten of the twenty couples in disagreement, (2) feelings of desirability which had nine of the twenty couples in disagreement, (3) frequency of sexual contacts which had eight of the nineteen couples in disagreement, (4) frequency of partner satisfaction which had eight of the twenty couples in disagreement, and (5) feelings about sex relations after injury which had

six of the eighteen couples in disagreement.

As there was not significant disagreement between partners on questions in the Index of Sexual Adjustment, the null hypothesis was accepted. The null hypothesis of no differences in the concerns of the spinal cord injured subjects and their partners was supported despite the fact that disagreement between partners did occur.

Agreement between partners was examined to further describe the responses of the couples. Agreement between partners was significant ($p \leq .05$) on four of the nine questions and occurred at least 50 percent or more of the time on all of the questions. Agreement between partners was significant in the following areas: (1) interest in sex with fifteen of the twenty couples in agreement, (2) feelings about the importance of discussing sexual function with the spinal cord injured with sixteen of the twenty couples in agreement, (3) sexual activity after injury with all twenty couples in agreement, and (4) comparison of pre- and post-injury sex relations with twelve of the fifteen couples in agreement.

Of the three selected disability factors of diagnosis, physical function, and mobility, none were significantly associated with the responses of the spinal cord

injured individuals to questions in the ISA (Appendix E).

Other findings of interest in the study were:

1. More than half of the twenty couples (78 percent) felt that sex relations were less than totally satisfactory.
2. Sex relations were reported to be better before injury by more than half of the couples (80 percent).
3. Physical problems during sex relations caused some problems for half of the subjects (50 percent).
4. Information concerning sexual function was affirmed by a majority of the couples (80 percent) as an area that should be discussed with the spinal cord injured individual.
5. Feelings of desirability were not disproportionately different for the spinal cord injured and their partners.
6. The majority of the couples (75 percent) felt that partner satisfaction occurred at least one-half of the time.

Conclusions

The conclusions of the study were generated on the basis of the limitations of the study which narrowed the

possible scope of the conclusions. The findings of this study indicated that:

1. When administered a questionnaire which dealt with sensitive subject matter in the area of sexuality, spinal cord injured individuals and their sexual partners gave answers which indicated there was a high level of agreement in partner opinion. While disagreement between couple's answers did occur, disagreement was not at significant levels. In the context of the questionnaire used for the purposes of the study, disagreement and agreement in partner answers did not necessarily indicate a negative or positive state in the sexual relationship.

2. Physical problems occurring during sexual relations were an area of partner concern. Problems such as bowel, bladder, catheter, or position were factors which created some problems in the mechanical aspects of sexual relations.

3. The need for information regarding sexual function was an area that subjects indicated was important. While the subjects indicated that there were problems in their sexual relationships, the majority of the subjects were actively engaged in some form of sexual activity. Sexual activity in the face of sexual dysfunction indicated that sexual expression had remained an important area for

couples in which one partner was spinal cord injured.

4. While the tool utilized in the study severely restricted the possible depth of subject responses regarding the sexual relationship, the subjects provided useful information with their reactions to questions about their sexual relationships.

Implications

Sexuality and the spinal cord injured is no longer an area that must not be spoken about or dealt with. Even though recent trends in the rehabilitation literature support the nature of the psychosexual needs of these individuals, documented and consistent efforts in the area of sexuality have not been realized (Cole and Glass 1977).

As medical care and emergency retrieval systems have improved, spinal cord injury is no longer a disability which significantly shortens the life of these individuals. The acknowledgement by health professionals of the increased life span of these individuals, has required that a comprehensive range of services be offered to fulfill their physical as well as psychological needs (Pierce and Nickel 1977).

The "age of the new sexuality" has become a trite phrase but not necessarily an invalid idea. Pioneering

efforts by such individuals as Kinsey (Marmor 1971) and Masters and Johnson (1966) have added a great deal to the body of knowledge about human sexual behaviors and needs. Despite the rather burgeoning body of literature being developed in this area, health professionals have been slow to include this area in their educational systems and their practice areas (Cole and Glass 1977).

"Rehabilitation" of the spinal cord injured does not necessarily occur during the rehabilitation hospitalization. Rehabilitation may occur over a two to five year time period. Only when the individual has dealt with each stage of the grief process, can his reactions then be integrated into a lifestyle (Romano and O'Connor 1978, Crigler 1975).

Health professionals who interact with the spinal cord injured are usually dealing with someone who is only at the "tip of the iceberg" in terms of acceptance of disability. The literature has shown that physical problems and the resumption of physical activities often preclude the ability of the individual to deal with areas such as sexuality (Hanson and Franklin 1975, Spergel, Rosenthal, and Albert 1976).

If information from the general literature is analyzed, many of the precepts formulated about sexual

dysfunction in the able-bodied population should have implications for the spinal cord injured individual (Kaplan 1974). Perhaps the most persuasive idea in the general literature is the need to include both partners in sexual counseling (Hoch 1977). The concept of the couple as the client has credence when all of the ramifications of a sexual relationship are considered.

While sexual dysfunction may occur primarily with one partner, the other partner may assist in the solving of shared problems (Diamond 1974). If spinal cord injured individuals and their partners are allowed to explore areas of conflict and need, the mutual support system can only strengthen their problem solving abilities (Masters and Johnson 1976).

Much remains to be learned from the spinal cord injured and their partners. Few able-bodied individuals have had to confront the sexual frontiers that these couples are faced with (Cole 1975). Identification of what these couples' needs are will provide valuable information in areas that range from health professionals' education to furthering the body of knowledge about sexual dysfunction and its implications.

Recommendations for Future Study

Recommendations for future study based on the

conclusions of this study are:

1. Further research is needed to explore the attitudes and feelings of both sexual partners toward their relationship and its physical expressions.

2. Normative values of sexuality and spinal cord injured individuals should be compared to those which are formulated for able-bodied individuals with sexual dysfunction.

3. Identification of effective modalities for dealing with sexual dysfunction in spinal cord injured individuals must be studied in terms of the benefits to rehabilitation outcome.

APPENDIX A

TEXAS WOMAN'S UNIVERSITY
DALLAS, TEXAS 75235



COLLEGE OF NURSING

April 22, 1976

Cynthia C. Connor
~~Graduate Student~~
~~1810 Inwood Road~~
~~Dallas, Texas 75235~~

*Grove Apts., Apt 161C
Woodway Drive
Jackson, Mississippi 39206*

Dear Ms. Connor,

Your protocol "Concerns of Quadriplegics and their Partners Regarding Sexual Activity and Function" has been reviewed and approved by the Human Research Review Committee in Dallas.

Sincerely,

Opal H. White
Opal H. White, Chairman

OHW/pw

OFFICE OF THE ASSOCIATE DEAN
TEXAS WOMAN'S UNIVERSITY
DALLAS CENTER
1810 INWOOD ROAD
DALLAS, TEXAS 75235

OFFICE OF THE DEAN
TEXAS WOMAN'S UNIVERSITY
BOX 23026, TWU STATION
DENTON, TEXAS 76204

OFFICE OF THE ASSOCIATE DEAN
TEXAS WOMAN'S UNIVERSITY
1130 M. D. ANDERSON BLVD.
HOUSTON, TEXAS 77025

TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING
DALLAS CAMPUS

HUMAN RESEARCH REVIEW COMMITTEE REPORT

STUDENT'S NAME Cynthia C. ConnorPROPOSAL TITLE Concerns of Quadriplegics and Their
Partners Regarding Sexual Activity and Function

COMMENTS: _____

DATE: 4/21/76

Opal H. White
~~Disapprove~~ Approve

Geris Loosen 4/18/76
~~Disapprove~~ Approve

Patricia Pearl Paradise 4/21/76
~~Disapprove~~ Approve

Disapprove Approve

1. Brief description of the study (use additional pages or attachments, if desired, and include the approximate number and ages of participants, and where they will be obtained).

This research study will be conducted to determine some of the concerns of quadriplegics and their partners regarding sexual activity and function. The study will focus on that baseline data that is necessary for competent and complete sexual counseling. The population will consist of twenty-five quadriplegics and their partners all at varying stages of sexual relationships. The population will be obtained from a rehabilitation center in The study will focus on similarities and differences in the concerns of quadriplegics and their partners. Age, previous sexual experience, and cultural background will be evaluated to determine if they affect the concerns of quadriplegics and their partners regarding sexual activity.

2. What are the potential risks to the human subjects involved in this research or investigation? "Risk" includes the possibility of public embarrassment and improper release of data. Even seemingly nonsignificant risks should be stated and the protective procedures described in (3) below.

Potential Risks: 1. Name of subject connected with the interview form.
2. Embarrassment of subjects with oral interview technique.

3. Outline the steps to be taken to protect the rights and welfare of the individuals involved:
 1. Number assigned to subjects to assure anonymity.
 2. Professional approach in interview technique.
 3. Name of institution to be deleted from the final paper.
 4. Each interview questionnaire will be kept confidential. Partners will not be allowed to view the others questionnaire.
4. Outline the method for obtaining informed consent from the subjects or from the person legally responsible for the subjects. Attach documents, i.e., a specimen informed consent form. These may be properly executed through completion of either (a) the written description form, or (b) the oral description form which are available from the committee chairmen or may be reproduced from the attached specimen copies. Other forms which provide the same information will be acceptable.

The oral consent form will be used to obtain and document consent.

5. If the proposed study includes the administration of personality tests, inventories, or questionnaires, indicate how the subjects are given the opportunity to express their willingness to participate. If the subjects are less than the age of legal consent, or mentally incapacitated, indicate how consent of parents, guardians, or other qualified representatives will be obtained:

All subjects will be given a full explanation of the nature of the study as well as the nature of the questions. Since a verbally administered questionnaire will be necessary, it is expected that this will contribute to the willingness of the subjects. If a negative attitude is expressed, the subject will not be approached again.

(Signed)	<u>Burt Vaughan-Walsh</u>	<u>4-14-76</u>
	Program Director	Date
(Signed)	<u>Cynthia C. Connor</u>	<u>April 14, 1976</u>
	Graduate Student	Date
(Signed)	<u>Burt Vaughan-Walsh</u>	<u>4-14-76</u>
	Dean, Department Head, or Director	Date

Date received by committee chairman: April 19, 1976

TEXAS WOMAN'S UNIVERSITY

DENTON, TEXAS 76204

THE GRADUATE SCHOOL
P.O. Box 22479, TWU Station

April 23, 1976

Ms. Cynthia C. Connor
8302 Cayton
Houston, Texas 77017

Dear Ms. Connor:

I have received and tentatively approved the Prospectus for your research project. Before I can give final approval for this Prospectus, you must file written authorization from the rehabilitation center in Jackson, Mississippi. This release must be on file in the Graduate Office.

It is very important for the University and our relations with the institutions where work is done that this clearance be obtained, in writing before the initiation of any research.

I have also noted from your Prospectus that you will need to exercise care in punctuation, spelling, and sentence structure in the writing of your thesis.

Please submit the written authorization for your research at the earliest possible time.

Best wishes to you in the research and writing of your project.

Sincerely,

B. B.

Phyllis Bridges
Acting Dean

PB:le

cc: Mrs. Beth Vaughan-Wrobel

APPENDIX B

TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING
DENTON, TEXAS

DALLAS CENTER
1810 Inwood Road
Dallas, Texas 75235

HOUSTON CENTER
1130 M.D. Anderson Blvd.
Houston, Texas 77025

AGENCY PERMISSION FOR CONDUCTING STUDY*

THE _____

GRANTS TO CYNTHIA C. CONNOR

a student enrolled in a program of nursing leading to a Master's Degree at Texas Woman's University, the privilege of its facilities in order to study the following problem:

"CONCERNS OF SPINAL CORD INJURED AND THEIR PARTNERS REGARDING SEXUAL ACTIVITY AND FUNCTION"

The conditions mutually agreed upon are as follows:

1. The agency (~~may~~) (may not) be identified in the final report.
2. The names of consultative or administrative personnel in the agency (~~may~~) (may not) be identified in the final report.
3. The agency (wants) (~~does not want~~) a conference with the student when the report is completed.
4. The agency is (willing) (~~unwilling~~) to allow the completed report to be circulated through interlibrary loan.
5. Other: _____

Date 3-30-78

TE Hart
Signature of Agency Personnel

Cynthia C. Connor
Signature of student

Gordon M. Lane
Signature of Faculty Advisor

*Fill out and sign three copies to be distributed as follows: Original -- Student; first copy -- agency; second copy -- T.W.U. College of Nursing.

APPENDIX C

TEXAS WOMAN'S UNIVERSITY

(Form B-- Oral presentation to subject)Consent to Act as a Subject for Research and Investigation:

I have received an oral description of this study, including a fair explanation of the procedures and their purpose, any associated discomforts or risks, and a description of the possible benefits. An offer has been made to me to answer all questions about the study. I understand that my name will not be used in any release of the data and that I am free to withdraw at any time.

Signature_____
Date_____
Witness_____
DateCertification by Person Explaining the Study:

This is to certify that I have fully informed and explained to the above named person a description of the listed elements of informed consent.

Signature_____
Date_____
Position_____
Witness_____
Date

APPENDIX D

SCI QUESTIONNAIRE

Number: _____

Age: _____

Age at injury: _____

Time since injury: _____

Disability: _____

Marital status: _____

Physical function:

Independent _____

Partially dependent _____

Dependent _____

Mobility:

Walk with crutches, braces,
cane _____Wheelchair, able to
transfer _____Wheelchair, unable to
transfer _____

Current annual income:

Under \$6,000 _____

\$6,001 to \$12,000 _____

\$12,001, to \$20,000 _____

More than \$20,001 _____

Education: _____

PLACE A CHECK ON THE BLANK THAT MOST CLOSELY ANSWERS THE
QUESTION FOR YOU.

1. Do you have any interest in sex?

 Yes _____
 Sometimes _____
 No _____

2. Have you tried sex since injury?

 Yes _____
 No _____

3. Do you feel you are a desirable partner?

 Yes _____
 Sometimes _____
 No _____

4. Do you think your partner is satisfied?

 Usually, 3/4 of the time _____
 1/2 of the time _____
 1/4 of the time _____
 Never _____

5. Do you have any physical problems during sex relations with bowels, bladder, catheter or position?
None _____
Some problem _____
6. Do you think it is important to discuss sexual function with people who have spinal cord injury?
Yes _____
No _____
Not sure _____
7. How many times would you say you had sex in the last three months?
Once weekly or more _____
Less than once weekly but more than once monthly _____
Once monthly or less _____
None for 3 months _____
8. How do you feel about your sex relations since injury?
Satisfactory _____
Somewhat satisfactory _____
Unsatisfactory _____
9. How does this compare with sex experience before injury?
Better now _____
Same _____
Better before _____

PARTNER QUESTIONNAIRE

Number: _____

PLACE A CHECK ON THE BLANK THAT MOST CLOSELY ANSWERS THE QUESTION FOR YOU.

1. Do you have any interest in sex?
Yes _____
Sometimes _____
No _____
2. Have you tried sex with your partner since his injury?
Yes _____
No _____
3. Do you feel you are a desirable partner?
Yes _____
Sometimes _____
No _____
4. Do you think your partner is satisfied?
Usually, 3/4 of the time _____
1/2 of the time _____
1/4 of the time _____
Never _____
5. Does your partner have any physical problems during sex relations with bowels, bladder, catheter or position?
None _____
Some problem _____
6. Do you think it is important to discuss sexual function with people who have spinal cord injury?
Yes _____
No _____
Not sure _____

7. How many times would you say you had sex in the last three months?
- Once weekly or more _____
Less than once weekly but more than once monthly _____
Once monthly or less _____
None for 3 months _____
8. How do you feel about your sex relations with your partner since his injury?
- Satisfactory _____
Unsatisfactory _____
Somewhat satisfactory _____
9. How does this compare with sex experience with your partner before his injury?
- Better now _____
Same _____
Better before _____

APPENDIX E

RESULTS OF FISHER EXACT PROBABILITY TEST

DIAGNOSIS

1.	.13
2.	1.00
3.	.4257
4.	.1873
5.	.6858
6.	.93
7.	--*
8.	.0924
9.	.2418

INDEX OF PHYSICAL FUNCTION

1.	.968
2.	1.00
3.	.783
4.	--*
5.	.709
6.	.986
7.	.823
8.	--*
9.	.846

MOBILITY

1.	.9274
2.	1.00
3.	.3955
4.	.3065
5.	.5000
6.	.968
7.	.664
8.	.1107
9.	.2028

*unable to compute

REFERENCES CITED

- Berger, S. 1952. The role of sexual impotence in the concept of self in male paraplegics. Dissertation Abstracts. 12:4:533.
- Berkman, A. H. 1975. Sexuality: a human condition. Journal of Rehabilitation. 41:13-15.
- Berkman, A. H.; Weissman, R.; and Frielich, M. 1978. Sexual adjustment of spinal cord injured veterans living in the community. Archives of Physical Medicine and Rehabilitation. 59:29-33.
- Blanchard, M. G. August 1976. Sex education for spinal cord injury patients and their nurses. Paraplegia News. 30-48.
- Bors, E. et al. 1950. Fertility in paraplegic males: a preliminary report of endocrine studies. Journal of Clinical Endocrinology. 10:381-398.
- Bors, E., and Comarr, A. E. 1960. Neurological disturbances of sexual function with special reference to 529 patients with spinal cord injury. Urological Survey. 10:191-222.
- Bregman, S., and Hadley, R. G. 1976. Sexual adjustment and feminine attractiveness among spinal cord injured women. Archives of Physical Medicine and Rehabilitation. 57:448-450.
- Burchell, C. R. 1975. Self-esteem and sexuality. Medical Aspects of Human Sexuality. 9:74-90.
- Cole, T. M. 1975. Sexuality and physical disabilities. Archives of Sexual Behavior. 4:389-403.
- Cole, T. M., and Glass, D. D. 1977. Sexuality and physical disability-commentary. Archives of Physical Medicine and Rehabilitation. 58:585-586.

- Comarr, A. E. 1966. Observations on menstruation and pregnancy among female spinal cord injury patients. Paraplegia. 3:263-272.
- _____. 1970. Sexual function among patients with spinal cord injury. Urologia Internationalis. 25:134-168.
- Comarr, A. E., and Gunderson, B. B. 1975. Sexual function in traumatic paraplegia and quadriplegia. American Journal of Nursing. 75:250-255.
- Comarr, A. E., and Vigue, M. 1978. Sexual counselling among male and female patients with spinal cord and/or cauda equina injury. American Journal of Physical Medicine. 57:107-122.
- Conomy, J. P. 1973. Disorders of body image after spinal cord injury. Neurology. 23:842-850.
- Crigler, L. 1974. Sexual concerns of the spinal cord injured. Nursing Clinics of North America. 9:703-715.
- Deyoe, F. S. 1972. Marriage and family patterns with longterm spinal cord injury. Paraplegia. 10:219-224.
- Diamond, M. 1974. Sexuality and the handicapped. Rehabilitation Literature. 35:34-40.
- Eisenberg, M. G., and Rustad, L. 1974. Sex and the spinal cord injured: some questions and answers. Cleveland, Ohio: Veterans Administration Hospital.
- _____. 1976. Sex education and counselling programs on a spinal cord injury service. Archives of Physical Medicine and Rehabilitation. 57:135-139.
- El Ghatit, A. Z., and Hanson, R. W. 1975. Outcomes of marriages existing at the time of a male spinal cord injury. Journal of Chronic Diseases. 28:383-388.
- _____. 1976. Marriage and divorce after spinal cord injury. Archives of Physical Medicine and Rehabilitation. 57:470-474.

- Frankel, A. 1967. Sexual problems in rehabilitation. Journal of Rehabilitation. 33:19-20.
- Grayson, M.; Powers, A.; and Levi, J. 1952. Psychiatric aspects of rehabilitation. New York: Institute of Medicine and Rehabilitation, New York University-Bellvue Medical Center.
- Griffith, E.; Tomko, M.; and Timms, R. 1973. Sexual function in spinal cord injured patients: a review. Archives of Physical Medicine and Rehabilitation. 54:539-543.
- Griffith, E., and Trieschmann, R. 1975. Sexual functioning in women with spinal cord injury. Archives of Physical Medicine and Rehabilitation. 56:18-21.
- _____. 1977. Sexual function restoration in the physically disabled: use of a private hospital room. Archives of Physical Medicine and Rehabilitation. 58:368-369.
- Guttman, S. 1964. The married life of paraplegics and tetraplegics. Paraplegia. 2:182-188.
- _____. 1973. Spinal cord injuries: comprehensive management and research. Oxford: Blackwell Scientific Publications.
- Guyton, A. C. 1971. Testbook of medical physiology. Philadelphia: W. B. Saunders Company.
- Halstead, L. S., et al. 1978. Sexual attitudes, behavior and satisfaction for able-bodied and disabled participants attending workshops in human sexuality. Archives of Physical Medicine and Rehabilitation. 59:497-501.
- Hanlon, K. 1975. Maintaining sexuality after spinal cord injury. Nursing 75. 5:58-62.
- Hanson, R. W., and Franklin, M. R. 1976. Sexual loss in relation to other functional losses in spinal cord injured males. Archives of Physical Medicine and Rehabilitation. 57:291-293.

- Hoch, Z. 1977. Sex therapy and marital counselling for the disabled. Archives of Physical Medicine and Rehabilitation. 58:413-415.
- Hohmann, G. W. 1972. Considerations in management of psychosexual readjustment in cord injured males Rehabilitation Psychology. 19:50-58.
- Horenstein, S. 1976. Sexual dysfunction in neurological disease. Medical Aspects of Sexuality. 10:7-31.
- Jackson, R. W. 1972. Sexual rehabilitation after cord injury. Paraplegia. 10:50-55.
- Kaplan, H. S. 1974. The new sex therapy: active treatment of sexual dysfunctions. New York: Quadrangle/The New York Times Book Company.
- Krozy, R. 1978. Becoming comfortable with sexual assessment. American Journal of Nursing. 78:1036-1038.
- Luckman, J., and Sorenson, K. C. 1974. Medical-surgical nursing. Philadelphia: W. B. Saunders Company.
- Manley, S. January-February 1973. A definitive approach to group counseling. Journal of Rehabilitation. 38-40.
- Marmor, J. 1971. Normal and deviant sexual behavior. The Journal of the American Medical Association. 217:165-170.
- Masters, W. H., and Johnson, V. E. 1966. Human sexual response. Boston: Little, Brown and Company.
- _____. 1970. Human sexual inadequacy. Boston: Little, Brown and Company.
- _____. 1976. The pleasure bond. New York: Bantam Books, Inc.
- Medelman, J. 1975. Does your husband know that you are bisexual. Playboy. 22:145-261.
- Nigro, G. 1975. Sexuality in the handicapped: some observations on human needs and attitudes. Rehabilitation Literature. 36:202-205.

- Paradowski, W. 1977. Socialization patterns and sexual problems of the institutionalized chronically ill and disabled. Archives of Physical Medicine and Rehabilitation. 58:53-59.
- Pierce, D. S., and Nickel, V. H. 1977. The total care of spinal cord injuries. Boston: Little, Brown and Company.
- Polit, D. G. and Hungler, B. P. 1978. Nursing research: principles and methods. Philadelphia: J. B. Lippincott Company.
- Romano, M. D., and Lassiter, R. E. 1972. Sexual counselling with the spinal cord injured. Archives of Physical Medicine and Rehabilitation. 53:568-572.
- Romano, M. D., and O'Connor, J. F. 1978. Sexual needs of the physically handicapped. Medical Aspects of Human Sexuality. 12:82-97.
- Schonfield, W. 1963. Body image in adolescents-a psychological concept for the pediatrician. Pediatrics. 31:845-855.
- Siegel, S. 1956. Nonparametric statistics for the behavioral sciences. New York: McGraw-Hill Book Company, Inc.
- Singh, S. P., and Magner, L. 1975. Sex and self-the spinal cord injured. Rehabilitation Literature. 36:2-10.
- Skipper, J. K.; Fink, S. L.; and Hallenbeck, P. N. 1968. Physical disability among married women: problems in the husband-wife relationship. Journal of Rehabilitation. 34:16-19.
- Smith, J., and Bullough, B. 1975. Sexuality and the severely disabled. American Journal of Nursing. 75:2194-2197.
- Spiegel, R.; Rosentahl, D.; and Albert, B. W. 1976. Sex-a rehabilitation issue: what priority and when. Archives of Physical Medicine and Rehabilitation. 57:566.

- Stephens, G. J. 1970. Mind-body continuum in human sexuality. American Journal of Nursing. 70:2194-2197.
- _____. 1978. Creative contraries: a theory of sexuality. American Journal of Nursing. 78:70-75.
- Stewart, L. D., and Rossier, A. B. 1978. Psychological considerations in the adjustment to spinal cord injury. Rehabilitation Literature. 39:75-80.
- Talbot, H. S. 1949. A report on sexual function in paraplegics. Journal of Urology. 61:265-270.
- _____. 1971. Psycho-social aspects of sexuality in spinal cord injury patients. Paraplegia. 9:37-39.
- Tarabulcy, E. 1972. Sexual function in the normal and in paraplegia. Paraplegia. 10:201-208.
- Teal, J. C., and Athelston, G. T. 1975. Sexuality and spinal cord injury: some psychosocial considerations. Archives of Physical Medicine and Rehabilitation. 56:264-268.
- Tomko, M. A. 1973. Sex: rehabilitation's stepchild. Proceedings of the workshop-continuing education in the treatment of spinal cord injuries. Indianapolis, Indiana: National Paraplegia Foundation.
- Treece, E. W., and Treece, W. J. 1973. Elements of research in nursing. Saint Louis: C. V. Mosby Company.
- Weber, D. K., and Wessman, H. C. 1971. A review of sexual function following spinal cord trauma. Physical Therapy. 51:290-294.
- Weiss, A. J., and Diamond, M. D. 1966. Sexual adjustment, identification, and attitudes of patients with myelopathy. Archives of Physical Medicine and Rehabilitation. 47:245-250.

- Woods, N. F. 1975. Human sexuality in health and illness.
Saint Louis: C. V. Mosby Company.
- Young, J. 1978. Selected statistical summaries of sci
data for 1973-1977. National Spinal Cord Injury
Model Systems' Conference. Phoenix, Arizona.

SELECTED BIBLIOGRAPHY

Books

- Abdellah, F. G., and Levine, E. 1965. Better patient care through nursing research. New York: MacMillan Company.
- Fox, D. J. 1966. Fundamentals of research in nursing. New York: Appleton-Century-Crofts.
- Isaac, S., and Michael, W. B. 1971. Handbook in research and evaluation. San Diego, California: Robert R. Knapp.
- McCary, J. L. 1967. Human sexuality. New York: Van Nostrand Reinhold Company.
- Murray, R., and Kijek, J. C. 1979. Current perspectives in rehabilitation nursing. St. Louis: C. V. Mosby Company.
- Reuben, D. 1970. Everything you always wanted to know about sex. New York: David McKay Company, Inc.
- Stryker, R. 1977. Rehabilitative aspects of acute and chronic nursing care. Philadelphia: W. B. Saunders Company.
- Turabien, K. L. 1973. A manual for writers of term papers, theses, and dissertations. 4th ed. Chicago: University of Chicago Press.

Articles

- Comarr, A. E. 1973. Sex among patients with spinal cord and/or cauda equina injuries. Medical Aspects of Human Sexuality. 222-238.
- Held, J. P., et al. 1975. SAR Workshops: effect on SCI adults, their partners and rehabilitation professionals. Archives of Physical Medicine and Rehabilitation. 56:14-18.

- Hodges, L. C. 1978. Human sexuality and the spinal cord injured: role of the clinical nurse specialist. Journal of Neurosurgical Nursing. 10:125-129.
- Jockheim, K. A., and Wahle, H. A. November 1970. A study on sexual function in 56 male patients with complete irreversible lesions of the spinal cord and cauda equina. Paraplegia. 166-172.
- Mitchell, K. R. 1970. The body image barrier variable and level of adjustment to stress induced by severe physical disability. Journal of Clinical Psychology. 16:49-52.
- Magi, S. Z., and Clark, D. 1964. Factors in marital adjustment after disability. Journal of Marriage and the Family. 26:215-216.
- Romano, M. D. Winter 1973. Sexuality and the disabled female. Accent on Living. 27-35.
- Sidman, J. M. 1977. Sexual functioning and the physically disabled adult. The American Journal of Occupational Therapy. 31:81-85.