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The Physical Therapist's Role in Sexual Education of People with Spinal Cord Injury During Inpatient Rehabilitation

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THE PHYSICAL THERAPIST'S ROLE IN SEXUAL EDUCATION OF PEOPLE WITH SPINAL CORD INJURY DURING INPATIENT REHABILITATION

By

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THESIS

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ABSTRACT

The purpose of this study was to explore the physical therapist's role in sexual education of spinal cord injured patients during inpatient rehabilitation. Descriptive data were collected by questionnaire from 72 licensed physical therapists working in CARF accredited inpatient spinal cord injury units. The results indicated that although therapists rated sexual education as an important and appropriate topic in physical therapy, they addressed sexual issues only 46% of the time and initiated these discussions only 30% of the time. Significant correlation was present between the frequency of addressing and initiating discussions of sexuality and the therapists' preparedness and comfort level in discussing issues of sexuality. This indicates a need for further education for physical therapists on the topic of sexuality and disability. It is essential for the profession of physical therapy to define its role in sexual education and provide standards for therapists' education in order to better meet the needs of clients.

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CHAPTER ONE

INTRODUCTION

The profession of physical therapy has changed substantially from its early beginnings in the late 1800s and early 1900s. It began with treatment of infantile paralysis or acute poliomyelitis with massage, muscle training and corrective exercises. No formal training was required and skills were learned through on the job training (Scully & Barnes, 1989). Today physical therapy encompasses a wide range of diagnoses, evaluations, and treatments. Entry level physical therapy positions require at minimum a baccalaureate degree with many requiring graduate education. As the scope of physical therapy expanded, the American Physical Therapy Association (APTA) began certification of physical therapy specialists. The specialties recognized were: cardiopulmonary, clinical electrophysiology, neurology, pediatrics, orthopaedics, and sports (Scully & Barnes, 1989). With the increased specialization in physical therapy and in health care as a whole, fragmentation of care often occurs.

Health care has traditionally focused on treating the illness or the site of injury, and not the person. The patient was referred to as "the knee in room 204", or "the C5 on the first floor". This reflected the fragmentation

that was occurring in the delivery of health care as each profession focused on the area of the body that was their specialty.

Today the trend in health care delivery is toward holistic medicine. The person's illness or injury should be treated as an integral part of the person as a whole. This is the key concept behind systems models, of which the Neuman's Systems Model is an example. Neuman (1989) states "Wholism, implicit within the Neuman's Systems Model, is both a philosophical and a biological concept, implying relationships and processes arising from wholeness, dynamic freedom, and creativity in adjusting to stress in the internal and the external environments". This model was designed as an isomorphic model for the nursing profession. It can be used for any system, an individual person, a group, or an issue. It recognizes that each system is unique, and that stressors are also unique, and that each system develops normal responses to stress. When the stressor, or the combination of stressors, becomes too great the system begins to break down. With a medical client as the system being analyzed, Neuman defines five key "interacting variables": physiological, psychological, sociocultural, developmental, and spiritual, which acting together stabilize the system (Neuman, 1989). The use of systems models provides a holistic method for assessing patients thoroughly, and also in formulating goals and treatments that are most beneficial to the patient. This is

especially true in cases of considerable complexity, such as spinal cord injury, where the issues of rehabilitation are numerous and interrelated.

Despite the increased focus on holistic health care and the advancements in the profession of physical therapy, there is still a significant area of rehabilitation that continues to be overlooked. That area is the sexual readjustment of patients after a disabling event such as a spinal cord injury.

Spinal cord injury represents a significant portion of the rehabilitation services provided in this country. It is estimated that there are over 200,000 people with spinal cord injury in the United States, with 7,000 to 10,000 new incidents of traumatic spinal cord injury every year. The demographics of this population show that 80% are male, over 50% are between the ages of 15 and 30, and the average age of onset is eighteen (Buchanan, 1987).

Spinal cord injury demands readjustment in virtually all aspects of the patient's life. One aspect that has been neglected by rehabilitation professionals in the past is sexuality. Sexuality is more than the ability to perform the physical act of intercourse. It is made up of biological, psychological, and sociocultural processes. The spinal cord injured patient faces changes in all facets of sexuality: altered physiological function, sexual identity, altered relationships, behavioral modifications, and response to society's misconceptions and stereotypes.

Sexuality is a vital element of the whole person and needs to be consistently addressed in the rehabilitation process.

The rehabilitation process relies on a multi-disciplinary approach, with each profession adding expertise to achieve rehabilitation goals, (Scully & Barnes, 1989). Sexuality should also be treated in the same way. Physical therapy has much to offer in regard to assessing sexual function and offering insights into possible adaptations through such areas as sensation testing, range of motion, manual muscle testing, spasticity control, transfers, and positioning. The goal of physical therapy is to help the patient attain the highest level of function possible. Physical therapy goals should include issues of sexuality. No one profession should be solely responsible for sexual issues, but rather all members of the rehabilitation team need to be knowledgeable, and proactively participating, in the process of sexual education for spinal cord injured patients. Studies have shown that people with spinal cord injury tend to choose a rehabilitation team member with whom they have a comfortable relationship to talk to about sexual issues (Drench, 1992; Dunn, 1983; Cole 1992). Physical therapists often form close relationships with spinal cord injured patients due to the extensive time spent together and the hands-on nature of practice, and therefore they should be prepared to address sexual topics. Physical therapists have a responsibility to be active advocates for

their patients and help them gain access to resources and services to obtain the knowledge they need.

In order for physical therapists to receive the education they need to be competent in providing sexual education, there must be a clarification of the physical therapist's role as a contributing member of the rehabilitation team.

The purpose of this study is to ascertain the level of involvement of physical therapists in sexual education of spinal cord injured patients. This includes their educational background as well as their present responsibilities in sexual education. Specifically, what is the role of the physical therapist in providing sexual education for people with spinal cord injuries in the inpatient rehabilitation setting?

CHAPTER TWO

LITERATURE REVIEW

Spinal cord injury became a significant medical diagnosis in the 1940's. Until this time, most people did not survive an injury of this magnitude. After World War II, the medical community was faced with a large number of disabled veterans who, due to the advances in medical technology, survived spinal cord injury. Much of the primary research in spinal cord injury was facilitated by this large group of available subjects.

The early 1950's marked a new era with the development of rehabilitation programs for veterans with spinal cord injury (Buchanan, 1987). These programs were not concerned with sexual rehabilitation. The most appropriate sexual adjustment to spinal cord injury was thought to be the "sublimation of sexual impulses" as reported in Nagler's study (1950). However, because the population of spinal cord injured veterans was exclusively male and of a young age, the problem of sexual function was studied extensively. These studies, published in the 1960's and early 1970's, focused almost exclusively on the anatomical and physiological changes that occurred. Comarr (1973) performed extensive research in order to determine how the level of injury affected sexual function. At this time sexual function was synonymous with the ability to perform

coitus (sexual intercourse). Data was collected to assist physicians in determining the sexual potential of a spinal cord injured patient. He stated that sexual potential could only be predicted after the physician completed a thorough neurological exam. The exam should assess sensory and motor segmental levels, reflex activity or the absence thereof, and whether the injury is complete or incomplete. Sexual function is classified on the basis of the neurological status of the sacral segments. Comarr and Gunderson (1975) summarized the four types of possible lesions and their affects on sexual capability.

1) Complete upper motor neuron lesion: no sensation or volitional control of the external rectal sphincter in the presence of external rectal sphincter tone, a positive bulbocavernosus reflex or both.

2) Incomplete upper motor neuron lesion: only light touch sensation or partial loss of pinprick sensation, and the loss of volitional control of the external rectal sphincter tone, a positive bulbocavernosus reflex, or both.

3) Complete lower motor neuron lesion: No sensation, volitional control, or tone of the external rectal sphincter, and no bulbocavernosus reflex.

4) Incomplete lower motor neuron lesion: partial sensation but no volitional control of the external rectal sphincter, no external rectal sphincter tone, and no bulbocavernosus reflex.

These classifications were used to generate assumptions about sexual capability for each type of injury by comparing the men in these categories to self-reports by these men about their sexual functions. The results presented this picture.

1) Complete upper motor neuron lesions: the majority of men with injuries in this category have reflexogenic erections, with 70% able to consummate coitus. Most cannot ejaculate or achieve orgasm.
2) Incomplete upper motor neuron lesions: the majority have reflexogenic erections, with 80% able to consummate coitus. Orgasmic and ejaculatory ability as well as fertility are dependent on the severity of the lesion.
3) Complete lower motor neuron lesions: approximately 75% are not able to have erections, orgasm, or ejaculation. The other 25% can have psychogenic erections, with less ability to perform coitus, orgasm or ejaculate. Chances of fertility are very low.
4) Incomplete lower motor neuron lesions: psychogenic erections are present in 86% of these men, with 90% of the men capable of coitus, and 50% to 70% are able to ejaculate. This group has the best chance at fertility with 10% able to have children.

A psychogenic erection is defined as an erection caused by feelings and thoughts, not by direct physical stimulation. A reflexogenic erection is caused by physical stimulation such as pulling on the catheter or stimulation of the inner thigh. It is not due to sensation but rather to reflexive pathways. Although these types of erections may be present,

this does not guarantee functionality due to the variable quality, duration, and the unpredictability of onset.

Fertility in males is affected by loss of innervation to the muscles that control ejaculation and retrograde ejaculation often occurs into the bladder. If ejaculation does occur, the sperm are seldom viable because of the body's inability to regulate the temperature of the sperm. The testicles are held too close to the body cavity increasing the temperature which becomes too high to promote effective spermatogenesis.

Comarr and Gunderson also noted that women's fertility was unaffected, in most cases, after spinal cord injury, regardless of the level and type of injury. Further, most were able to deliver vaginally. Most lost the ability to achieve orgasm, but sexual activity continued.

The work of Comarr and Gunderson contributed greatly to the body of knowledge concerning the anatomical and physiological effects of spinal cord injury. Sadly, during this time period, many of the psychological and sociological aspects of sexuality were overlocked.

With the 1960's came the sexual revolution. In society it became more acceptable to explore sexual identity and behaviors. Masters and Johnson's (1966) landmark work identified the normal human sexual response. They divided it into four stages: excitement, plateau, orgasm and resolution. Several different pathways can be taken through these stages. Each stage is accompanied by specific

anatomical and physiological changes. These findings could then be used for comparison to other populations including spinal cord injury. This study provided legitimacy to research in the field of sexuality and provided impetus for further research.

In the 1970's, the "me generation" absorbed psychological and sociological theories and terminology that were integrated into the popular culture and applied to all people, especially one's self. The professional literature regarding spinal cord injury reflected the changing nature of society. The researchers expressed concerns that rehabilitation was not meeting the needs of people with disabilities regarding sexuality.

Teal and Athelson (1975) reported that clinically, "sexual adjustment for the spinal cord injured patient can be facilitated by providing him with knowledge of his capabilities." This review article was assembled to facilitate research efforts in sexuality and spinal cord injury.

Berkman (1975) states, " Rehabilitation has too long ignored a vital concern for those who are disabled - their sexuality. Because people who are disabled have been denied recognition as sexual human beings, their need for expression of their sexual concerns has been repressed by professionals who themselves feel inadequate to deal with the subject". She also indicated that professionals who were trained in the medical model of health care delivery were

not as likely to be involved in addressing the sexual concerns of their patients. Their relationships with their clients were on an authoritarian level which served as a deterrent to successful communication. She stated her belief that rehabilitation professionals had an obligation to include sexual counseling in the rehabilitation services for the spinal cord injured patient.

Hahn (1981) believed that the social aspect of sexuality and disability are important in the rehabilitation process and that this aspect was being overlooked. The potential for marriage partners may be reduced, and the need for comprehensive sexuality education was addressed.

Berkman, Weissman, and Frielich (1978) collected data on sexual adjustment from 145 spinal cord injured veterans. This was a multi-dimensional approach that assessed sexuality, not just sexual function, as a component in meeting the person's rehabilitation needs. Three elements of sexuality were analyzed: 1) psychosexual - involving the person's self-concept, 2) social-sexual - the person's relationships with others, and 3) behavioral - specific sexual behaviors. The authors stated " One of the myths concerning the sexuality of spinal cord injured patients is that a great many cannot engage in sexual activity after injury". Yet this study found that most of the subjects were sexually active. This helped to dispel a common misconception. The results also showed a correlation between successful sexual adjustment and increased community

and vocational activities. It promoted the idea that sexual adjustment was a valid and necessary component of the rehabilitation process.

Concern was expressed in the literature not only about the need for sexual education for spinal cord injured patients but also for those professionals involved in their rehabilitation. Comarr and Vigue (1978) observed, after interviewing and evaluating many spinal cord injured patients, that "health professionals, reflecting the society in general, have been guilty of perpetuating the myth that disabled individuals are asexual... counseling should be directed at supporting a patient's ability to make choices in every aspect of his life, including the use of sexual expression". They set forth a model for sexual counseling involving communication skills, attitudes of the counselor, as well as, specific content matter on the anatomy and physiology of sexual response, masturbation, relationships, alternate methods of achieving sexual satisfaction, and technical aids.

Cole (1975) perceived the issue of sexuality as being acknowledged as important by the psychological community but noted that clinical guidelines were lacking for professionals who were working with the patients. Cole compared the sexual response cycles of able-bodied men to spinal cord injured men and found very little difference except in the area of ejaculation and emission.

Both Cole (1975) and Comarr (1978) commented on the disparity in the treatment of men versus women regarding the amount of research and education about the effects of spinal cord injury on female sexuality. Because women's fertility is largely unaffected and society's acceptable sexual role for women was passive, they were not receiving help in adjusting to spinal cord injury. The importance for providing sexual education for all spinal cord injured people was emphasized.

The Sexual Attitude Reassessment (SAR) was developed by the National Sex Forum in San Francisco, CA. Cole, Chilgren, and Rosenberg (1973) modified it for use in training rehabilitation professionals. Cole stated "the seminar's objectives are accomplished by demythologizing sexual behavior, desensationalizing sexual stimuli, and aiding handicapped persons and health professionals to come to a better understanding and acceptance of their own sexuality as well as the sexuality of others". These seminars have been widely utilized in rehabilitation centers.

The effectiveness of the SAR seminars have been studied by Held, Cole, Held, Anderson and Chilgren (1975). Spinal cord injured persons and their spouses reported that 92% felt the seminars were worthwhile. Rehabilitation professionals reported that 99% felt the seminars were beneficial and that 88% felt it should be part of the rehabilitation professional's curriculum. Ducharme (1987)

has also evaluated the SAR's effectiveness with very similar results to Held et al.

As different methods of sexual education for patients and professionals developed, researchers began to ask people with spinal cord injuries how well their needs were being met. Cole, in unpublished data cited in Teal and Athelstan (1975), reported that in a sample of paraplegics and quadriplegics, 70% reported that they had no education or counseling in sexual adjustment during initial rehabilitation, and yet 70% reported an active sex life as important, and 75% felt that explicit sexual counseling was needed in the first six months after injury. Zwerner (1982) found that only 55% of the women in her sample had received sexuality counseling. When asked if sexual education was desired in specific forms, 46% chose individual counseling, 37% chose sexuality workshops, and 29% chose ongoing group counseling. Only 10% requested sexual education in the rehabilitation process. She concluded that sexual education should be addressed with all people with spinal cord injuries, even if they don't ask.

Remarkably, even recent literature indicates that the need for sexual education in spinal cord injury rehabilitation is not being met. Donohue and Gebhard (1995) compiled comprehensive data comparing pre-injury and post-injury sexual outlet and response for people with spinal cord injuries. They stated that "the sexual knowledge of our sample was primarily obtained through the efforts of the

individuals themselves; many fewer had it offered to them." The sources of knowledge were ranked: 1) personal experience, 2) reading, 3) professionals other than physicians, 4) other spinal cord injured people or their families, 5) physicians. Responses to the question "What else helpful have you learned?" were varied, but several answers related or referred to sexual education by rehabilitation professionals. They expressed the need for sex education for physicians, sexual seminars and conferences, sexual counselors on staff, and further research. They also expressed frustrations with health care professionals by such comments as: "One needs other spinal cord injured people to talk with about sex since professionals avoid the subject." and "Professionals should not place their biases and misinformation on the spinal cord injured." and "The spinal cord injured should receive immediate information and counseling about sex." (Donohue and Gebhard, 1995).

Tepper (1992) found that less than 50% of his sample had received sexual education or sexual counseling services. He also found that when sexual education does occur, it is often superficial, dealing primarily with sexual function. Psychosocial issues, alternative positions, and assistive devices were generally not covered. He offered these recommendations:

1) Discussion of sexuality be initiated early

2) At a minimum, a combination of written materials, videos, and individual counseling be offered
3) Four or more sessions are dedicated to topics relating to sexuality
4) Other people with spinal cord injuries who have more sexual experience be available for consultation
5) The individual's physician be open and available for consultation.

Drench (1992) quotes a 20 year old client. " Why won't they talk about it? It's my sex life...or is it?" She expresses a need for professionals to treat sexuality as an aspect of total rehabilitation, for it affects many aspects of life. This holistic view is shared by many other researchers. Cole (1993) carried this idea further by identifying sexuality as a dynamic process that continues throughout the lifetime, not just during adjustment to an injury. He cautions that "inherent in this modern approach to health care is the assumption that the physician and other health professionals are educated and knowledgeable, both about human sexuality and the individual and the specific disability".

The nursing profession has accepted a purported holistic model (P-LI-SS-IT) for the sexual education of clients developed by Annon (Goddard, 1988; Spica, 1989; Chicano, 1989). The P represents permission granted by the professional for the client to have and express sexual concerns. The LI represents limited information provided to

the client on his or her direct sexual concerns. The SS represents specific suggestions for the client and his or her significant other to help change a behavior. The IT represents intensive therapy that is provided if brief therapy was ineffective (Spica, 1989). The model did incorporate physical and psychological approaches, but it appeared to be based on the authoritarian medical model rather than on a holistic, patient-focused, model of health care delivery.

Mackelprang (1993) described a holistic approach from a sociological perspective. This program included: anatomy and physiology of sexual response, condition-specific education, emotional concerns, practical physical sexual knowledge, sexual options and relationships. The program described is lacking in dimension. While social work could provide some services, other rehabilitation professionals have much knowledge to offer in their areas of expertise.

Novak and Mitchell (1988) investigated the perceived importance of sexual counseling for spinal cord injured patients by rehabilitation nurses and occupational therapists. They found a gap between the high theoretical importance of counseling expressed and the actual amount of counseling done in practice. They stated concerns about the training of professionals, specifically occupational therapists, in sexuality.

In reviewing the literature, the most beneficial approach to sexual education with the spinal cord injured

population seemed to be a comprehensive holistic program proactively provided by a multi-disciplinary team (Drench, 1992; Chubon, 1981; Cole, 1973). The implications of spinal cord injury affect all aspects of a person's life. Sexuality affects all aspects of any person's life. Therefore comprehensive sexual education to help people with spinal cord injury achieve optimum sexual satisfaction is a responsibility of all members of the rehabilitation team. Dunn (1983) states, " Patients don't necessarily ask medical questions of M.D.s, nursing questions of nurses, or psychological questions of the psychological staff. All staff must be competent in answering questions or in knowing to whom to refer". Rusk (cited in Drench, 1992) related that "Clients are likely to approach anyone on the professional staff with whom they feel comfortable about sensitive issues, such as sexuality and sexual function, so all staff must be educated to deal with these issues." Breske (1996) offers recommendations regarding rehabilitation staff competencies; including values, knowledge, and skill needed for a successful sexual education program for people with disabilities.

Staff Values

- how their religious beliefs influence their sexual attitudes
- their attitudes toward masturbation, oral sex, and alternative forms of sexual expression
- their attitudes about homosexuality
- their reaction to sexually explicit language

- their reaction to sexual behavior among partners who are not in a loving relationship
- their emotional reaction to the occasional disfiguring qualities of injury
- their own feelings of attachment, anger, frustration, pity, and love toward people they work with.

Staff Knowledge

- physical changes in sexual functioning
- cognitive and perceptual difficulties that affect intimacy and sexual satisfaction
- emotional sequelae and adjustment issues affecting intimacy and sexuality
- emotional reactions and feelings toward the person

Staff Skills

- permit and recognize that sexual issues are relevant to rehab
- provide information and suggestions to promote sexual satisfaction
- provide training in communication and social skills that encompass intimacy
- facilitate emotional and sexual adjustment through counseling, role playing, and empathetic listening
- provide referrals for specific sexual problems
- promote an atmosphere in which caring for others, dignity and mutual respect are encouraged

Drench (1992) stated " Health care professionals can educate the individual about sexuality and sexual behaviors in the same manner as they teach mobility, activities of daily living, and other important rehabilitation skills. This intervention can enhance sexual adjustment and overall acceptance and adjustment to spinal cord injury."

Although physical therapists are an integral part of the rehabilitation team, there have not been any studies that directly assess the physical therapist's role in sexual education of persons with spinal cord injury. Physical therapists have much to offer in the evaluation and

education of spinal cord injured clients about sexual issues. This includes specific areas of expertise, as well as receiving education in a holistic, multi-disciplinary approach to health care delivery during the professional curriculum. It is essential for the profession of physical therapy to define its role in sexual education and provide standards for education in order to meet this end.

The purpose of this study is to collect data by survey to help define the role of the physical therapist in the sexual education of people with spinal cord injury during inpatient rehabilitation.

CHAPTER THREE

METHODOLOGY

Descriptive data was collected by questionnaire in an attempt to define the current practices for physical therapists in regard to sexual education of people with spinal cord injuries during inpatient rehabilitation. The population sampled was licensed physical therapists working in spinal cord injury units in inpatient rehabilitation facilities.

A purposive sampling method was used to delineate the subjects for this study. There are over 5000 spinal cord injury units across the United States. Of these 5000 facilities, only ninety-three have been accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF) as of May 1, 1995. The commission was formed in 1966 to provide standards for care and a method of evaluation for rehabilitation facilities. The CARF mission is " to serve as the preeminent standards-setting and accrediting body promoting the delivery of quality services to people with disabilities" (CARF standards manual). The standards are set by a national consensus of a multi-disciplinary committee and are evaluated and revised continually. CARF is a non-profit commission whose members are from a wide variety of professional disciplines as well as client-specific organizations. Included are the American Physical

Therapy Association, the National Spinal Cord Injury Association, and the American Spinal Cord Injury Association. The commission has set forth values for CARF that are included as appendix A. In view of the high standards set forth by CARF (both physical therapists and people with spinal cord injuries contributed to setting the criteria of these standards and evaluation processes), only CARF accredited spinal cord injury programs were used in this investigation. From these CARF facilities, a random sample of 50 facilities was drawn. This number was determined by a random survey of five facilities as to the number of physical therapists employed in the spinal cord injury unit. The average number was four. A total of 200 surveys was sent determining the facility sample size of 50 spinal cord injury units, with four surveys sent to the physical therapists in each facility.

The subject inclusion/exclusion criteria are:

1) The subject must have at least one or more years of experience working as a licensed physical therapist in an inpatient spinal cord injury program.

2) The subject must be presently working in a spinal cord injury program as a licensed physical therapist.

The survey instrument was designed by the investigator because a suitable instrument was not found that combined the issue of patient sexual education in direct relationship to physical therapy practice. The survey questions were

formulated from four guiding questions: (1) Are physical therapists involved in sexual education of spinal cord injured patients? (2) What factors contribute to a physical therapist's involvement or lack thereof? (3) At what level is this involvement? (4) How did the therapist attain his or her knowledge on the subject of spinal cord injury and sexuality? The survey instrument is included as appendix B.

Four surveys, with cover letters and instructions (appendix C), and a stamped return envelope were sent to the director of physical therapy at each CARF accredited facility. The surveys were kept strictly confidential. To ensure this end, the subjects were not asked for their names or for personal information that could potentially identify them. Further, the return envelopes were coded with each facility designated by a specific number one through fifty. When the surveys were received, the investigator separated the surveys from the marked envelopes. In this manner the investigator was unable to trace which surveys came from which facility while still being able to contact those facilities which did not respond. The surveys were mailed December 21, 1995 and completed surveys were expected on January 15, 1995. Reminder postcards were sent to facilities which did not respond by this date. February 12, 1996 was the last date surveys were accepted. Data analysis began at this time.

The data were analyzed using descriptive statistics. Frequency of response counts and percentages were recorded.

Statistical analysis was performed on the data collected to see if relationships existed between key variables. Analysis included scatterplots and correlation coefficients between continuous variables, t-tests and Wilcoxon rank sum tests between categorical and continuous variables, and chi-square analysis between categorical variables.

CHAPTER FOUR

RESULTS

Surveys were accepted for six weeks to allow for maximum sample size. The resulting sample size was n=72. The gross return rate was 39.5%, with 36% meeting the inclusion criteria. Seven surveys received could not be included in this study because either the surveys arrived after the deadline, or they did not meet the inclusion criteria of one year of clinical experience as a licensed physical therapist. Multiple surveys were sent to each facility and the gross response rate did not reflect the facility response rate which was 78%.

Demographics

The demographic data is shown in table 4-1. To summarize, seventy-two licensed physical therapists (11 males and 61 females), who reported at least one year of experience working full time in an inpatient rehabilitation CARF accredited spinal cord injury unit, returned surveys. The average age of the study participants was 30.6 years. Of the sample studied, 53 (73.6%) of the people held an undergraduate degree, while 19 (26.4%) held a graduate degree, in physical therapy. Forty-two people studied held degrees in fields other than physical therapy with 37 (88.1%) holding undergraduate and 5 (11.9%) holding graduate

Table 4-1: Demographics

GENDER	**#**
Male	11
Female	61

AGE	**YEARS**
Avg	30.6
SD	6.3
Median	28.0
Min	24.0
Max	60.0

EXPERIENCE	**YEARS**
Lic. PT:	
Mean	7.0
SD	5.0
Median	5.0
Min	1.0
Max	21.0
Lic. PT in SCI unit:	
Mean	4.8
SD	3.9
Median	4.0
Min	1.0
Max	18.0

PT DEGREES	**#**	**PERCENT %**
Undergrad	53	73.6
Grad	19	26.4

OTHER DEGREES	**#**	**PERCENT %**
Undergrad	37	88.1
Grad	5	11.9

degrees. The average number of years of practice in physical therapy was 7.0; and the mean number of years worked in a spinal cord injury unit was 4.8.

Closed-Ended Questions

These questions collected categorical data on a variety of topics and the responses are summarized in table 4-2.For one of the closed-ended questions a comment section was included. The results were as follows. Do you think a course on sexuality and disability should be a required portion of the professional curriculum for physical therapists? Fifty-eight people (82.9%) said yes, and 12 people (17.1%) reported no. Seven of the therapists who answered no felt an entire course was not necessary but indicated that the subject should be covered as part of a course or as a seminar.

Multiple Response Questions

These questions were designed to collect general information on referral, practice issues, and educational background. Physical therapists were asked to indicate to whom they refer when they do not feel prepared to answer a patient's questions about sexuality, and record the percentage of referrals made to each professional indicated. The responses are recorded in table 4-3. Twelve people indicated the category marked other. Of these, three made no comment. The remaining responses reported referral to urologists (3), a urology sex clinic, a neuropsychologist, a licensed professional counselor, a peer counselor, an education specialist, and a case manager.

Table 4-2. Closed-Ended Questions

Closed-Ended Questions	YES (%)	NO (%)	N=
Have you worked with spinal cord injured persons in another capacity?	28.8	71.2	66
Have you had a spinal cord injury?	0.0	100.0	72
Do you have family members or close friends who have had spinal cord injuries?	25.0	75.0	72
Do you address sexual issues with spinal cord injured patients only when asked?	63.2	36.8	68
Do you think it is appropriate for physical therapists to be involved in the sexual education of spinal cord injured patients?	97.0	3.0	67
Do you think a course on sexuality and disability should be a required portion of the professional curriculum for physical therapists?	82.9	17.1	70

Table 4-3. Referrals to Other Professionals

PROFESSIONAL	# of RESPONSES	AVERAGE%
Physician	54	30
Nurse	34	19
Psychologist	46	29
Social worker	16	8
Occupational therapist	10	4
Other	12	8

n= 67

The investigator inquired where physical therapists obtained their information/education about issues of sexuality and spinal cord injury. They were asked to circle all categories that applied. The responses to this question are displayed in table 4-4.

Table 4-4. Sources of Information Obtained by Physical Therapists on Sexuality and Spinal Cord Injury

SOURCES	# of RESPONSES
Professional curriculum	48
Continuing education	41
In-services/workshops at facility	43
Independent study	34
Information from a person with SCI	30
Haven't received any (information)	3
Other	3

n=70

The three people who chose the category marked other indicated these sources were by word of mouth in the SCI unit, nursing, and a spinal cord injury patient manual distributed to all spinal cord injured patients at that facility.

The survey asked where resources regarding sexuality and spinal cord injury were available to the physical therapists. They could choose as many locations as were applicable. This data is expressed in table 4-5. The category marked other contained references to staff in general, other physical therapists, rehab unit staff, occupational therapist, nurse specialist in spinal cord injury, a sexuality program (in facility), and friends.

Table 4-5. Location of Resources

LOCATION	# of RESPONSES
Personal library	43
Department	39
Facility	61
None available	1
Unsure	3
Other	8

n=70

The survey inquired about the types of resources physical therapists used with spinal cord injured patients during sexual education. They were instructed to indicate all that applied from the list. The resulting data follows in Table 4-6. Sixteen participants chose the category marked other; of these eight made no comment and one indicated no resources were used. The other types of resources recorded in this category were verbal discussion, one on one counseling, staff from the sex education program, information from in services and courses, computer education series, and models.

Table 4-6. Types of Resources Used with Spinal Cord Injured Patients During Sexual Education

TYPES of RESOURCES	# of RESPONSES
Books	40
Periodicals	29
Films/videos	33
Audio tapes	2
Catalogues	6
Other	16

n=60

In order to determine the types of topics physical therapists have discussed with their patients in regard to sexuality and spinal cord injury, they were asked to

indicate which topics they covered from a list. They were then asked to estimate the percentage of patients with whom they had discussed the topic. The data collected from this question is presented in table 4-7.

Continuous Variables

For these questions the participants were asked to mark their position on a line scale with an x with the two end points being opposite extremes. The distance from the left origin of the line to the x was measured and recorded by the investigator. These questions asked the physical therapists about their attitudes toward sexual education for the general population and for people with disabilities. They were asked about practice issues concerned with addressing sexual issues with spinal cord injured patients versus initiating discussions of sexual issues. They were asked to report their feelings regarding preparedness and comfort level in handling issues of sexuality with spinal cord injured patients. The resulting data are presented in table 4-8.

Statistical analyses were performed. Scatterplots and correlation coefficients, t-tests and Wilcoxon rank sum tests, and chi-square analysis were used where appropriate to see if relationships existed between key variables.

Pearson and Spearman correlation coefficients were calculated between continuous variables, and scatterplots were used to assess the linearity of these relationships.

Table 4-7. Topics Covered by Physical Therapists During Sexual Education with Spinal Cord Injured Patients

TOPICS	# of RESPONSES	AVERAGE %
Erection/vaginal lubrication	25	18
Orgasm	16	10
Intercourse	29	22
Fertility and birth control	27	18
Sensation	30	21
Oral/anal stimulation	9	5
Sexual positions	20	12
Transfers	23	18
Sensual massage	6	2
Masturbation	5	4
Body image	31	28
Self Confidence	35	32
Incontinence	19	18
Catheters during sex	11	7
Spasticity control	23	16
Autonomic dysreflexia	37	38
Communication with partner	35	26
Dating	31	22
Marriage	26	15

n=60

Table 4-8. Responses to Continuous Variables

Continuous Variables	MEAN	SD	MED.	MIN.	MAX.	N=
How important do you feel sexual education is for the general population? Very important=0mm Very unimportant=110mm	12.2	15.6	5.5	0.0	75.0	72
How important do you feel sexual education is for people with disabilities? Very important=0mm Very unimportant=110mm	7.0	11.8	4.0	0.0	91.0	72
Do you address issues of sexuality with your spinal cord injured patients? Always=0mm Never=120mm	65.4	33.7	71.5	2.0	119.0	68
Do you initiate discussions of sexuality with your spinal cord injured patients? Always=0mm Never=120mm	84.9	31.5	94.0	3.0	120.0	67
How prepared do you feel to handle questions about the impact of spinal cord injury on sexuality? Very prepared=0mm Very unprepared=120mm	52.7	34.7	51.5	0.0	116.0	70
Please assess your comfort level in discussing sexual issues with members of the opposite sex in the clinical setting. Completely at ease=0mm Extreme discomfort=110mm	47.7	26.8	49.0	0.0	117.0	72
Please rate your comfort level in discussing sexual issues with members of the same sex in the clinical setting. Completely at ease=0mm Extreme discomfort=110mm	32.2	25.5	25.5	0.0	107.0	72

There appear to be strong linear relationships (expressed as Pearson coefficients) between the therapists' level of preparedness in dealing with sexual issues with spinal cord injured patients and their comfort level in discussing sexual issues with members of the same (.6807) or opposite sex (.5768), between preparedness and the frequency that therapists address sexual issues (.7513), and between preparedness and the frequency that therapists initiate discussions of sexuality (.6133). There was moderate correlation between the physical therapists' comfort level in discussing issues of sexuality with members of the opposite sex and the frequency of addressing issues of sexuality (.4823) as well as the frequency of initiating discussions of sexuality (.4449) with spinal cord injured patients. There was similar correlation between therapists' comfort level in discussing sexual issues with members of the same sex and the frequency of addressing sexual issues (.5346), and in initiating discussions of sexuality (.4302), with spinal cord injured patients. The scatter plots are included as Appendix D, and the correlation coefficients are expressed in table 4-9.

T-tests and Wilcoxon rank sum tests (alpha=.05) were performed to test for relationships between continuous and categorical variables. The data from the t-tests follows in table 4-10. The assumptions for normality of the t-tests appeared reasonable. All the t-tests showed no statistical significance except for the relationship between males and

Table 4-9. Pearson and Spearman Correlation Coefficients between Continuous Variables

VARIABLES	PEARSON	SPEARMAN
Age		
Comfort level discussing sexual issues with the opposite sex:	-0.2518	-0.2241
Comfort level dicussing sexual issues with the same sex:	-0.2812	-0.2173
Preparedness regarding the impact of SCI on sexuality:	-0.2559	-0.2271
Frequency of addressing sexual issues with SCI patients:	-0.2974	-0.3108
Frequency of initiating discussions of sexuality with SCI patients:	-0.1841	-0.2281
Years of practice as a PT		
Comfort level discussing sexual issues with the opposite sex:	-0.2629	-0.2286
Comfort level dicussing sexual issues with the same sex:	-0.2725	-0.2253
Preparedness regarding the impact of SCI on sexuality:	-0.3059	-0.2841
Frequency of addressing sexual issues with SCI patients:	-0.2910	-0.2851
Frequency of initiating discussions of sexuality with SCI patients:	-0.2093	-0.2350
Years of practice as a PT in SCI unit		
Comfort level discussing sexual issues with the opposite sex:	-0.3433	-0.3328
Comfort level dicussing sexual issues with the same sex:	-0.2900	-0.2466
Preparedness regarding the impact of SCI on sexuality:	-0.4244	-0.4486
Frequency of addressing sexual issues with SCI patients:	-0.3942	-0.4544
Frequency of initiating discussions of sexuality with SCI patients:	-0.2702	-0.3506
Preparedness		
Comfort level discussing sexual issues with the opposite sex:	0.5768	0.5450
Comfort level dicussing sexual issues with the same sex:	0.6807	0.6318
Frequency of addressing sexual issues with SCI patients:	0.7513	0.7515
Frequency of initiating discussions of sexuality with SCI patients:	0.6133	0.6598
Comfort level with opposite sex		
Preparedness regarding the impact of SCI on sexuality:	0.5768	0.5450
Frequency of addressing sexual issues with SCI patients:	0.4823	0.4279
Frequency of initiating discussions of sexuality with SCI patients:	0.4449	0.3609
Comfort level with same sex		
Preparedness regarding the impact of SCI on sexuality:	0.6807	0.6318
Frequency of addressing sexual issues with SCI patients:	0.5346	0.5446
Frequency of initiating discussions of sexuality with SCI patients:	0.4302	0.4465

Table 4-10. Relationships between Key Variables as Determined by T-tests.

RESPONSE	GROUP	MEAN	STD	t	d.f.	p
Education						
Importance of sexual education for the general population:	undergraduate	13.3	17.1	0.99	70	0.07
	graduate	9.2	10.1			
Importance of sexual education for people with disabilities:	undergraduate	7.5	13.3	0.53	70	0.35
	graduate	5.8	6.2			
Comfort level discussing sexual issues with the opposite sex:	undergraduate	45.4	26.3	-1.22	70	0.23
	graduate	54.1	27.8			
Comfort level discussing sexual issues with the same sex:	undergraduate	30.6	23.1	-0.85	70	0.21
	graduate	36.5	31.5			
Preparedness regarding the impact of SCI on sexuality:	undergraduate	51.0	33.8	-0.66	68	0.41
	graduate	57.3	37.5			
Frequency of addressing sexual issues with SCI patients:	undergraduate	62.1	32.6	-1.32	66	0.70
	graduate	74.1	36.1			
Frequency of initiating discussions of sexuality with SCI patients:	undergraduate	84.2	31.0	-0.26	65	0.57
	graduate	86.5	33.9			
Gender						
Importance of sexual education for the general population:	male	12.3	13.2	0.01	70	0.98
	female	12.2	16.1			
Importance of sexual education for people with disabilities:	male	6.5	5.8	-0.18	70	0.55
	female	7.1	12.7			
Comfort level discussing sexual issues with the opposite sex:	male	52.7	27.3	0.62	70	0.42
	female	46.9	26.8			
Comfort level discussing sexual issues with the same sex:	male	29.3	25.0	-0.41	70	0.57
	female	32.7	25.7			
Preparedness regarding the impact of SCI on sexuality:	male	64.2	25.2	1.13	68	0.08
	female	50.8	35.8			
Frequency of addressing sexual issues with SCI patients:	male	76.2	25.9	1.10	66	0.04
	female	63.6	34.8			
Frequency of initiating discussions of sexuality with SCI patients:	male	88.8	27.9	0.43	65	0.157
	female	84.2	32.3			
Addressed sexual issues only when asked						
Importance of sexual education for people with disabilities:	yes	7.8	14.6	0.49	66	0.27
	no	6.3	6.0			
Comfort level discussing sexual issues with the opposite sex:	yes	52.5	23.1	1.56	66	0.06
	no	42.4	30.0			
Years of practice as a licensed physical therapist:	yes	6.9	5.4	-0.47	66	0.83
	no	7.5	4.7			
Years of practice as a licensed P.T. in a SCI unit:	yes	4.4	4.1	-1.2	66	0.57
	no	5.6	3.9			
Age:	yes	30.1	6.6	-0.82	64	0.79
	no	31.4	5.4			
Family members/close friends with SCI						
Importance of sexual education for the general population:	yes	12.1	16.9	-0.06	70	0.56
	no	12.3	15.3			
Importance of sexual education for people with disabilities:	yes	8.4	9.0	0.55	70	0.45
	no	6.6	12.7			
Comfort level discussing sexual issues with the opposite sex:	yes	49.4	28.9	0.32	70	0.50
	no	47.1	26.3			
Comfort level discussing sexual issues with the same sex:	yes	29.6	24.4	-0.49	70	0.70
	no	33.0	26.0			
Preparedness regarding the impact of SCI on sexuality:	yes	42.7	31.9	-1.43	68	0.61
	no	56.2	35.2			
Frequency of addressing sexual issues with SCI patients:	yes	58.4	31.0	-1.00	66	0.41
	no	67.8	34.6			
Frequency of initiating discussions of sexuality with SCI patients:	yes	81.6	27.8	-0.49	65	0.37
	no	86.0	32.9			

females addressing sexual issues with SCI patients. Females reported a higher frequency of addressing sexual issues than did their male counterparts. This may not be an accurate assumption due to the small number of males in the study sample.

Wilcoxon rank sum tests were used on relationships that did not satisfy the distributional assumptions of the t-test. The first relationship tested was the therapist's feelings of preparedness to handle sexual issues and whether he or she addressed sexual issues only when asked by SCI patients. The mean rank reflected a significant difference between subjects that said yes and subjects that said no indicating that physical therapists who felt less prepared addressed sexual issues only when asked, whereas therapists who felt more prepared did not wait for patients to ask and presumably initiated some discussions of sexuality with their patients. The second relationship tested was the therapist's comfort level discussing sexual issues with members of the same sex and whether he or she addressed sexual issues only when asked. The mean ranks reflected a significant difference between subjects that said yes and subjects that said no, indicating that physical therapists who felt less comfortable discussing sexual issues with members of the same sex addressed sexual issues only when asked, whereas therapists who felt more comfortable did not wait for patients to ask and presumably initiated some

discussions of sexuality with their patients. The third tested was the relationship between addressing issues of sexuality with SCI patients and gender (of the therapist). This relationship did not show significant differences. These results are expressed in table 4-11.

Table 4-11. Relationships Tested by Wilcoxon Rank Sum Tests

RESPONSE	GROUP	MEAN RANK	CASES	P
Preparedness				
Addressed sexual issues only	yes	40.02	43	0.0025
when asked:	no	25.00	25	
Comfort level (same sex)				
Addressed sexual issues only	yes	39.84	43	0.0035
when asked:	no	25.32	25	
Addressed sexual issues				
Gender:	yes	39.95	10	0.3452
	no	3.56	58	

Chi-square analysis was used for the categorical data, and was performed on three possible relationships. The relationship of addressing sexual issues with SCI patients only when asked, to gender resulted in a p-value= 0.63095. Analysis of the relationship between addressing sexual issues only when asked, to education level resulted in a p-

value=0.56952. Addressing sexual issues only when asked, analyzed with having a family member or close friend with a spinal cord injury resulted in a p value=0.17442. None of these relationships was significant.

CHAPTER FIVE

DISCUSSION & CONCLUSION

Discussion

This study was designed as a descriptive study to gather information about the physical therapist's role in the sexual education of spinal cord injured patients. The survey questions were formulated from four guiding questions: (1) Are physical therapists involved in sexual education of spinal cord injured patients? (2) What factors contribute to a physical therapist's involvement or lack thereof? (3) At what level is this involvement? (4) How did the therapist attain his or her knowledge on the subject of spinal cord injury and sexuality? The four questions will be used to direct the discussion.

Are physical therapists involved in sexual education of spinal cord injured patients? The survey results indicate that physical therapists are involved in sexual education. The physical therapists addressed issues of sexuality 46% of the time (mean of 65.4 on a scale of 0 to 120, 0=always and 120=never). The physical therapists initiated these discussions of sexual issues 30% of the time (mean of 84.9 on a scale 0 to 120, 0=always and 120=never). When asked specifically if they addressed sexual issues with patients only when asked, 63% indicated yes, while 36% said no,

presumably indicating that these 36% did initiate discussions with patients. It is not clear whether the therapists who answered no to this question were indicating that they initiate discussions or that they did not discuss sexual issues at all. Less than half of the patients are receiving any sexual education information from physical therapists (assuming that the frequency of addressing issues of sexuality can be equated to the number of patients with which they have addressed sexual issues and not only the number of times they have addressed these issues). If patients don't initiate the discussions, only one third of the people are getting any information regarding sexuality and spinal cord injury. The results of this study correspond with several studies of spinal cord injured patients and the sexual education they received during rehabilitation. Tepper (1992) found that less than 50% of his sample had received sexual education or sexual counseling services. Donohue and Gebhard (1995) indicated that the primary (26%) and secondary sources (17%) of sexual knowledge were personal experience and reading, respectively. The trend that has been observed in studies looking at sexual education in rehabilitative programs as a whole has also been reflected in this study for physical therapy. Although neither of the previous studies looked at physical therapy specifically, there was agreement in the amount of services provided in this area of rehabilitation for people with spinal cord injury. Medlar (1996) relates

"when I ask consumers or their families if they've received sexuality education or counseling during rehabilitation, they consistently say "no". The needs of clients with spinal cord injury are not being met in regard to education about sexuality by physical therapists or the rehabilitation system.

What factors contribute to a physical therapist's involvement (in sexual education) or lack thereof? The first step was to ascertain whether physical therapists thought that sexual education was important for people with disabilities. The sample attached high importance to this topic, with an average score of 7.0 (0=very important and 110=very unimportant). Ninety-seven percent of the therapists agreed that sexual education during rehabilitation of spinal cord injured patients was an appropriate area for physical therapy involvement. The results of this study correspond with the results obtained by Novak and Mitchell (1988) who investigated the professional involvement of rehabilitation nurses and occupational therapists in sexual counseling for spinal cord injured patients. They found a gap between the high theoretical importance of counseling expressed and the actual amount of counseling done in practice. These results mesh with the results of this study. Although physical therapists rate sexual education as an important topic, this did not correspond with their level of involvement in sexual education in practice. Because there was widespread

agreement in the sample about the importance of sexual education and the appropriateness of physical therapists' involvement in sexual education, these variables were not considered as predictors for the therapists' level of involvement in this area of rehabilitation. Analysis of demographic variables did not show any significant relationships or serve as predictors to the level of involvement of the therapist in sexual education.

There does appear to be significant correlation between the therapist's level of preparedness about the impact of spinal cord injury on sexuality and the frequency of addressing sexual issues with spinal cord injured patients. This was found in analysis of scatter plots, correlation coefficients, and in a t-test. The therapists who felt more prepared about the impact of spinal cord injury on sexuality reported higher frequencies of addressing sexual issues with clients, while therapists who felt less prepared reported a lower frequency. A lack of preparedness or education was also noted as a reason for rehabilitation nurses and occupational therapists to be uninvolved in sexual education of spinal cord injured patients (Novak & Mitchell, 1988).

Breske (1996) provided the following guidelines regarding rehabilitation staffs' knowledge about the impact of disability on sexuality, and skills "to promote healthy sexual development after an injury":

Staff Knowledge

- physical changes in sexual functioning
- cognitive and perceptual difficulties that affect intimacy and sexual satisfaction
- emotional sequelae and adjustment issues affecting intimacy and sexuality
- emotional reactions and feelings toward the person

Staff Skills

- permit and recognize that sexual issues are relevant to rehab
- provide information and suggestions to promote sexual satisfaction
- provide training in communication and social skills that encompass intimacy
- facilitate emotional and sexual adjustment through counseling, role playing, and empathetic listening
- provide referrals for specific sexual problems
- promote an atmosphere in which caring for others, dignity and mutual respect are encouraged

Physical therapy, as a profession, needs to provide this type of education for all therapists in order to better meet the needs of rehabilitation clients. There is a need for education on sexuality and disability to be included in professional curricula and in the continuing education of physical therapists already in practice.

The other predictor that is significantly correlated with the frequency of involvement in addressing and/or initiating discussions of sexuality is the physical therapist's comfort level in discussing sexual issues. There was no significant difference in comfort level in discussing sexual issues with members of the same or opposite sex. With either sex, as comfort level increased the frequency of involvement in sexual education increased.

This indicates a need for physical therapists to find ways to become more comfortable in order to improve the sexual education services provided. The first step is for the therapists to understand and become comfortable with their own sexuality. Breske (1996) outlined values and attitudes that rehabilitation staff should identify for themselves so as not to deny sexual education services to patients or to impose their attitudes on their patients.

Staff Values

- how their religious beliefs influence their sexual attitudes
- their attitudes toward masturbation, oral sex, and alternative forms of sexual expression
- their attitudes about homosexuality
- their reaction to sexually explicit language
- their reaction to sexual behavior among partners who are not in a loving relationship
- their emotional reaction to the occasional disfiguring qualities of injury
- their own feelings of attachment, anger, frustration, pity, and love toward people they work with.

The Sexual Attitude Reassessment (SAR) was developed by the National Sex Forum in San Francisco, CA. Cole, Chilgren, and Rosenberg (1973) modified it for use in training for rehabilitation professionals. Cole stated "the seminar's objectives are accomplished by demythologizing sexual behavior, desensationalizing sexual stimuli, and aiding handicapped persons and health professionals to come to a better understanding and acceptance of their own sexuality as well as the sexuality of others". The effectiveness of the SAR seminars has been studied by Held, Cole, Held, Anderson and Chilgren (1975). Rehabilitation professionals

reported that 99% felt the seminars were beneficial and that 88% felt it should be part of the rehabilitation professional's curriculum. This type of seminar could be utilized in physical therapy curricula and in continuing education programs to improve the therapists' comfort level in discussing sexual issues with their patients.

At what level is this involvement of physical therapists in sexual education of spinal cord injured patients? Descriptive data was collected about the frequency of involvement as mentioned above, but also about the topics covered, the types of resources used with patients, and to whom patients were referred when the therapist was unable to answer the patients questions.

Table 4-6 shows the most common topics covered by physical therapists with spinal cord injured patients in regard to sexuality were 1) autonomic dysreflexia, 2) self-confidence, and also communication with partner, 3) body image, 4) dating, and 5) sensation. The therapists were asked to estimate the percentage of patients with which they discussed each topic. The average percentages estimated by the therapists were quite low. The six topics that received the five highest percentages were as follows: 1) autonomic dysreflexia 38%, 2) self-confidence 32%, 3) body image 28%, 4) communication with partner 26%, 5) intercourse and dating 22%. A category marked other would have been appropriate for this two part question about topics covered during sexual education of spinal cord injured patients, but was

not included due to oversight by the investigator. With the exception of sensation, the topics covered did not include the areas in which physical therapy has expertise and could be the most helpful to patients, such as transfers, positions, spasticity control and, as an extension of altered sensation, alternate forms of stimulation. It is unclear whether the therapists discuss the common issues reported because they are more comfortable and/or knowledgeable with them and less comfortable and/or knowledgeable with more specific or explicit topics, or whether these topics are addressed because they are of the most concern to the patients and driven by the patients' desire for information on the commonly reported topics. Whatever the reason, the small percentages reported on specific topics covered seem to indicate that when sexual issues are discussed with people with spinal cord injury it is often on a superficial level. This has been indicated in other studies of people with spinal cord injury and their perception of the services they received (Tepper, 1992; and Donohue & Gebhard, 1995).

The types of resources physical therapists used during sexual education are listed in table 4-5. They are recorded according to the frequency selected: 1) books, 2) films and videos 3) periodicals, 4) other (which included many references to other staff members, to in service materials, and to sexual education programs), 5) catalogues, and 6) audio tapes.

The physical therapists were asked to whom they refer when they didn't feel prepared to answer a patient's questions. The results, shown in table 4-2, ranked other professionals in this order 1) physicians, 2) psychologists, 3) nurses, 4) social workers, 5) other (which included urologists, peer counselors, an education specialist, and a case manager), and 6) occupational therapists. The listing of referral sources could reflect the physical therapists' perceptions about which professions are more knowledgeable about sexuality in their facilities. In this study, physicians were the most common referral source for physical therapists, and yet a recent study has shown that physicians may be the least likely source of information according to the patient, Donohue and Gebhard (1995). As seen from this comparison, clients' perceptions and physical therapists' perceptions differ about the delivery of sexual education services by physicians. Possible explanations for this could be the therapists' perception of the physician as all knowing, or the assumption that the physician has more information about the impact of spinal cord injury on sexuality than other members of the rehabilitation team. Several studies have shown that the most beneficial approach to sexual education with the spinal cord injured population seems to be a comprehensive holistic program proactively provided by a multi-disciplinary team (Drench, 1992; Chubon, 1981; Cole, 1973). Physical therapists must accept more

responsibility as a member of this team and take steps to improve their knowledge for this purpose.

How did the therapist obtain his or her knowledge on the subject of spinal cord injury and sexuality? This question was addressed directly and the results are shown in table 4-3. The therapists reported 1) professional curriculum, 2) in services/workshops at facility, 3) continuing education, 4) independent study, 5) information from a person with a spinal cord injury, and 6) haven't received any information and other. Although professional curriculum was the most common source indicated, one third of the therapists did not report this as a source of information. Concern was expressed in the literature not only about the need for sexual education for spinal cord injured patients but also for those professionals involved in their rehabilitation (Comarr & Vigue, 1978; Drench, 1992; Cole, 1993). Rusk (cited in Drench, 1992) related that "Clients are likely to approach anyone on the professional staff with whom they feel comfortable about sensitive issues, such as sexuality and sexual function, so all staff must be educated to deal with these issues." Cole (1993) cautions that "inherent in this modern approach to health care is the assumption that the physician and other health professionals are educated and knowledgeable, both about human sexuality and the individual and the specific disability". Physical therapy as a profession has a responsibility to provide the necessary

education for its therapists to offer patient education on sexuality and disabilities. This need does not appear to have been met according to the results of this study.

Limitations

This research represents the first study (known by the investigator) of the role of the physical therapist in sexual education of people with spinal cord injury during inpatient rehabilitation. The main purpose of the study was to gather descriptive data to bring this topic to the forefront as an important practice issue for the profession of physical therapy. Therefore the instrument was designed by the investigator and was not tested for reliability and validity as that was not essential to the purpose of the survey. The sample size was small and specific in nature so the results may not be generalized to all physical therapists. Issues specific to spinal cord injury may not be viewed as important for physical therapists whose patient population does not include the spinal cord injured. But this study may increase awareness about the need for physical therapists to see all people who have had disabling events as individuals who have a right to the information and services regarding their sexuality from physical therapists and other health care professionals.

Future Research

Further research is suggested to further define the role and responsibilities of physical therapists in sexual education in various treatment settings and with different diagnoses. A larger sample size would give a more accurate portrayal of current practice; and a sampling method that would target individuals rather than facilities could reveal more information. Research is needed into the education of physical therapists about sexuality and disability in professional curriculums and also within continuing education.

Conclusions

Although physical therapists rate sexual education as very important for people with disabilities and feel it is an appropriate area of practice for physical therapists, this does not correspond to the reported frequencies of addressing sexual issues with their spinal cord injured patients. The results of this study correspond with the results obtained by Novak and Mitchell (1988) who investigated the perceived importance of sexual counseling for spinal cord injured patients by rehabilitation nurses and occupational therapists. They found a gap between the high theoretical importance of counseling expressed and the actual amount of counseling done in practice.

The key variables which correlated with frequency of addressing sexual issues with spinal cord injured patients

during inpatient rehabilitation were the therapists' comfort level in discussing sexuality and their level of preparedness on the impact of spinal cord injury on sexuality. Both of these issues indicate a need for further education on this topic for physical therapists.

REFERENCES

Berkman, A.H. (1975). Sexuality: a human condition. Journal of Rehabilitation, 41(1), 13-15.

Berkman, A.H., Weissman, R., & Frielich, M.H. (1978). Sexual adjustment of spinal cord injured veterans living in the community. Archives of Physical Medicine and Rehabilitation, 59, 29-33.

Breske, S. (1996). The forgotten ADL: addressing sexuality and disability in rehab. Advance/Rehabilitation, 1, 43-48.

Buchanan, L.E. (1987). An overview. In L.E. Buchanan & D.A. Nawoczenski (Eds.), Spinal cord injury concepts and management approaches (pp. 1-19). Baltimore: Williams/Wilkins.

Chicano, L.A. (1989). Humanistic aspects of sexuality as related to spinal cord injury. Journal of Neuroscience Nursing, 21, 366-369.

Chubon, R.A. (1981). Development and evaluation of a sexuality and disability course for the helping professions. Sexuality and Disability, 4, 3-15.

Cole, S.S., & Cole, T.M. (1993). Sexuality, disability, and reproductive issues through the lifespan. Sexuality and Disability, 11, 189-205.

Cole, T.M. (1975). Sexuality and physical disabilities. Archives of Sexual Behavior, 4, 389-403.

Cole, T.M., Chilgren, R., & Rosenberg P. (1973). A new programme of sex education and counseling for spinal cord injured adults and health care professionals. International Journal of Paraplegia, 11, 111-124.

Comarr, A.E. (1973). Sex among patients with spinal cord and/or cauda equina injuries. Medical Aspects of Human Sexuality, 7, 222-238.

Comarr, A.E., & Gunderson, B.B. (1975). Sexual function in traumatic paraplegia and quadraplegia. American Journal of Nursing, 75, 250-255.

Comarr, A.E., & Vigue, M. (1978). Sexual counseling among male and female patients with spinal cord and/or cauda equina injury. American Journal Of Physical Medicine, 57, 215-227.

Donohue, J., & Gebhard, D. (1995). The Kinsey Institute/ Indiana University report on sexuality and spinal cord injury. Sexuality and Disability, 13, 7-85.

Drench, M.E. (1992). Impact of altered sexuality and sexual function in spinal cord injury: a review. Sexuality and Disability, 10, 3-14.

Ducharme, S.H. (1987). Developing training programs for sexuality and disability: A personal perspective. Sexuality and Disability, 8, 36-46.

Dunn, M. (1983). Sexual questions and comments on a spinal cord injury service. Sexuality and Disability, 6, 126-134.

Goddard, L.R. (1988). Sexuality and spinal cord injury. Journal of Neuroscience Nursing, 20, 240-244.

Hahn, H. (1981). The social component of sexuality and disability: some problems and proposals. Sexuality and Disability, 4, 220-233.

Held, J.P., Cole, T.M., Held, C.A., Anderson, C., & Chilgren, H. (1975). Sexual attitude reassessment workshops: Effect on spinal cord injured adults, their partners, and rehabilitation professionals. Archives of Physical Medicine and Rehabilitation, 56, 14-18.

Mackelprang, R.W. (1993). A holistic social work approach to providing sexuality education and counseling for persons with severe disabilities. Journal of Social Work and Human Sexuality, 8(2), 63-87.

Masters, W.H., & Johnson, V.E. (1966). Human sexual response. Boston: Little and Brown.

Medlar, T. (1996). Is your sexuality education program achieving your objectives? Advance/Rehabilitation, 1, 45.

Nagler, B. (1950). Psychiatric aspects of cord injury. American Journal of Psychiatry, 107(1), 49-56.

Neuman, B. (1989). The Neuman systems model. Norwalk, Connecticut: Appleton & Lange.

Novak, P.P., Mitchell, M.M. (1988). Professional involvement in sexuality counseling for patients with spinal cord injuries. The American Journal of Occupational Therapy, 42, 105-112.

Scully, R. M., & Barnes, M.R. (1989). Physical therapy. Philadelphia, PA : J.B. Lippincott Company.

Spica, M.M., (1989). Sexual counseling standards for the spinal cord-injured. Journal of Neuroscience Nursing, 21, 56-60.

Teal, J.C., & Athelstan, G.T. (1975). Sexuality and spinal cord injury: some psychosocial considerations. Archives of Physical Medicine and Rehabilitation, 56, 264-268.

Tepper, M.S. (1992). Sexual education in spinal cord injury rehabilitation: Current trends and recommendations. Sexuality and Disability, 10, 15-31.

Zwerner, J. (1982). Yes we have troubles but nobody's listening: Sexual issues of women with spinal cord injury. Sexuality and Disability, 5, 158-171.

APPENDIX: A

COMMISSION ON ACCREDITATION OF REHABILITATION FACILITIES

STATEMENT OF VALUES

* The standards and the accreditation process are predicated on respect for the worth and dignity of the persons served.

* The empowerment of people with disabilities is the underlying principle of the standards and the accreditation process.

* People with disabilities should have access to quality programs and services.

* Accreditation is designed so that organizations support the persons served to achieve optimum outcomes.

* Nationally accepted standards and accreditation promote programs and services of consistent quality.

* Ethical practices are inherent in the provision of quality programs and services.

* The standards and the accreditation process promote an environment which facilitates service and program enhancement and accountability.

* The quality of programs and services is enhanced through the application of the standards by practitioners in the field.

* People with disabilities, service providers, third-party purchasers, and national/regional organizations set the primary direction for the Commission's activities.

* The Commission has the responsibility to provide the products and services that are efficient and effective and are responsive to and valued by its various constituencies.

(CARF standards manual)

APPENDIX B

COVER LETTER/INSTRUCTIONS

December 21, 1995

To the Director of Physical Therapy,

My name is Karen Ellexson and I am a candidate for the degree of Masters of Science in Physical Therapy at Grand Valley State University. I am surveying physical therapists to determine their role in sexual education of spinal cord injured patients during inpatient rehabilitation. The survey questions were formulated from four guiding questions: (1) Are physical therapists involved in sexual education of spinal cord injured patients? (2) What factors contribute to a physical therapist's involvement or lack thereof? (3) At what level is this involvement? (4) How did the therapist attain his or her knowledge on the subject of spinal cord injury and sexuality?

Your facility was selected at random from the list of CARF accredited spinal cord injury rehabilitation units. In view of the high standards set forth by CARF (both physical therapists and people with spinal cord injuries contributed to setting the criteria of these standards and evaluation processes), only CARF accredited spinal cord injury programs will be used in this investigation.

Please distribute the enclosed surveys to licensed physical therapists with at least one year of experience working with spinal cord injured patients and who are currently working in your spinal cord injury unit.

The surveys should take 10-15 minutes to complete and can be returned in the self-addressed stamped envelopes by January 15, 1996. I value your input and appreciate your help in delineating the role of physical therapy in sexual education of people with spinal cord injury.

Thank you.

Sincerely,
Karen Ellexson, S.P.T.

APPENDIX C

SURVEY

Section I:

1. What is your age?

2. What is your gender?
   a) male b) female

3. What is the highest degree you've obtained in physical therapy?
   a) Bachelor's b) Master's c) Doctorate d) other

4. What is the highest degree you've obtained in fields other than physical therapy?
   a) Bachelor's b) Master's c) Doctorate d) M.D. e) other

5. Please list other degrees.
   _____

6. How many years of practice do you have as a licensed physical therapist? _____

7. How many years have you worked in a spinal cord injury unit as a licensed physical therapist?_____

8. Have you worked with persons with spinal cord injury in another capacity?
   a) yes b) no
   If yes, please specify:_____

9. Have you had a spinal cord injury?
   a) yes b) no

10. Do you have family members or close friends who have had spinal cord injuries?
    a) yes b) no

11. How important do you feel sexual education is for the general population? (Please mark your position with an X)

Very Important_____Very Unimportant

(EXAMPLE) How do you feel about broccoli?

Love it----------X-Hate it

12.How important do you feel sexual education is for people with disabilities? (Please mark your position with an X)

Very Important_____Very Unimportant

Section II:

1. Do you address issues of sexuality with your spinal cord injured patients? (Please mark your position with an X)
   Always_____Never

2. Do you initiate discussions of sexuality with your spinal cord injured patie (Please mark your position with an X)
   Always_____Never

3. Do you address sexual issues with spinal cord injured patients only when asked?
   a) yes b) no
   If no, please explain_____
   _____

4. How prepared do you feel to handle questions about the impact of spinal cord injury on sexuality? (Please mark your position with an X.)

Very Prepared_____Very Unprepared

5. If you do not feel prepared to handle a question, to whom do you refer? (Please estimate % referred to each professional, total must equal 100%)

	%
a) Physician	a)_____
b) Nurse	b)_____
c) Psychologist	c)_____
d) Social worker	d)_____
e) Occupational therapist	e)_____
f) Other_____	f)_____

6. Where did you obtain your information on sexuality as it relates to spinal cord injury?
   (Please circle all that apply.)
   a) Professional curriculum
   b) Continuing education course(s)
   c) In services or workshops in house at your facility
   d) Independent study
   e) Information from a person with spinal cord injury
   f) Haven't received any
   g) Other_____

7. Where do you have resources available on spinal cord injury related to sexuality? (Please circle all that apply.)
   a) personal library
   b) in your department
   c) in your facility
   d) none available
   e) unsure
   f) other_____

8. Please indicate the types of resources you have used with spinal cord injured patients during sexual education. (Please indicate all that apply.)
   a) Books
   b) Periodicals
   c) Films/videos
   d) Audio tapes
   e) Catalogues
   f) Other

9. Please indicate the topic areas you have covered with spinal cord injured patients in regards to sexuality. (Circle all that apply. Then put the percentage of patients with whom you have discussed the topic. Note the %s need not equal 100%)

	%
a) erection/vaginal lubrication	a)_____
b) orgasm	b)_____
c) intercourse	c)_____
d) fertility and birth control	d)_____
e) sensation	e)_____
f) oral/anal stimulation	f)_____
g) sexual positions	g)_____
h) transfers	h)_____
i) sensual massage	i)_____
j) masturbation	j)_____
k) body image	k)_____
l) self confidence	l)_____
m) incontinence	m)_____
n) catheters during sex	n)_____
o) spasticity control	o)_____
p) autonomic dysreflexia	p)_____
q) communication with partner	q)_____
r) dating	r)_____
s) marriage	s)_____

10. Please assess your comfort level in discussing sexual issues with members of the opposite sex in the clinical setting. (Please mark your position with an X.)

completely at ease_____extreme discomfort

11. Please rate your comfort level in discussing sexual issues with members of the same sex in the clinical setting. (Please mark your position with an X.)
completely at ease _____ extreme discomfort

12. Do you think it is appropriate for physical therapists to be involved in the sexual education of spinal cord injured patients?
a) yes b) no
Why or why not? _____

13. Do you think a course on sexuality and disability should be a required portion of the professional curriculum for physical therapists? _____

14. Comments: _____

APPENDIX D

SCATTERPLOTS