

Sexual Education in Spinal Cord Injury Rehabilitation: Current Trends and Recommendations¹

Mitchell S. Tepper, M.P.H.²

Persons with spinal cord injuries (SCI) (N=458) representing a national sample were surveyed by mail to determine trends in the provision of sexual education and sexual counseling services in rehabilitation programs. Of the completed responses (N=251), 45% remembered receiving such services. When sexual education/counseling services were provided, the components of the services varied considerably, and; for the most part, the subject of sexuality was superficially treated. Only 48% of those who received such services reported the services they received met their needs (N=53). The odds of not receiving sexual education or sexual counseling services for female respondents were about two times greater than for male respondents. The study also reveals a gap between services provided during rehabilitation and services desired by consumers. Recommendations are then offered for the development of sexual education and sexual counseling programs that may better meet the needs of persons with SCI.

KEY WORDS: sexuality; spinal cord injury; education; counseling; rehabilitation.

INTRODUCTION

Successful rehabilitation is part physical and part mental. This is supported by the fact that two people with identical physical impairments might have very different disabilities. A person can learn to compensate for physical impairments through physical, occupational, and speech therapies. However, personal

¹A thesis presented to the Department of Epidemiology and Public Health, Yale University, New Haven, Connecticut, 1991.

²Correspondence should be directed to Mitchell Tepper, One Tamarac Ridge Circle, Huntington, Connecticut 06484.

“mind set” or attitude is an important factor in overcoming disability. A person overcomes disability with creativity, ingenuity, fortitude, education, and support. Belief that one can lead a fulfilling life despite physical impairment can be a motivational factor for working hard to minimize disabilities.

This study focuses on sexual education and sexual counseling services in spinal cord injury (SCI) rehabilitation and recognizes that SCI is only one of many possible impairments that may affect one’s sexuality. Spinal cord injury can result in paralysis and impairment of bowel, bladder, and sexual function. Other than the obvious physiological effects, these changes can often have a negative impact on one’s sexuality and self-esteem. Sexual education and sexual counseling may help diminish the impact of these changes on a person’s self-esteem and contribute to a better quality of life after hospitalization.(1)(2)

The main questions being considered in this paper are (1) is sexual education or sexual counseling being offered on a broad basis in spinal cord injury rehabilitation programs?; (2) if such services are offered, by what means are they presently being delivered, and by whom, when, and how often?; (3) is there a perceived need for sexual education and sexual counseling among persons with spinal cord injuries?; and (4) if so, what services are desired by people with spinal cord injuries? Sexual education and sexual counseling services provided are compared with sexual education and sexual counseling services desired, and recommendations for program planning and provision are made based on this comparison. Other questions were considered to identify problems to be studied by analytical methods and to suggest other areas that may deserve further investigation.

LITERATURE REVIEW

In a review of the literature, a number of articles discussed the significance of sexual counseling in rehabilitation from the vantage point of physicians, rehabilitation counselors and nurses.(2)(3)(4)(5)(6)(7)(8)(10) Theodore and Sandra Cole, pioneers in the study of sexuality and disability, provide a discussion of sexuality and its meaning for rehabilitation in *Krusen’s Handbook of Physical Medicine and Rehabilitation 4th Edition*. (1) In addition, the Coles offer practical advice to clinicians for addressing rehabilitation of problems of sexuality in physical disabilities for a number of specific impairments.

A few articles studied the effectiveness of sexual education and counseling procedures among individuals with spinal cord injury.(11)(12)(13) These studies evaluated individual sexual counseling programs. The objectives of one program, Sexual Attitude Reassessment Workshops (SAR), were to assist the professional to be more helpful with others and persons with disabilities to be more helpful to themselves. These objectives were accomplished by de-

mythologizing sexual behavior, desensationalizing sexual stimuli and aiding participants to come to an understanding and acceptance of the sexuality of themselves as well as others.(14)(15) Participants in SAR's found them enlightening and personally beneficial. One paper studied the reliability and validity of the *Sexual Attitude and Information Questionnaire* when it was used to measure the effectiveness of specific sexual information and counseling programs.(16)

There is very little literature with regard to how much sexual education and sexual counseling is actually being delivered in spinal cord injury rehabilitation programs and how these services are perceived by the population they serve. Two studies that were found in this search attempted to uncover recent trends in the provision of sexual counseling services.(17)(18) Only one of these was directed specifically towards persons with spinal cord injuries, but the study was limited to women only. (18) Sixty-eight women who had sustained spinal cord injuries responded to an anonymous questionnaire on the availability of and perceived need for sexual counseling. Less than half of the participants received some type of sex education or counseling post-injury. Eighty-five percent believed some education or counseling would be beneficial to their sexual adjustment.

SAMPLE

The survey sampled 458 members of the National Spinal Cord Injury Association (NSCIA). NSCIA's mailing list is maintained in zip code order; the first 500 people that were coded as having a disability were selected. Of the 500 addresses obtained, 42 addresses were no longer current and no attempt was made to find the new addresses. The sample population was distributed over 38 states, but some states were represented better than others. The following is a list of the states and the number of surveys mailed to each: MA 4, RI 13, NH 6, VT 3, CT 49, NJ 7, NY 29, PA 16, WV 12, MD 2, NC 34, SC 2, GA 1 FL 30, AL 2, TN 3, MS 2, OH 19, IN 29, MI 20, IA 1, WI 26, MN 7, IL 75, KS 4, MO 7, NB 2, NE 6, LA 3, CA 17, OK 1, TX 32, AZ 2, NM 1, HI 1, OR 30, WA 1, AK 1.

RESEARCH DESIGN

A self-administered, anonymous questionnaire was designed for this investigative thesis. The design followed the "Total Design Method" (TDM) as detailed in Dillman's *Mail and Telephone Surveys*.(19) Aday's *Designing and Conducting Health Surveys* was also consulted.(20) After pretesting and revising, questionnaires were mailed to the selected members of the NSCIA with a

cover letter and a self-addressed stamped envelope. A follow-up postcard was mailed seven days after the initial mailing. An anonymous questionnaire was the most appropriate tool considering the sensitivity of the subject matter, the national scope of the sample, and financial constraints.

The questionnaire was organized into three sections. The first section consisted of demographic questions that were formulated so that the sample statistical information obtained from this study could be compared to those published by the University of Alabama at Birmingham.⁽²¹⁾ Additional questions were included to incorporate other variables that may also have an effect on self-esteem like access to transportation and primary caretaker arrangements.

The second section dealt with sexual activity, sexual function and self-assessment. Questions were formulated to measure activity, function, and attitudes before and after injury. Questions about sexual function were asked to see if there is a relationship between sexual function and self-assessment. Questions about the level of injury and the degree of sexual function were formulated to be comparable with other data that relates the level of injury to the degree of sexual function.

The last section focused on sexual education and sexual counseling services. Questions were asked to determine if the person received such services during their rehabilitation. If either sexual education or sexual counseling was received, then follow-up questions were asked to determine how often such services were provided, what services were offered, who provided the services, and what topics were covered. Respondents who received sexual education or sexual counseling services were asked whether such services met their needs. Finally, all respondents were asked what type of sexual education and sexual counseling services they would have used if available, who they would be most comfortable discussing sexuality with, and how soon after their injury they thought sexuality should have been first discussed with them.

RESPONSE RATE

Of the 458 people who received questionnaires, 268 people returned them, resulting in a response rate of 59%. Seventeen did not complete their questionnaires because of one of the following reasons: they had a disability other than spinal cord injury, they thought they were inappropriate because their injury did not affect their sexual function, they were children, they thought the questions were too personal, or they were upset because they did not authorize the NSCIA to share their name and address. Thus, the number of responses used in the data analysis for the results of this study was 251. Over a dozen respondents included letters of support for the study in addition to their questionnaires.

Table I. Select Comparisons of Statistics

Characteristics	UAB ^a (N > 12,300)	This Study (N = 251)
Male	82%	71%
Female	18%	29%
Highest per Cap. Rate of Injury	16-30yrs	16-30yrs
Average Age Onset	29.7	27.7
Median Age Onset	25	24
Mode Age Onset	19	20
Auto/Motor Vehicle Accidents	48%	44%
Falls	20%	13%
Acts of Violence	15%	5%
Sports	14%	22%
Leading Cause After Age 45	Falls	Falls
Marital Status at Injury		
Single	59%	59%
Married	29%	34%
Divorced	7%	4%
Other	5%	2%
Employment Status at Injury		
Employed	60%	67%
Student	20%	27%
Unemployed	12%	3%
Retired	3%	1%
Homemaker	3%	2%
Other	2%	0%
Complete ^b	46%	46%
Incomplete	54%	54%
Quadriplegia	Over ½	52%

^aNSCISC collects data on all people with spinal cord injuries that were treated at one of thirteen designated Model Spinal Injury Systems Programs throughout the country.

^bComplete injuries are defined in the UAB study as total loss of sensation or function. Complete injuries used for comparison from this study were those with total loss of sensation. Fifty-three percent of injuries in this study resulted in total loss of movement.

Characteristics of respondents to this study were compared with spinal cord injury statistical information published by the Spinal Cord Injury Statistical Center(SCISC) at the University of Alabama at Birmingham.(21) Participants in this study appear to be representative of SCISC's broader population of persons with spinal cord injury. Selected comparisons are presented in Table I. The sample from this study had fewer injuries resulting from acts of violence and more injuries resulting from sports than SCISC's sample. Because only the name and address was available on 40% of the persons sampled in this study, a comparison of the characteristics of the people (other than geographic location) who responded to the people who did not respond could not be made.

Table II. Cause of Injury by Age Group

Age Group	Auto	Fall	Motor Cycle	Other	Sports	Violence	Total
0 TO 15	5	4	0	10	7	0	26
16 TO 30	54	10	17	13	37	8	139
31 TO 45	25	8	2	11	10	2	58
>=46	6	11	0	5	2	2	26
Total	90	33	19	39	56	12	249

UNIVERSE OF RESPONDENTS

The respondents in this study, like the population of persons sustaining spinal cord injuries in general, are relatively young and seriously impaired. Of the respondents, 71% were male and 29% were female. Only 36% of the respondents were employed or going to school full-time after their injury as compared to 85% who were employed or going to school full-time before their injury.

The mean age of the respondents at the time of their injury was 28; the mean number of years since their injury was 13. Table II relates age at the time of injury to the cause of injury. The highest per capita rate of injury occurs between ages 16 and 30. The leading cause of injury was automobile accidents, followed by sports or recreational accidents, then followed by falls. Falls were the leading cause of injury after age 45.

The spinal cord injury resulted in quadriplegia (C2-C8) for 52% of the respondents. The balance of injuries resulted in paraplegia, with injuries in the T1 to T11 range most prevalent. Movement and sensation below the level of injury was affected in nearly all the respondents with, 53% reporting no movement and 46% reporting no feeling. Ten percent of the respondents can walk-only 2% without crutches, braces or orthotics. The larger majority depend on manual or power wheelchairs for mobility. Five of the respondents used assistive devices for breathing.

SEXUAL FUNCTION

Sexual function and sexual response was impaired in men and women with 52% reporting no sensation in the genitals and 40% reporting only partial sensation. Only 32% were sure they experienced orgasm since their injury.

For men, 80% reported they get erections. Of that 80%, 27% reported that

they get erections when they want; 39% reported that they sometimes get erections when they want; 25% reported that their erections last long enough to have intercourse; 35% reported that their erections sometimes last long enough to have intercourse. Of the men who reported getting erections, some used assistive devices to attain the erection. The devices included external vacuums, injections, surgical implants, and vibrators. All the men, whether they can attain an erection or not, were asked if they can ejaculate; 24% of men reported they had the ability to ejaculate.

For women, 61% reported that they respond physically when sexually excited; 18% reported that they sometimes respond physically when sexually excited. Of the women who reported that they respond physically, 70% notice their nipples becoming erect and 65% reported vaginal lubrication similar to before their injury. If they choose to participate in intercourse, 61% get lubricated when they want; 24% reported that they sometimes get lubricated when they want; 54% reported that they feel there is sufficient lubrication for intercourse; 25% reported that they feel there is sometimes sufficient lubrication for intercourse.

SEXUAL ACTIVITY

Respondents reported reduced dating and sexual activity after sustaining their injury. For dating, 74% of respondents reported dating prior to their injury compared with 65% who reported dating since their injury. A similar reduction was reported in sexual activity with 84% of respondents reporting they were sexually active prior to sustaining their injury, and 72% reporting they were sexually active at some point since their injury. Fifty-one percent of respondents reported that the amount of sensation they had in their genitals was an important factor in their degree of participation in sexual activity. One-hundred and forty-eight respondents reported they were not currently engaging in sexual activity. The reason reported most often for not engaging in sexual activities was *no sexual partner but looking*. For 144 persons who were employed prior to their injury and who were not employed after their injury, 29% felt their lack of employment has interfered with dating and/or establishing a relationship and 13% were not sure.

SEXUAL ATTITUDE

The most significant event that affected how the respondents feel about themselves sexually since their injury was a relationship with a significant other 77%, followed by involvement with sports 5%, and sexual education or coun-

Table III. Self-Assessment Ratings

	N =	Strongly Agree	Agree	Neither	Disagree	Strongly disagree
I feel good about myself.	248	45%	37%	8%	8%	2%
I believe I am lovable.	247	45%	46%	7%	1%	1%
I feel I am sexually desirable.	244	18%	37%	20%	16%	9%
Sexual activity makes me feel better about myself.	237	27%	34%	25%	7%	6%
I was comfortable with the way my body looked before my injury.	248	48%	40%	4%	7%	1%
I am comfortable with the way my body looks now.	248	8%	25%	17%	31%	18%
I get mentally aroused often.	243	23%	38%	20%	14%	5%
I get physically aroused often.	245	13%	27%	26%	21%	13%
I was comfortable with my sexuality before my injury.	243	49%	35%	8%	5%	2%
I am comfortable with my sexuality now.	241	12%	28%	21%	21%	17%
My sexuality has not been affected in any significant way as a result of my injury.	245	6%	12%	7%	28%	47%

seling 3%. Of 125 respondents who reported they were with a partner or married before their injury and reported they were not with the same partner at the time of this study, 49% felt it was because of their disability and 15% were not sure. Responses to the self-assessment scores are summarized in Table III.

SEXUAL EDUCATION AND SEXUAL COUNSELING

Eight-three percent of the respondents received inpatient rehabilitation in specialized rehabilitation centers, 13% received rehabilitation in general hospitals. The remainder of respondents received rehabilitation in a Veterans Administration Hospital or did not receive any rehabilitation. Only 45% of the respondents received sexual education or sexual counseling services during their rehabilitation (N = 112). Of those who received such services, 8% reported that they remembered receiving them more than two or three times, and 48% reported that the services they received met their needs (N = 53). Of those that did not receive sexual education or sexual counseling services in rehabilitation or did not remember (N = 139), 76% reported that such services were not offered, 8% reported that they were not interested in the services because they had too many other medical problems, 9% refused services, and 2% responded that the services conflicted with other rehabilitation. Other reasons respondents

Table IV. Sexual Education or Sexual Counseling by Years Since Injury

Years Since Injury	Sexual Education or Sexual Counseling		Total
	Yes	No	
< = 10	76	54	130
> = 11	35	77	112
Total	111	131	242

Odds Ratio 3.10:1 (1.75 < OR < 5.49)

gave for not receiving services included the following: they were not interested, they had no problem, or they were impotent.

Seventy-seven percent of the respondents who received sexual education or sexual counseling, responded positively that they wanted more sexual education or counseling services after being discharged, but only 29% of them reported they received these services.

Table IV compares the number of years since injury and whether sexual education or sexual counseling was received. Respondents were stratified by the number of years since their injury to see if people injured within the last ten years had a greater chance of receiving education than people injured 11 or more years ago. The odds of receiving sexual education or sexual counseling if the injury was sustained ten or less years ago were three times greater than if sustained eleven or more years ago.

The relationship between gender and sexual education or sexual counseling was also examined. Table V demonstrates that the odds of not receiving sexual education or sexual counseling if the respondent was female were about two times greater than if they were male.

The relationship between the type of facility where inpatient rehabilitation

Table V. Sexual Education or Sexual Counseling by Gender

Gender	Sexual Education or Sexual Counseling		Total
	No	Yes	
Female	43	23	66
Male	81	89	170
Total	121	112	236

Odds Ratio 2.05:1 (1.09 < OR < 3.89)

was received and whether sexual education or sexual counseling services was received was also explored to see if patients in a specialized rehabilitation center had a better chance of receiving such services than patients in a general hospital. No significant difference was detected. A comparison was also made between length of stay in the rehabilitation center or the hospital and whether sexual education or sexual counseling services were received. The length of stay was grouped into two categories: less than six months and greater than or equal to six months. Once again, no significant difference was detected.

FIRST DISCUSSED

For respondents who received sexual education or sexual counseling services, 22% reported that sexuality was first discussed with them 1-5 weeks after their injury, 28% reported that sexuality was first discussed with them 6-10 weeks after their injury, 14% reported 11-15 weeks, 20% reported more than 15 weeks, and 16% reported that they did not remember when sexuality was first discussed with them. All study participants were asked how soon after their injury they thought sexuality should be discussed with them. The results showed that 17% reported they thought sexuality should have been discussed with them immediately, 30% reported sexuality should have been discussed with them 1-5 weeks after their injury, 19% reported 6-10 weeks, 8% reported 11-15 weeks, and 8% reported that they thought sexuality should have been discussed with them more than 15 weeks after their injury. The most frequent other response was when the person is medically stable and over the initial shock of being injured.

WHO INITIATED

Nurses and rehabilitation counselors initiated the discussion about sexuality most frequently (19% of the time each), followed closely by psychologists 17%, doctors 15%, social workers 12%, patients 8%, and other spinal cord injured persons 2%. When the study participants were asked who they would be comfortable discussing sexuality with (choosing as many as applied), the most frequent response was another spinal cord injured person 66% (N = 164), followed by a doctor 49% (N = 121), a nurse 36% (N = 89), a psychologists 31% (N = 77), a rehabilitation counselor 31% (N = 77), and a social worker 13% (N = 33). A number of respondents identified other people they would feel comfortable discussing sexuality with. These included their spouse, girlfriend, boyfriend, parents, sex therapists, sex surrogates, and anyone genuinely concerned.

Table VI. Areas Covered in Sexual Education or Counseling (N = 114).

Sexual Function	79%
Bowel and Bladder Function	70%
Relationships	45%
Body Image	33%
Self-esteem	41%
Fertility and Contraception	32%
Alternative Positions and Assistive Devices	33%
All of the Above	11%
Don't Remember	13%

WHO CONDUCTED

Sexual education or sexual counseling was conducted most often by psychologists, 41% of the time, and nurses, 35% of the time. Rehabilitation counselors conducted sexual education or sexual counseling 29% of the time; doctors, 28%; followed by social workers 20%; and other spinal cord injured persons, 12%.

SERVICES OFFERED

For respondents who received sexual education or sexual counseling services, the types of services they reported were most frequently offered were booklets, pamphlets or other written materials 57% (N = 64); followed by group discussions 42% (N = 47); videos 39% (N = 44); individual counseling 27% (N = 30); and group counseling 18% (N = 20). Twenty percent of respondents (N = 23) had the opportunity to talk with another experienced person with a spinal cord injury.

AREAS COVERED

Table VI shows the areas that respondents reported were covered in sexual education or sexual counseling. The areas most frequently covered included sexual function, 79% of the time; and bowel and bladder function, 70% of the time. Relationships, self-esteem, body image, and alternative positions and assistive devices were covered 45%, 41%, 33% and 33% of the time, respectively. Fertility and contraception were covered 32% of the time and 11% were exposed to all of the above areas.

SUMMARY OF FINDINGS

Despite widespread agreement that sexual education or sexual counseling services should be part of the spinal cord injury rehabilitation program, this study indicates that less than one-half of the survey respondents received such services. Although 58% of respondents injured within the past 10 years received sexual education or sexual counseling, there is still room for improvement. There is also a cohort of individuals with spinal cord injuries, many of whom are women, who did not receive sexual education or sexual counseling services, or who expressed the need for additional services. For instance, one woman wrote, "I live in a community where there is not any information available . . . Most of my knowledge about my sexuality is through experience . . . The closest rehab is 2 hours away, so I seldom get there. I would appreciate it if you could send me some information . . ." Another woman wrote, "I really didn't get any education or even information on sex education in rehab. Most of what I learned was through reading after rehab and probably still know little of what is available. I am happily married but still frustrated."

The majority of respondents would welcome more sexual education and sexual counseling, if available. As one respondent expressed this need:

It has been 25 years since my injury/rehab. In that time I had a variety of sexual experiences; some very good, some unmitigated nightmares I would like to forget. I was so overwhelmed by my loss of sexual function that initially I emotionally shut down. I guess I tried to bullshit myself that if I kept my feelings/frustrations to myself "it" (S.C.I.) would go away. "It" obviously did not. I, today, have a good sexual relationship with my wife that basically allows me oral sex in upper extremity areas (nipples) and to vicariously achieve a mental orgasm with my wife's.

I feel like I (we) could benefit from a comprehensive sex education course for long term S.C.I.'s. I have achieved great satisfaction from my life so far, in everything *but* my sexuality.

It should be addressed immediately upon admission to a S.C.I. unit. Rehab professionals at this time, however, are not trained or qualified to provide adequate information.

When sexual education or sexual counseling services are provided, the components of these programs vary considerably; and, for the most part, the subject of sexuality is superficially treated. Sexual function is often covered along with bowel and bladder function. Topics such as body-image, relationships, self-esteem, and alternative positions and assistive devices are generally not covered. This may be an indication that many sexual educators still limit the focus of sexuality on the narrow definition of penial-vaginal intercourse. The broader aspects of sexuality that also have an impact on the individual's conception of self-worth such as intimacy, sex roles, how people present themselves, and acceptable sexual expression are still often being ignored. A male

Table VII. Services Offered Versus Services Desired

Weeks after injury sexuality was first discussed.	N = 116 (a)	Weeks after injury sexuality should be discussed.	N = 108 (b)	N = 237 (c)
1-5	22%	Immediately or 1-5	51%	47%
6-10	28%	6-10	20%	19%
11-15	14%	11-15	7%	8%
16-20	10%	16-20	6%	5%
>20	10%	>20	1%	3%
Who conducted the education or counseling.	N = 111	Persons most comfortable discussing sexuality with.	N = 110	N = 247
Doctor	28%	Doctor	54%	49%
Nurse	35%	Nurse	40%	36%
Psychologist	40%	Psychologist	36%	31%
Social Worker	20%	Social Worker	16%	13%
Rehab Counselor	29%	Rehab Counselor	33%	31%
Other SCI person	12%	Other SCI person	66%	66%
What type of services were offered.	N = 113	Which services would you use if available	N = 105	N = 247
Booklets, pamphlets, other written materials	57%	Booklets, pamphlets, other written materials	70%	78%
Videos	39%	Videos	53%	63%
Sex and disability course	15%	Sex and disability course	43%	53%
Group discussions	42%	Group discussions	31%	43%
Social skills training	11%	Social skills training	17%	30%
Individual counseling	26%	Individual counseling	49%	55%
Group counseling	18%	Group counseling	20%	32%
Couples counseling	5%	Couples counseling	27%	37%
Ob/gyn urological care	8%	Ob/gyn urological care	22%	38%
All of the Above	2%	All of the Above	16%	19%

(a) (b) N represents all the respondents who reported receiving sexual education or sexual counseling in rehabilitation and who answered the question.

(c) N represents all the respondents, those who received sexual education or sexual counseling and those who did not, who answered the question.

respondent with a C3 injury, complete quadriplegia, describes the extent of his sexual education as follows:

At a large university rehab hospital, we had one lecture by a psychologist given to an audience of patients and spouses for all levels of injury. At the conclusion a few questions were answered and if more information were desired individual appointments could be made. Spinal cord injury causes such drastic change in sexual activity that it demands close, one to one counseling with someone who understands.

Table VII compares services offered with services desired. Although providers are likely to wait more than five weeks before discussing sexuality, for

the most part, people with spinal cord injuries would like sexuality discussed sooner. The most common services offered are written materials, group discussions, videos, and individual counseling, in that order. The most demanded services that would be used if available are written materials, videos, individual counseling, and a sex and disability course. Psychologists and nurses are the most likely providers of sexual education or sexual counseling services, and another spinal cord injured person the least likely. Survey respondents reported they would be most comfortable discussing sexuality with another spinal cord injured person or their doctor. A 49 year-old psychiatrist who has been injured for five years reported, "There's no comparison between getting info from a spinal cord peer and from a professional, in any category. What we need is peer support early on."

Over one-half of the persons who received sexual education or sexual counseling services reported that such services did not meet their needs. The reasons given for sexual education or sexual counseling services not meeting the respondents' needs included that services were not offered often enough and were not sufficiently comprehensive. Many respondents reported they wanted to focus more on loving and caring, or they wanted more couples counseling and more guidance on how to find a partner. Other reasons respondents gave for sexual education or sexual counseling not meeting their needs included that the sexual education or sexual counseling was geared towards men, that it was hard to talk with able-bodied individuals, that it was hard to talk in groups of males and females, and that the information they received was inaccurate.

Despite the lack of sexual education or sexual counseling, for the most part respondents reported that they feel good about themselves and that they are loveable. At the same time, respondents were less comfortable with their body image and their sexuality after their injury, and sexual activity was reduced. Many people without disabilities may also be less sexually active than they would like. In a study with individuals attending a Sexual Attitude Reassessment workshop, 56% of the participants without disabilities, and 57% of participants with disabilities were not as sexually active as they would like to be.⁽¹⁴⁾ However, a disability adds to the problem. An unpublished study by Cole and his co-workers studied sexual attitudes and experiences of people with spinal cord injuries after discharge from the hospital.⁽¹⁾ In Cole's study, the most common reason for reduced sexual activity offered one year after injury was lack of partners; two years after injury, lack of activity was attributed not only to lack of partners but also to fear of rejection, health concerns, and problems with erections; three years after injury, males listed problems with erections as being the major reason for lack of activity.

Of the 148 respondents in this study not engaging in sexual activity, 46% reported it was because they had no sexual partner but they were looking. Although the lack of available sex partners is not a problem isolated to people

with disabilities, once again, having a disability adds to the challenge. As one respondent put it, "Sex has failed to be seen by most as another important and natural part of life . . . Unfortunately, people who are not disabled believe that people who are or who become disabled, should give up sex or don't engage in it! Nonsense!"

We should not overlook the fact that a partner's attitude toward sexuality can play a key role in sexual adjustment. This is reflected in that the most significant event that affected how respondents feel about their sexuality since their injury was a relationship with a significant other. The effects of those relationships were both positive and negative. For example, one respondent reported their spouse was unwilling to engage in sexual activity with them anymore. For many others, a significant other was the reason they became more sexually active. Of 125 respondents who are not with same partner as before their injury, 64% think it was or might have been because of their disability.

RECOMMENDATIONS

This study reveals an obvious gap between services offered and services desired. The study results suggest a program that meets the needs of persons with spinal cord injury would include the following features:

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

Many of these features have been elaborated on by Cole and others in the literature.(1)(10) For examples of comprehensive sex education and counseling programs, providers can look to Eisenberg and Rustad's outline of an eight session program used on a spinal cord injury service at the Cleveland VA or Brockway, et al.'s description of the program developed in the Department of Rehabilitation Medicine at the University of Washington School of Medicine.(11)(13) More professionals responsible for delivering care to people with spinal cord injuries need to recognize sexual concerns as a legitimate and important part of a well balanced rehabilitation program, and examine sexual education and sexual counseling services in their own spinal cord injury programs against the recommended standards outlined above.

For those facilities that do not offer any sexual education or sexual counseling and do not foresee the ability to adopt a comprehensive program in the short-run, some basic steps toward sexual education can be taken at little cost. The physician and other members of the rehab team can let people with spinal cord injuries know that the team considers sexual concerns legitimate and important and that they will do their best to answer any questions or refer them to someone else that can help. At the very least, the facility can offer written materials and videos for people.

REFERENCES

1. Cole TM, Cole SS: Rehabilitation of Problems of Sexuality in Physical Disability. In Krusen's Handbook of Physical Medicine and Rehabilitation, fourth edition, EH Wickland Jr (ed). Philadelphia, WB Saunders Company, 1990, pp 988-1008
2. Teal JC, Athelstan GC: Sexuality and Spinal Cord Injury: Some Psychosocial Considerations. Archives of Physical Medicine and Rehabilitation 56:264-268, 1975
3. Stewart TD: Sex, Spinal Cord Injury and Staff Rapport. Rehabilitation Literature 42(11-12): 347-350, 1981
4. Sawyer HW, Allen HA: Sexuality and Spinal Cord Injured Individuals, A Challenge for Counselors and Trainers. Journal of Applied Rehabilitation Counseling 14(4):14-17, 1983
5. Robbins KH: Traumatic Spinal Cord Injury and Its Impact Upon Sexuality. Journal of Applied Rehabilitation Counseling 16(1):24-28, 1985
6. Hohmann GW: Sex and the Spinal Cord Injured Male. Accent on Living Spring, 1973
7. Spica MM: Sexual Counseling Standards for the Spinal Cord Injured. Journal of Neuroscience Nursing 21(1):56-60, 1989
8. Chicano LA: Humanistic Aspects of Sexuality as Related to Spinal Cord Injury. Journal of Neuroscience Nursing 21(6):366-369, 1989
9. Goddard LR: Sexuality and Spinal Cord Injury. Journal of Neuroscience Nursing 20(4): 240-244, 1988
10. Glass DD: Sexual Rehabilitation of the Spinal-Cord Injured. Medical Aspects of Human Sexuality 2(4):257-266, 1978
11. Brockway JA, Steger JC, Berni R, Ost VV, Williamson-Kirkland TE, Peck CL: Effectiveness of a Sex Education and Counseling Program for Spinal Cord Injured Patients. Sexuality and Disability 1(2):127-136, 1978
12. Steger JC, Brockway JA: Sexual Enhancement in Spinal Cord Injured Patients: Behavioral Group Treatment. Sexuality and Disability 3(2):84-96, 1980
13. Eisenberg MG, Rustad LC: Sex Education and Counseling Program on a Spinal Cord Injury Service. Archives of Physical Medicine and Rehabilitation 57:135-140, 1976
14. Halstead LS, Halstead MM, Joyce JT, Stock DD, Sparks RW: A Hospital-Based Program in Human Sexuality. Archives of Physical Medicine and Rehabilitation 58:409-412, 1977
15. Held JP, Cole TM, Held CA, Anderson C, Chilgren RA: Sexual Attitude Reassessment Workshops: Effect on Spinal Cord Injured Adults, Their Partners and Rehabilitation Professionals. Archives of Physical Medicine and Rehabilitation 56:14-18, 1975
16. Brockway JA, Steger JC: Sexual Attitude and Information Questionnaire: Reliability and Validity in a Spinal Cord Injured Population. Sexuality and Disability 3(4):49-60, 1980
17. Chipouras S, Cornelius C, Daniels SM, Makas E: Who Cares? A handbook on sex education and counseling services for disabled people. The Sex and Disability Project, George Washington University, 1979
18. Zwerner J: Yes We Have Troubles but Nobody's Listening: Sexual Issues of Women with Spinal Cord Injury. Sexuality and Disability 5(3):158-171, 1982
19. Dillman DA: Mail and Telephone Surveys: The Total Design Method. John Wiley and Sons, Inc., 1978

20. Aday LA: *Designing and Conducting Health Surveys, A Comprehensive Guide*. Jossey-Bass Publishers, 1989
21. National Spinal Cord Injury Association, Fact Sheet No. 2: *Spinal Cord Injury Statistical Information*. Summarized and excerpted from *Spinal Cord Injury: The Facts and Figures*. Spinal Cord Injury Statistical Center at the University of Alabama at Birmingham, 1986