Yes We Have Troubles but Nobody's Listening: Sexual Issues of Women with Spinal Cord Injury

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ABSTRACT: Information concerning the sexual functioning of SCI females is scarce—generally and in comparison to the literature on SCI males. In an effort to uncover recent trends in the provision of sexuality counseling services, numerous agencies, representing a national sample, offering rehabilitaton programs to the SCI were contacted. Sixty-eight women who had sustained SCI within the past seven years responded to an anonymous questionnaire on the availability and perceived need for sexuality counseling services. Findings reveal less than half of the participants received some type of sex education or counseling post-injury. However, 85 percent believed that individual or group counseling and workshops would be beneficial to their sexual adjustment. Only in a minority of SCI women was there a marked decrease in sexual activity.

Only since 1972 has rehabilitation literature considered sexuality as integral to an individual's adjustment to disability.[1] While references are available in specialized medical journals concerning specific disabilities and their sexual concomitants, this information has rarely been brought to the attention of rehabilitation counselors and has received little attention in rehabilitation journals.[2]

Moreover, the literature that does exist is almost exclusively male-oriented. In regard to spinal cord injury, this discrepancy is partly due to the fact that four of every five cord injured individuals are males.[3] Numbers, however, are not the only issue. There is a prevailing attitude that sexual dysfunction is not as traumatic for the SCI woman due to continued fertility, pretrauma attitudes toward sexuality[4], and a more passive role in sexual relations.[5] Thus the sexual problems of

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Sexuality and Disability, Volume 5, Number 3, Fall 1982
0146-1044/82/1500-0158$02.75

SCI females have not received the same level of serious inquiry as that of their male counterparts.

REVIEW OF THE LITERATURE

This trend started early, and in 1917 Riddoch[6] reported on the sexual response of paraplegic men. Since then numerous studies have produced detailed information, classified according to the level and completeness of the spinal lesion, coupled with a statistical prognosis of the probability of sexual dysfunction in males. Very little similar descriptive data is available on the physiologic and psychogenic aspects of sexual response in women with lesions at various levels.[7] Griffith and Trieschmann[8] postulated the presence of a "genital reflex" in SCI females paralleling the reflex found in SCI males, yet clinical observations are scarce, and research on SCI women is still severely lacking.

The large majority of reports that do exist concentrate on the reproductive aspect of female sexuality, such as menstruation, fertility, and pregnancy.[9,10] In some cases this preoccupation with the childbearing capacity of SCI women has led to the erroneous belief that they "have no loss of physical sexual function".[11] Crigler[12] suggested that this assumption may be due to the fact that erectile and ejaculatory functions are often impaired in men, whereas sexual dysfunction "is not as graphically apparent in an injured woman." While facts detailing neurological and vascular function are an important remedy to this dilemma, it is clear that this taps only the most superficial aspects of sexual functioning.

The study of function was paralleled by the study of activity. Thus early reports investigating patterns of sexual activity among SCI individuals did not even include female subjects. Many focused on the post-injury effects of potency on self concept, and defined libido as interest in intercourse, with "successful" attempts at coitus being the predominant mode of sexual interaction.[13,14] Several investigations reported a marked decrease in sexual activity from pre-injury levels while others did not differentiate between desire for sexual activity and opportunity for sexual activity, a factor greatly affected by hospitalization.[15] But the common notion of "the sex act" (male superior position) as the foundation for sexual intimacy is no longer a valid concept for many individuals, and particularly for severely disabled women. Societal pressures indicating that intercourse and

orgasm are imperative to sexual satisfaction may therefore lead to a sense of failure for disabled women. This appears crucial in light of recent research with SCI couples showing that those with a greater acceptance of sexual variety tended to be more satisfied with their frequency of sexual activity. It was speculated that other couples settled for less sexual interaction due to a lack of adequate information about their sexuality.[16] Similarly, after interviewing 19 SCI women, Becker[17] found those with the most accurate and extensive information regarding their sexuality have fewer emotional problems emerging from sexual conflicts. These findings support the need for more thorough information dissemination, and sexuality counseling designed to increase sexual repertoire and acceptance of sexual variety.

Feelings of feminine attractiveness has more frequently been studied in SCI women.[18,19] Perhaps not surprisingly, many aspects of femininity and personal attractiveness are the same for SCI women as they are for non-disabled women. However, several women stressed that although they were presently involved in sexual relationships and had a positive self image, the first few years after injury were extremely difficult. Most of the women mentioned a lack of understanding and sensitivity by health professionals of their sexual needs and viewed this as a hindrance in adjusting to their disability.

A trained counselor can provide emotional support and assistance in working through problems related to a changed self image and performance fears as a result of stress at the time of injury. In her work with SCI women, Thornton[20] revealed that brief therapy initiated for emotional problems related to sexuality was often very successful. Important issues in sexuality counseling were outlined, including exploring one's body and experimenting with new methods of sexual expression. Although it has been believed that a great deal of practice over a long period of time is essential to a satisfactory sex life among the cord injured, little correlation was found between sexual adjustment and time since injury.[19] This finding suggests that time alone is not enough, and the kinds of opportunities and experiences which enhance sexual adjustment would be worthy of further investigation.

It has been suggested that the burden of the responsibility for bringing up matters of a sexual nature lies with the rehabilitation counselor.[21] However, very few counselors have been adequately trained or feel comfortable getting involved in even short term sexuality counseling. Client's anxieties are thus often compounded by the counselor's hesitation, lack of training, and expertise in dealing effectively with sexual issues.[22,23] In such cases consultation or referral to a professional experienced in handling sexual problems in disabled persons would be in order.

It appears that what is most needed during the post-injury rehabilitation process is offering assistance rather than avoiding or over emphasizing the issue. In most cases clients will take advantage of available resources when they feel prepared to do so. Some rehabilitation counselors are qualified to engage in sexuality counseling or offer educational programs to their clients. But many more are capable of serving as advocates for services available elsewhere.[24] Advocacy does not require highly specialized training and is within the abilities of all counselors.

Perhaps the belief that SCI males go through a more difficult sexual identity readjustment process has contributed to the scarcity of research regarding women in this area. Several of the studies espousing such beliefs were published in the late 60's and early 70's. While these assumptions may have held true for some women at the time, they are certainly rapidly changing in the present. In an era where exploration of non-traditional vocational and social roles are being encouraged for women, these beliefs uphold sex role stereotypes and attitudinal barriers regarding disabled women. Despite the recent emphasis on sexuality in the SCI, rehabilitation professionals remain unaware of available resources and indifferent to the unique concerns of their female clients. The inclusion of psychosocial and sexual components in an attempt to facilitate overall adjustment to disability are essential.

Purpose of the Study

The present study focused on SCI women in the general population who already completed the major phases of the rehabilitation process. This investigation was designed to assess the current trend of availability of sexuality counseling services offered by rehabilitation professionals, and to examine sexual activity frequencies, using a broad definition of behaviors along a continuum of possible sexual practices. With respect to the spirit of consumer concern, special consideration is paid to those types of services and kinds of information perceived as most beneficial to post-injury sexual adjustment.

METHODOLOGY

Subjects

Fifty Spinal Cord Injury Treatment Hospitals, Independent Living Centers, and Disabled Student Centers were sent an information packet describing and

requesting their participation in this project. Fourteen geographically dispersed agencies cooperated: six Independent Living Centers, two campus-based Disabled Student Centers, and six Spinal Cord Injury Treatment Hospitals. Participating agencies were asked to distribute questionnaires to SCI women amongst their population who were receiving, continuing, or returning for services, at least one month but no more than seven years post-injury. With the exception of the Disabled Student Centers, all the agencies service rather large geographic areas and are well known by virtue of their comprehensive treatment programs.

Instruments

A self administered questionnaire was designed for use in this study. After pretesting and revision, the forms were sent to an employee from each agency who distributed them to all eligible female subjects. Each questionnaire included an explanatory cover letter and a self-addressed stamped envelope. Participants were told to mail anonymously the completed questionnaire to the investigator. The 21 questions required approximately 30 minutes to complete and the respondents were encouraged to comment and fully explain their answers. Biographical information such as age, marital status, sexual preference, educational level, age at injury, and injury type was requested. There were several questions dealing with the type and amount of general and sexuality counseling received as a result of disability. Respondents were requested to list the kinds of services and information they believed would be useful in meeting their needs and interests in the area of sexual adjustment. Subjects were also asked about their pre- and post-injury frequency of sexual interaction, with such activity being defined along a continuum, for example, from prolonged kissing and stroking, to sexual intercourse.

RESULTS

Background Data

A total of 225 questionnaires were mailed to 14 rehabilitation service agencies. Of the 225 sent out, 170 questionnaires were distributed, and 88 ultimately returned, resulting in a return rate of 52 percent. Twenty of the questionnaires were not used because the respondents' disability was other than SCI, or injury had been sustained for more than seven years. Thus, data analysis for the results of this study was based upon 68 qualified and completed questionnaires.

The mean age of respondents was 29 years (range 17-60). Mean age at the time of injury was 25 years (range 12-58), with the modal age of occurrence being 20. Fifty percent of the sample was injured between the ages of 16-25, and a mean of 3.9 years had elapsed between the

time of injury and questionnaire collection. Thirty-six (53 percent) of the women were quadriplegics and 25 (37 percent) were paraplegic; 7 (10 percent) had multiple disabilities including SCI or had much improved as a result of incomplete spinal lesions. In comparison to the statistics from the National Spinal Cord Injury Data Research Center[3], the mean age of occurrence for the total population is 29, with a mode of 20. Fifty percent were injured between the ages of 15-25, and there is approximately an even number of quadriplegics and paraplegics. The high number of quadriplegics in the present study may be due to a large number of participants (50 percent) being drawn from Independent Living Centers whose services are more apt to be utilized by quadriplegics. Thus, the present sample statistically parallels the national sample in terms of age and type of injury.

Questionnaires were returned from 17 states with the majority (84 percent) of women living in private homes or apartments. Three (4 percent) resided in hospitals and 8 (12 percent) indicated they were living in special housing for the disabled. The remaining biographical data is described in Table 1.

Pre- and Post-Injury Sexual Activity Frequency

Participants were asked to indicate their pre-and post-injury frequency of sexual activity, including, but not limited to, episodes of sexual intercourse. Respondents were requested to cite specific reasons if they were sexually inactive. A cross-tabulation of change in sexual activity frequency can be seen in Table 2.

Just under one half (45 percent) of the respondents experienced a decrease in their sexual activity frequency, a finding substantially less than previous studies with SCI males.[15] Approximately 37 percent had no change, and 15 percent had an increase in sexual activity. Women with very high or very low pre-injury sexual frequency, that is, daily or less than once a month, respectively, changed the least following disability. In contrast, women whose pre-disability frequency averaged once to three times a week showed greater variability post-injury.

A major drawback of earlier studies investigating post-injury patterns of sexual interaction is their failure to take into account subjective factors contributing to a decrease in frequency, as well as their reliance on coitus as the predominant mode of sexual activity. For example, one woman stated that she was not engaging in sex because "my partner has problems dealing with my disability." Another wrote that due to a "lack of sensation in my vulva, sexual activities . . . rarely include intercourse."

Table 1

Biographical Composition of Sample
(N = 68)

		Number and Percent of Subjects	
Marital Status	Single	35	(51%)
	Married	21	(31%)
	Divorced	12	(18%)
Sexual Preference	Heterosexual	62	(91%)
	Homosexual	2	(3%)
	Bisexual	4	(6%)
Religion	Protestant	20	(29%)
	Catholic	19	(28%)
	Jewish	3	(4%)
	Other*	26	(38%)
Educational Level (Grade Completed)	Some High School	2	(3%)
	High School	17	(25%)
	1 Yr. College	6	(9%)
	2 Yrs. College	11	(16%)
	3 Yrs. College	4	(6%)
	4 Yrs. College	11	(16%)
	Graduate	10	(15%)
	Post-Graduate	7	(10%)
	Mean Years of Education = 14.8 (range 9-20)		

*Other includes: Atheists, and those with no religious affiliations, as well as members of specialized sects, such as Unitarian and Pentacostal.

At the time of questionnaire collection, 32 (47 percent) of the respondents were not engaging in any sexual activities, and 16 (23 percent) of these women had no current sexual partner. In a study with individuals attending a Sexual Attitude Reassessment (SAR) workshop, 56 percent of the non-disabled, and 57 percent of the disabled participants were not as sexually active as they would like to be.[25] Thus, the lack of available sex partners is not a problem isolated to the disabled population.

Eight (12 percent) of the women in this study reported abstention from sexual activity due to complications arising from their injury, and another 8 (12 percent) were celibate, or chose not to engage in a sexual relationship at this time. For example, a 40-year-old woman who had been disabled for five years wrote that she had "embarrassing

Table 2

Cross-tabluation of Change in Sexual Activity Frequency Before and After SCI (N = 66)*

	FREQUENCY BEFORE INJURY					
FREQUENCY AFTER INJURY	Daily	3 Times A Week	Once A Week	Once A Month	Less Than Once A Month	AFTER INJURY TOTALS
Daily	3	2	—	—	—	5
3 Times A Week	1	7	1	1	2	12
Once A Week	—	8	4	—	3	15
Once A Month	1	1	3	—	1	6
Less Than Once A Month	1+	6	6	4+	11+	28
BEFORE INJURY TOTALS	6	24	14	5	17	66

*Two women did not answer this item on the questionnaire.
+These women were still living in rehabilitation hospitals due to recency of their injury.

bladder control and no feeling, not proud of my figure, not sure how my vagina feels to my partner without the necessary muscles for intercourse." Remarks such as this tend to support findings suggesting that women with poor self images have more difficulty adjusting sexually.[19] However, only a few women commented on physical complications, whereas problems related to social interaction were more numerous. For example, one woman reported that "most guys think I'm too fragile." Another stated the dilemma more acutely: "My partner resides quite far away and I choose not to become involved in other relationships [because] opportunities to develop social relationships with men—where they relate to you seriously as a woman [and] not as a helpless victim or someone to be taken care of—are nonexistent."

The results presented here should not be taken to indicate a declining interest in sex or involvement in sexual relationships. Age and marital status also played a significant role. Two women who were celibate were divorced, and one stated that she had "no interest in sex out of wedlock." It is reasonable to assume that disability is a factor accounting for part of the decrease in sexual activity frequency, but it

is only the tip of the iceberg. A chronic disability can too easily be transformed into a handicap by the perceptions of the world "outside." Beneath the surface lies the problem of attitudinal barriers, and it is not surprising so many women felt that social issues were the most crucial.

General and Sexuality Counseling

Participants were queried as to whether or not they had any type of counseling or therapy as a result of their physical disability. Fifty-four (79 percent) participants indicated they had received such counseling, whereas 14 (21 percent) had not received any counseling post-injury. The women who did not have any counseling represented 7 of the 14 rehabilitation agencies utilized in this study, and why this occurred is unknown. When asked if they had ever received any kind of sexuality counseling it was found that the majority had not. Only 30 (44 percent) respondents reported they had specifically been the recipients of sexuality counseling as a result of their injury.

The sample composition of the source of general and sexuality counseling for those women who had some type of professional contact post-injury is described in Table 3. Several women received general counseling from more than one person so the number of contacts (N = 131) exceeds the number of women receiving counseling (N = 54). Included in this table is the individual who brought up the topic of sexuality in the general counseling session. It is notable that the issue of sexuality was not mentioned in 17 of the 54 cases. One woman wrote that she tried to talk about sexuality with several counselors but "they felt it shouldn't be discussed." Only four of the women who discussed sexual issues in the general counseling session were given referrals to seek out sexuality counseling elsewhere, yet 30 actually obtained it.

Of the women who received sexuality counseling, 11 (16 percent) noted they had discussed sexual issues with their primary counselor on only one occasion. Sixteen (24 percent) women had two to five sexuality counseling sessions, and 3 (4 percent) had ten or more sessions with their primary counselor.

The mean age of clients who received sexuality counseling was 26.5, 3 years younger than the mean of the total sample. The mean years disabled was 3.75, as compared to 5.25, the mean years disabled for those who did not receive any type of sexuality counseling. It would appear that there is a tendency for younger and more recently injured women to have a higher probability of receiving sexuality counseling, although this was not statistically supported.

Table 3
General and Sexuality Counseling
(N = 54)

	Was Sexuality Mentioned In The General Counseling Session?				Number And Percent Of Clients Receiving Sexuality Counseling
	YES			NO	
	By The Client	By The Counselor	Do Not Remember		
Rehabilitation Counselor	5	10	11	5	5 (7.3%)
Psychologist or Psychiatrist	6	5	10	9	9 (13.2%)
Social Worker	3	2	7	6	2 (3.0%)
Physician*	3	3	7	2	7 (10.3%)
Nurse	2	3	6	3	1 (1.4%)
Disabled Peer Counselor	0	1	0	0	2 (3.0%)
Sex Therapist	0	0	0	0	2 (3.0%)
Other+	0	0	1	0	2 (3.0%)
TOTALS	8(14.8%)	10(18.5%)	19(35.2%)	17(31.5%)	30 (55.5%)

*Includes Gyn/OB
+Includes a Physical and Occupational Therapist, a member of the clergy, and group therapy sessions with non-disabled participants.

Almost half (40 percent) of all subjects receiving sexuality counseling services came from two Spinal Cord Injury Treatment Hospitals. Their combined incidence of sexuality counseling among respondents was quite high, approximately 61 percent, as compared to the combined incidence per agency of the total sample, roughly 34 percent. These two agencies had a combined questionnaire return rate of 37 percent, somewhat less than the overall return rate of 52 percent. In regard to sexuality counseling these two agencies serviced 18 clients, representing a disproportionate amount of the total population who had sexuality counseling.

It should be noted that three of the participating Rehabilitation Hospitals are known to sponsor the SAR workshop, and at least two of the Independent Living Centers cover the issue of sexuality in their social skills training programs. Despite efforts to include topics pertinent to sexual adjustment in large scale rehabilitation programs, it appears that the specific needs of numerous SCI women are not being met in this fashion. Only five of all the women in this study have participated in a SAR program.

In light of these factors sexual adjustment does not appear to be an integral part of the majority of rehabilitation programs surveyed in this study. Very few women received referrals advocating sexuality counseling as a potentially beneficial experience, and those who obtained counseling did so from a wide variety of sources. It seems likely that many women took advantage of opportune moments to bring up their sexual concerns to an individual with whom they felt comfortable. For a few women this was the nurse on the floor of the hospital where they had been living for months, for others it was a disabled peer counselor. In some instances sexual matters were discussed in situations where it was sanctioned, such as visits to a gynecologist or birth control clinic. Rather than being a substantial component of rehabilitation programs for SCI women, sexuality counseling seems an option available predominantly to those who seek it out in their own behalf.

Desire for Sexuality Counseling and Educational Opportunities

An area of special consideration in this study dealt with specific opportunities for meeting needs and interests in the realm of sexuality. Respondents were asked to choose services they would take advantage of if made available to them, and to write in those experiences they had already found useful. Thirty-one (46 percent) of the women indicated they would like to receive individual sexuality counseling. Twenty-five (37 percent) respondents requested sexuality workshops, and twenty (29 percent), ongoing group sexuality counseling. Although many women wanted greater access to "video, books, etc., *in* the rehabilitation process," only 7 (10 percent) requested formal sex education. This may not be surprising, however, in light of society's emphasis on sexual expertise, and the resultant reluctance to admit ignorance about what people often believe they should know.

At least three participants specified they would like an informal "rap group" to talk with disabled women having similar problems. Two other women indicated experimentation had been most beneficial to their sexual awareness, and a third wrote "I've fumbled on my own and am satisfied, but mad about how the subject is still in the closet, so to speak." Only ten women out of the entire sample did not desire any of the given opportunities, three of whom previously had sexuality counseling.

Respondents who already received some type of sexuality counseling and information were asked to list topics they felt had not been adequately covered in their session(s). All of these women indicated a

far greater need for more information than they received, most notably in the areas of "My Disability in Relation to Sexual Complications," "Birth Control Methods and Their Side Effects," and "Orgasm." The heightened interest in these topics may reflect a lack of knowledge and available information concerning the sexual functioning of SCI women, underscoring the need for extensive research in this area.

Items designed to increase sexual exploration and acceptance of sexual variety, such as "Masturbation," "Sexual Positions," and "Sexual Aids," were paid little attention in their previous counseling sessions. A few participants complained about the inadequacy of their sessions. One woman who discussed sexuality with her rehabilitation counselor wrote that it was a "very informal short talk about sex [being] possible but not orgasm!" Another said: "I received a book to read. I did not think it was enough." It is interesting to note that half of the 30 women who received sexuality counseling wanted more emotional counseling on the following topics: "My Partner(s)," "My Sexuality," and "Other's View of My Sexuality." As one woman expressed, "the most important topic is 'My Sexuality'—because we as people are sexually active and always changing and growing." Several respondents indicated that interpersonal and social issues were the most pressing. For example, women wanted to know more about the "emotional aspects, like what makes you feel sexy" and "social situations—where to go, how to meet partners." Twenty-one of these women were single, the mean age of occurrence of injury was 23, and the mean years disabled was 3.75, representing a relatively young, unmarried, and recently injured group. These findings emphasize the importance of issues relating to self understanding, both psychologically and physically, and those items relevant to the formation of meaningful interpersonal relationships.

CONCLUSION

Despite the increasing awareness of sexual needs amongst the disabled population, less than half of the participants in this study received some type of sexuality counseling service as result of their injury. Rehabilitation counselors contributed only a small portion to this number. While quite a number of women actually discussed sexual matters at some point following their injury, only eight initiated conversation regarding sexuality in their general counseling session(s). It seems likely that many women thought this an inappropriate topic for discussion, especially if it was not brought up by a member of their

rehabilitation team. Nevertheless, it might prove beneficial to include assertiveness training in post-injury adjustment programs. Increasing communication skills will facilitate pointing out one's special needs and desires, helping to overcome attitudinal barriers, while enhancing interpersonal relationships. These skills can also be integrated into the social and sexual areas of one's life, thereby serving to counteract assumptions that SCI women are or want to be passive.

Women of all ages with diverse backgrounds perceived a need for sexuality counseling services, yet there appeared to be a tendency for younger, single, and more recently injured women to receive sexuality counseling. Thus, while there may be a growing awareness of the desire for such services among younger women, the available resources still fall far short of the overall need. I shall close by calling attention to the unique predicament of SCI women. Yes, we have troubles, but nobody's listening.

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