STATED OPINIONS ON SEXUAL COUNSELING BY SPINAL CORD INJURED MALES

by

Diana Marie Sims

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This thesis has been approved on the date shown below:

Beverly McCord for Karen Sechrist — September 1, 1976

KAREN SECHRIST
Assistant Professor of Nursing — Date

This thesis is dedicated to my parents who stressed the importance of education all my life. Their support, understanding and love made not only this thesis possible, but my life.

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ABSTRACT

Sexuality is an area of concern for spinal injured males. After cord injury, sexual problems can be approached through sexual counseling. This descriptive study was designed to discover what spinal injured males believed to be important in sexual counseling.

Marmor's concepts of sexuality were the basis for the theoretical framework. A patient profile collected biographical information and a written rating scale of selected sexual topics explored what the subjects believed important in counseling.

Analysis of the data by frequency of topic ratings showed all but three topics to be highly rated. Pearson correlation between social variables and topics ratings was performed. Education at time of injury correlated significantly with ratings on two topics at the .01 level and with one topic at the .04 level. Level of injury correlated with the ratings on one topic at the .02 level of significance. Analysis of variance explored mean differences in topic ratings by marital status at time of injury. No significant differences were found.

The conclusion of the study was that sexual counseling for cord injured males is important and counseling programs should relate to physical and psychosocial aspects of sexuality.

CHAPTER 1

INTRODUCTION

The first written description of a spinal cord injury was written on papyrus in the first half of the third millenium B.C. (Chaiklin and Warfield, 1973) and in it, mention is made of the presence of erection in the injured male (Talbot, 1970). However, for three thousand years, the belief of the majority of health professionals and lay public has been that once a person became cord injured, his sexual life was for the most part over--a dead issue. From the extensive amount of research that has been compiled on sexual function among spinal cord injured males, it is now clear that sex is not a dead issue, but very much alive.

In this country, there are approximately 10,000 new civilian spinal cord injured persons every year. Added to this are several thousand spinal cord injured patients who were hurt in the Viet Nam conflict. There are approximately 75,000 to 125,000 living spinal cord injured persons in the United States (Talbot, 1971). The number of spinal cord injuries has been on the upswing over the last decade due to combat casualties and an increase in recreational related

accidents. An increase in violent crimes in our society has also added to the rise in the number of spinal cord injured patients.

After an injury to the spinal cord, the person will have not only a varying degree of physical limitation depending upon the level and extent of injury, but may also have a disruption of "normal" sexual function. Sexual functioning is an expression of one's sexuality and is an important aspect of life. The fact that people are sexual beings is not eradicated with the cessation of normal sexual function after a spinal cord injury. The growing awareness of the adaptability rather than the obliteration of psychosexuality after cord injury has provided the impetus for the creation of sexual counseling programs in many rehabilitative facilities (Griffith, Tomko and Timms, 1973).

Sexual expression as an important aspect of a person's life is a need that has not been met by health professionals in the past. Cole (1971a) has stated the response of health professionals has indicated that sexual dysfunction was a problem which rehabilitation teams had to confront. Most rehabilitation programs for the disabled deal primarily with restoration of physical function and adaptation and only secondarily to social or psychological rehabilitation. More attention needs to be focused on the psychosocial aspects of disability. One of these aspects is human sexuality.

Cord injured patients need help not only in physical rehabilitation, but rehabilitation aimed toward the management and continuation of the sexual aspects of their lives. Sexual rehabilitation to meet patient needs is a necessary component of total rehabilitation. Assessment of patient needs in sexual counseling is mandatory in the development of effective sexual counseling programs. Research of what should be included in sex counseling of cord injured people is needed before the process of restoration of sexuality reaches a level of expertise commensurate with that of other phases of rehabilitation.

While extensive literature on the mechanics and physiology of cord injuries as it relates to sexual function is available, little or no data exist on sexual counseling needs as stated by patients. Several descriptive examples of sexual counseling programs for spinal injured patients have been published, but these programs have not stated the relationship between the content of the programs and what patients actually might want to know in counseling.

With the number of new cord injured patients as well as the number of spinal cord injured persons in the community, a wealth of data related to needs for sexual counseling could be collected from the patients themselves. Patients need to feel that all the therapy and re-training they receive is relevant to their goals. As Odhner (1973, p. 78) stated, "They must, must, must, be a contributory

member of the rehab (sic) process, not a broken machine others are trying to repair." Cord injured people who need help with sexual rehabilitation are in the best position to comment on what their needs are in this area. Romano and Lassiter (1972, p. 572) state:

> As with all rehabilitation, the focus in a program of sexual counseling is on understanding, on making knowledgeable choices, and on compensation and the use of what one has in order to live a satisfying and responsible life. Directing our attention toward meeting the patient's needs, immediate or projected, in regard to sexual understanding and behavior should thus be an integral part of a rehabilitation program.

Statement of the Problem

The study explores the following questions:

1. When after injury do questions about sexuality occur?
2. How soon after injury do cord injured males feel sexual counseling should be started?
3. Who should give sexual counseling?
4. Should sexual partners or potential sexual partners also receive counseling?
5. What topics should be included in a sexual counseling program?
6. How do patient stated sexual counseling needs correlate with participants' demographic data?

Significance of the Problem

Spinal cord injured patients of today are beginning to demand answers to their sexual questions. The male population in the past was, in general, willing to dismiss or let the subject of sex be dismissed. Sex was more or less a non-discussed subject; however, young men of today are less inhibited about sex and its discussion and are more demanding of answers to sexual questions than preceding generations (Hohmann, 1972).

Winston et al. (1969) stated that the ability to perform sexually is of great importance and is one of the major problems facing paraplegics. Several authorities have also written on the high incidence of marital and social conflict that arise when spinal cord injured patients are discharged to home (Romano and Lassiter, 1972; Comarr, 1962, 1963a). Romano and Lassiter (1972) believed the basis of the conflicts appeared to be sexual ignorance or misinformation.

With the recent development of sexual counseling programs for the spinal cord injured, it behooves health professionals to look for the answers to what spinal cord injured people want to know in a counseling program. There is not sufficient data on what should be included in such

programs (Romano and Lassiter, 1972). Therefore, health professionals should seek answers not only to effective methods of counseling but also to what should be included in the content of sexual counseling programs based on patient stated needs.

Purpose of the Study

The purpose of the study was to determine needs for sexual counseling as stated by spinal cord injured males. Also, issues related to the counseling milieu were explored.

Theoretical Framework

Human sexual behavior is usually referred to as an instinct. This assumes that it is inherently a biologically dependent behavior although it may be set off by external cues. Human inherited instinctual patterns tend to become less preformed and more subject to modification by learning. At birth, man's instinctual patterns tend to be more or less unfocused biological drives which are subject to modification by learning and experiences. Hampson and Hampson (1961) have referred to this unfocused quality of infant sexual drive as "psychosexual neutrality." This neutrality is not a driveless state, but rather a drive with no inborn object. With experience, the individual will find gratification by means available to him. Thus, this neutrality has been referred to by Marmor as "psychosexual

multipotentiality" (Marmor, 1971). As this neutral or "multipotentiality" state becomes altered by an individual's learning and experience there develop diverse patterns of psychosexual orientation and function corresponding with the life experiences encountered (Marmor, 1971; Hampson and Hampson, 1961).

Patterning of human sexual behavior begins at birth. Certain gender role expectations are communicated to the child by multitudinous cues over years. This identity becomes so profoundly fixed by three years of age, that efforts to reverse this identity after that time are almost always a failure (Opler, 1965; Marmor, 1971).

As the child grows and becomes acculturated, he has usually learned to channel his sexual urges into socially acceptable expressions. Apart from Freud's psychoanalytic theory of sexuality is the ego-psychological theory. This theory starts with the premise that an infant's sexual needs are primitive and poorly differentiated, but are still expressed through reflex actions such as suckling. As the child develops, he discovers his own body. In the ego-psychological theory, the anal and phallic periods are not due to an inherent psychological characteristic, but are explained by the correlation to the time when emphasis is being placed on bowel and bladder training.

In contradiction to Freud, Marmor (1971) has stated that as the child becomes interested in issues such as the

differences between sexes and where babies come from, his questioning and curiosity may be discouraged or treated as shameful. This is the time that repression of a child's sexuality really begins and after this acculturation, it is not hard to understand why there is a "latency period". Basically, then, sexuality is an individual entity and there are as many definitions of it as there are people (Marmor, 1971).

After a spinal cord injury, the patient will go to a rehabilitative facility or acute care setting, not with an altered concept of personal sexuality, but with physical disabilities that may prevent him from expressing his sexuality in a learned and experienced manner. Certainly, the sexual aspect of the injured man is not obliterated, but his ability to express it may be. Hence, comes the source of much stress and frustration for the patient. Based on the premise that sexuality is incorporated into one's concept of self at a very early age and is a part of one's ego identity which by adulthood is a set characteristic, it is a fallacy to consider the possibility that a person can dispense with this integral part of his being without significant detriment.

If one is prevented from expression of his normal role activities, a social handicap is superimposed upon a physical handicap. Kutner (1971) listed two major social components of disability: (1) an individual's own sense

of inadequacy or incompetence to perform, and (2) an individual's consensus that social prejudices against the disabled are legitimate. Thus, if one is prevented from taking part in expression of his role, he falls under this definition of disabled.

In contemporary society, physical wholeness and beauty are highly desirable and imperfections tend to create feelings of inferiority and lowered self-esteem (Mann, Godfrey and Dowd, 1973). Spinal cord injured patients typically have a decrease in self-esteem or sense of personal worth. One of the reasons for this decrease is the loss of sexual function (O'Connor and Leitner, 1971). Therefore, for the cord injured male to be successfully helped by rehabilitation, he needs help with whatever difficulties he may have with sexuality.

Sexual identity is an important component of one's self-concept. Sexuality has a different meaning for every person and helping patients to maintain their sexual integrity would imply the necessity of determining from the patient what sexuality means to him and what he feels his needs are in the area of sexual counseling.

Limitations

The limitations of the study included the following:

1. Subject population was small, fifteen subjects.

2. The researcher has had long term previous experience with the subject population and the relationship may have affected answers on the questionnaire responses.

Assumptions

The following assumptions were made as a basis for the study:

1. All subjects would have sufficient knowledge of their physical injury to identify the level and extent of their injury.
2. The subject population would be representative of a cross section of spinal cord injured males in this country.
3. Spinal cord injured males have opinions regarding sexual counseling.

Definitions of Terms

For use in this study, the following terms are defined:

1. Cord injured. One who has had a traumatic injury to the spine resulting in loss of motor function and sensory perception below the level of spinal cord damage.
2. Sexuality. A total spectrum of attitudes and behaviors expressed by a human either inwardly, outwardly, conscious or unconscious which identifies one, either to himself or others as male or female; an inclusive

concept of psychological, social, hormonal, biological and neuromuscular components (Griffith et al. 1973; Hohmann, 1972).

3. Sexual functioning. Physical expression of one's sexuality by whatever means are possible and enjoyable for him.

4. Sexual Counseling. The process by which the injured person and those sexually involved with the injured person obtain information about the aspects of sexuality including the physical, psychological and social functions.

CHAPTER 2

REVIEW OF THE LITERATURE

An extensive base of published information exists on the subject of sexual function in spinal cord injured males. This literature is, however, largely restricted to the mechanical and biological aspects of conventional sexual behavior (Griffith et al. 1973). Much attention has been focused on erection, ejaculation, and orgasm. Coitus, fertility, and libido have been researched to a lesser extent and have been treated in an all or none fashion reminiscent of neuronal physiology. Sexual neurophysiology is repeatedly reviewed.

Marital statistics and family life have been researched to some extent (Zeitlin, Cottrell and Lloyd, 1957; Comarr, 1962, 1963b; Deyoe, 1972; Masham, 1973). None of these articles show a correlation between marital status and sexual function.

No literature was found that related what spinal cord injured males wanted to learn in sexual counseling. Answers to the questions such as: do patients want sexual counseling, when should counseling begin, what should be included in counseling, and what is the best counseling approach, were not found in a review of the literature.

The importance of sexual counseling for spinal cord injured persons is referred to by several authors. Griffith and associates (Griffith et al. 1973) wrote that including sexual counseling in rehabilitation programs is a necessity for total rehabilitation of the patient, and have been involved in studying the effectiveness of methods of modifying attitudes, and supplementing knowledge of professionals. They have also accented the role of psychosexual factors, particularly that of effective communication between partners. Cole (1971a and 1971b) has produced explicit films dealing with sexual attitudes of spinal cord injured males.

Jackson (1972) reviewed and summarized pertinent previous literature on the subject of sexuality as it relates to sexual functioning of spinal cord injured males. He became aware of the need for sexual rehabilitation from his association with the Canadian Wheelchair Sports Association. Jackson gained his information by surveying a group of paraplegic and quadriplegic athletes involved in the National Wheelchair Games. His subjects were given a questionnaire and an interview which dealt with what this group of cord injured males could do sexually, i.e., how many had erections, how often, positions for intercourse, preference for and use of artificial devices during sexual activity.

Several sexual counseling programs were described in the literature but none of these were based on patient stated needs or were evaluated afterward to see if patient needs were met. Romano and Lassiter's (1972) counseling group included both men and women, married and unmarried with an age range of 16 to 63 years. A group approach was used for reasons of time, economy, and to give the participants the feeling of not being alone in their problem. The group was given a review of anatomy and physiology of the human reproductive system based on the authors' observation of a striking lack of accurate information about these areas. Technical as well as vernacular language was used in counseling. There was no limitation on what could be discussed in the group and effort was made to make the group self-directing. The major problem mentioned by Romano when he began to set up the counseling program was a striking lack of data that gave clues about what should be included in a program of this type.

Mann et al. (1973) used group counseling in the sexual rehabilitation of spinal cord injured patients. His program was based on the self-concept theory and was aimed at increasing the sense of personal worth among severely disabled men. It stressed development of coping mechanisms to aid readjustment. A group approach was used to give the patients a supportive milieu. Patients who had been injured

longer and were returning from the community for general check-ups were used to help the more newly injured with adjusting and much of the group work became patient led. Accent was on the positive assets that the patient still had and the strengths he could draw from for further development. Focus was on what remained not on what had been lost. The discussion content of this group appeared to be patient defined (Mann et al. 1973). However, the topics that these patients wanted to discuss were not delineated. Bailey (1968) and Hohmann (1972) stressed that the psychological aspects of sexual counseling are as important as the physiological and anatomical aspects, and the necessity for both the patient and his partner to receive counseling.

In a review of literature, no data could be found that explored the question of whether group or individual counseling was more effective. Hohmann (1972) believed that group approaches to sexual counseling were fraught with danger while Mann et al. (1973) and Romano and Lassiter (1972) used group therapy for reasons of time, economy and to give patients the feeling of not being alone in their problem. Yalom (1970) stated that group psychotherapy was constructive because it encouraged altruism, universality (not being alone with a problem), increased imparting of information and increased group cohesiveness.

Several authors mentioned the possible benefits of using former patients in counseling. This approach was based on the rationale that using patients who had been successful would lead to imitative behavior (modeling) and give new patients positive attitudes toward potential sexual functioning (Romano and Lassiter, 1972; Mann et al. 1973; Yalom, 1970).

The answer to the question of who should give sexual counseling was not found in the literature. Opinions by several authors were found. Weber and Wessman (1971) stated that it was the responsibility of the physician, while Hohmann (1972) held the position that anyone who has developed a good relationship with the patient and has accurate knowledge of the subject can give sexual counseling.

The problem of the spouse in adjusting to the changes in a sexual relationship have been mentioned by Hohmann (1972) and Wendland (1969). No authors mentioned counseling with any other sexual partner other than the spouse or the potential spouse. Weber and Wessman (1971) stated that before an individual with a cord injury marries, the future spouse should get counseling to make sure there is an understanding of all the limitations and complications involved since after a man is injured, there is usually a role reversal in sexual intercourse and, thus, the wife must become the aggressive and active partner. Weber does not state if there are positive aspects to be found in a

sexual relationship with a spinal cord injured man, or sexual partner should receive sexual counseling because a sexual relationship is composed of more than one person and is more than just a physical exchange of energy. Wendland (1969) mentioned that to some extent, sexual problems were handled in group therapy sessions for husbands and wives of patients and an attempt was made to discuss the matter of sex relations prior to the patient's first weekend pass or first overnight pass.

CHAPTER 3

METHODOLOGY

This chapter includes the research design, the tools, the setting, the population and sample, data collection, and proposed analysis of the data.

Research Design

A descriptive study involving fifteen spinal cord injured males was conducted to explore what these men believed to be important aspects of sexual counseling. The subjects were all adult males who had sustained permanent spinal cord damage due to trauma at least two and one-half years prior to the study and had been living in the community for at least one and one-half years.

To explore what cord injured males believed to be important in sexual counseling, a research designed paper and pencil questionnaire was developed.

The study was approved by the Human Rights Committee of The University of Arizona.

The Tool

To explore what spinal cord injured males feel are important aspects of counseling, a written six page questionnaire was devised (Appendix A). The questionnaire

had three sections, each designed to gain specific information. The first section was devised to collect data on a biographical profile of each participant. Pertinent medical data were also obtained in this section such as when and how each participant was injured and their level of injury. The second section was designed to gain data concerning the help a participant may or may not have received in the area of sexuality from the time he was first injured until the present. The third section was designed to obtain data about what the participants see as important content in sexual counseling at this time. Sufficient space was given on the questionnaire for participant comment.

The Setting

The study was conducted in a community of approximately 350,000 population in the Southwestern United States. The subject population participated in the study in their homes exclusively.

The Population and Sample

The population consisted of paraplegic and quadriplegic males in one community with whom the investigator had been working for time periods of eight months to one and one-half years in the area of sexual counseling. The following criteria were used for participant selection: (1) male, (2) existence of a permanent spinal cord injury due to

trauma, (3) living in a private community setting for a minimum of one year, (4) agreement to participate in the study through signing of the consent form for participation in a study as required by the Committee of Human Rights (Appendix B). Participants meeting the criteria and agreeing to participate became the sample.

Data Collection

The purpose of the study was explained to each participant. Consent to participate in the study was obtained in writing, and confidentiality was assured. The questionnaire was delivered to each participant at his home and the directions for completion of the questionnaire were explained in addition to the written direction contained in the questionnaire. Emphasis was again made at this time to each participant that he could withdraw from the study or omit answering any question which he objected to for any reason. The investigator gave each participant a phone number where she could be reached if there were any questions. Each participant was given a pre-stamped, pre-addressed envelope for return of the questionnaire to the investigator.

Data Analysis

Percentage of frequency of responses was the chosen method used for interpretation of what needed to be included

in sexual counseling. Each question was analyzed for its importance to the subjects.

The variables of education at time of injury, age at time of injury and level of injury from each participant's biographical profile were correlated with the rating responses to the sexual topics in Part Three of the questionnaire.

Analysis of variance was employed between the variable of marital status at the time of injury and the rating responses to the sexual topics.

The criteria used for statistical significance was set at the .05 level.

CHAPTER 4

PRESENTATION AND ANALYSIS OF DATA

This chapter presents patient characteristics, description of data, and statistical analysis of the data.

Patient Characteristics

The patient characteristics of age, race, income, education before injury, education at present, level of injury, how injury occurred and age at the time of injury are presented in Table 1.

The age range for the fifteen subjects was from 25 to 37 years with a mean of 28.9 years. Twelve subjects were Caucasian, two were Mexican-American, and one subject was Negro. Two subjects had incomes of under $5,000 a year, three subjects had incomes of $5,000 to $10,000 annually, seven of the subjects received from $10,000 to $15,000 per year and three subjects had incomes of over $15,000 annually.

The educational range for subjects before injury was from ten years to sixteen years of education. The mean education for subjects at the time of injury was 12.1 years. The range for educational attainment at this time is from ten years to eighteen years, with a mean educational attainment of 13.2 years. Seven of the subjects have continued their education since injury.

Table 1. Patient Characteristics by Age, Race, Present Income, Education before Injury, Education at Present, Level of Injury, How Injury Occurred, and Age at Time of Injury

Subject	Age	Race	Present Income	Education Pre-Injury (years)	Education at Present (years)	Level of Injury	How Injury Occurred	Age at Time of Injury
1	37	Caucasian	below $5,000	12	16	T-6	GSW*-civilian	31
2	28	Caucasian	above $15,000	12	15	T-12	GSW-VN**	20
3	29	Mexican-American	$10,001-15,000	12	12	T-10	Land Mine-VN	25
4	34	Caucasian	$10,001-15,000	16	18	T-12	GSW-VN	27
5	27	Caucasian	$5,001-10,000	12	12	T-6	GSW-hunting	21
6	27	Caucasian	$10,001-15,000	12	14	T-7	GSW-VN	20
7	30	Mexican-American	$10,001-15,000	12	12	L-1	Work Accident	25
8	25	Caucasian	above $15,000	12	13	T-3	GSW-VN	19
9	30	Caucasian	above $15,000	12	14	T-10	GSW-VN	25
10	25	Caucasian	$10,001-15,000	12	12	T-8	Jeep-VN	22
11	27	Caucasian	$5,001-10,000	12	12	T-4	Motorcycle	23
12	25	Caucasian	$5,001-10,000	12	12	T-10	GSW-civilian	19
13	31	Caucasian	$10,001-15,000	12	12	C-5	Work Accident	27
14	32	Negro	below $5,000	10	10	C-5	GSW-civilian	29
15	25	Caucasian	$10,001-15,000	12	15	T-8	GSW-VN	20

*GSW = Gun Shot Wound
**VN = Viet Nam

Two subjects were quadriplegics, four subjects had high thoracic injuries (thoracic vertebrae 1 to 6), eight subjects had injuries that ranged from thoracic level 7 to 12, and one respondent had an injury level below the twelfth thoracic vertebra.

Of the fifteen subjects, eight were injured in the Viet Nam War, three received injuries secondary to civilian crimes, one subject was injured in a hunting accident, one subject was injured in a motorcycle accident and two subjects were injured in job-related accidents. Subject age at the time of injury ranged from 19 years to 31 years.

Patient characteristics according to pre-injury marital status, years married at the time of injury, present marital status, years now married and ages of children are found in Table 2.

At the time of injury, five subjects were single and dating no particular person, three were dating one particular person, two were engaged and five subjects were married. The range for years married at the time of injury was from two years to ten years. At the present time, one subject is single and dating no particular person. Five subjects are dating one certain person, four are engaged and one subject is divorced. Four subjects are married with the years now married listed as one, two, three and ten years. Of the five subjects that were married at the time of their injury, only one has remained married to the

Table 2. Patient Characteristics by Pre-injury Marital Status, Years Married at Time of Injury, Present Marital Status, Years Now Married, and Ages of Children

Subject	Marital Status	Years Married at Time of Injury	Present Marital Status	Years Now Married	Present Ages of Children
1	Married	10	Divorced	--	13,12,8,7
2	Single dating no particular person	--	Married	3	6 (step-son)
3	Engaged	--	Engaged	--	None
4	Engaged	--	Single dating one particular person	--	None
5	Single dating no particular person	--	Single dating one particular person	--	None
6	Single dating one particular person	--	Engaged	--	None
7	Married	2	Single dating one particular person	--	6
8	Single dating no particular person	--	Married	1	None
9	Single dating no particular person	--	Engaged	--	None
10	Single dating one particular person	--	Single dating one particular person	--	None
11	Married	3	Single dating no particular person	--	7,5
12	Single dating no particular person	--	Single dating one particular person	--	None
13	Married	6	Married	10	9,8,6
14	Married	9	Married	2	12,11,9,8
15	Single dating one particular person	--	Engaged	--	None

same spouse. Four of the subjects married at the time of injury listed their present marital status in one of the categories other than "Divorced" although they had in fact undergone a divorce since injury.

Nine of the subjects have no children. Two subjects have one child, one has two children, one subject has three children and two respondents have four children. The children's ages ranged from six to thirteen years with the mean of 8.5 years of age. None of the subjects have had children born to them since injury.

Patient characteristics according to type of rehabilitation facility use, length of stay, was sexuality a source of worry after injury, when first sexual questions arose, who was asked for sexual information, who gave information, were these questions answered satisfactorily and rating of information received are presented in Table 3.

Six subjects went to private rehabilitation facilities, eight subjects went to veterans' hospitals and one subject went to a state-operated rehabilitation program as an outpatient. The length of time spent at the facilities ranged from three months to eight months with the mean length of stay being 4.8 months.

Sexuality was a source of worry after injury for all subjects. Ten subjects began to have sexual questions one to two days after injury. Five subjects began to have sexual questions within one to two months after injury.

Table 3. Patient Characteristics by Type of Rehabilitation Facility Used, Length of Stay, Was Sexuality a Source of Worry after Injury, When First Sexual Questions Arose, Who Was Asked for Sexual Information, Who Gave Sexual Information, Were Questions Answered Satisfactorily, Subject Rating of Sexual Information Received

Subject	Type of Facility	Length of Stay (Months)	Sex a Source of Worry	When Questions First Arose	Who Was Asked for Information	Who Gave Information	Were Questions Answered Satisfactorily	Rating of Information Received
1	State	3	yes	1-2 days	doctor	doctor	no	extremely poor
2	VAH	6	yes	1-2 months	doctor, patients	doctor, patients	no	extremely poor
3	VAH	7	yes	1-2 days	doctor, patients	doctor, patients	no	extremely poor
4	VAH	4	yes	1-2 days	doctor, patients, nurse, therapists	doctor, patients, nurse	no	extremely poor
5	Private	4	yes	1-2 months	doctor, patients	doctor, patients	no	below average
6	VAH	5	yes	1-2 days	doctor, patients	doctor, patients	no	below average
7	Private	3	yes	1-2 days	doctor, patients nurse	doctor, patients	no	extremely poor
8	VAH	7	yes	1-2 months	patients	doctor, patients, nurse	no	extremely poor
9	VAH	5	yes	1-2 days	doctor, patients	doctor, patients	no	below average
10	VAH	4	yes	1-2 days	doctor, patients	doctor, patients	no	extremely poor
11	Private	3	yes	1-2 days	doctor, patients	doctor, patients	no	below average
12	Private	3	yes	1-2 days	doctor, patients, nurse	doctor, patients, nurse	no	below average
13	Private	8	yes	1-2 months	doctor	doctor	no	below average
14	Private	7	yes	1-2 months	doctor, patients	doctor	no	extremely poor
15	VAH	4	yes	1-2 days	patients	doctor	no	extremely poor

Thirteen subjects asked health workers for answers to their sexual questions. Two subjects asked questions only of other patients. Two subjects questioned only the physician. Two subjects asked the physician, nurse and other patients sexual questions. Eight subjects asked the doctor and other patients for answers to their sexual questions. One subject asked the doctor, nurse, physician, therapist and other patients for answers.

All fifteen subjects received sexual information from a doctor: ten from other patients and three from nurses. All fifteen subjects felt that their questions were not answered satisfactorily.

Nine of the subjects rated the sexual information they received as extremely poor and six of the subjects rated the information as below average.

Subject characteristics according to availability of sexual counseling during rehabilitation, sexual counseling received, type of session used, counseling received by sexual partner and counseling received since return to the community are presented in Table 4.

Three subjects had sexual counseling available at their rehabilitative facility. Three subjects did not have sexual counseling availability and nine subjects did not know if counseling was available. Three subjects received counseling and twelve did not.

Table 4. Patient Characteristics by Availability of Sexual Counseling during Rehabilitation, Was Sexual Counseling Received, Type of Session Used, Counseling Received by Sexual Partner, Counseling Received Since Return to Community

Subject	Availability of Counseling	Counseling Received?	Session Type	Partner Counseled?	Counseling Since Return to Community
1	Do not know	yes	Private	no	yes
2	Do not know	no	None received	no	yes
3	Do not know	no	None received	no	yes
4	Do not know	no	None received	no	yes
5	No	no	None received	no	yes
6	Yes	yes	Private	no	yes
7	No	no	None received	no	yes
8	Do not know	no	None received	no	yes
9	Do not know	no	None received	no	yes
10	Yes	no	None received	no	yes
11	No	no	None received	no	yes
12	Do not know	no	None received	no	yes
13	Do not know	no	None received	no	yes
14	Yes	yes	Private	no	yes
15	Do not know	no	None received	no	yes

For the three subjects who received sexual counseling, private sessions were used. Although nine subjects had a sexual partner at the time of injury, none of the partners received sexual counseling. All subjects have received sexual counseling since their return to the community.

Patient opinions regarding aspects of sexuality and/or sexual counseling are in Table 5. Opinions on the following questions were included:

1. Should sexual counseling be a part of the rehabilitation program?
2. When should sexual counseling be started?
3. Who should give sexual counseling?
4. Should sexual counseling be in a private or group session?
5. Should a sexual partner receive sexual counseling?

All subjects stated that sexual counseling should be a part of the rehabilitation program. Twelve subjects thought sexual counseling should be started within the first month after injury and three subjects believed counseling should begin when the patient begins to ask sexual questions.

All subjects felt that anyone could give sexual counseling as long as they had accurate and complete information. All subjects preferred private counseling sessions and all believed that a sexual partner or

Table 5. Patient Opinions Relating to Aspects of Sexuality or Sexual Counseling

Subject	Should sexual counseling be part of the rehabilitation program?	When should sexual counseling be started?	Who should give sexual counseling?	Should sexual counseling sessions be in private or group session?	Should sexual partner be counseled with patient?
1	yes	When patient asks for it	Anyone with knowledge	private	yes
2	yes	Within 1 month	Anyone with knowledge	private	yes
3	yes	Within 1 month	Anyone with knowledge	private	yes
4	yes	Within 1 month	Anyone with knowledge	private	yes
5	yes	When patient asks for it	Anyone with knowledge	private	yes
6	yes	Within 1 month	Anyone with knowledge	private	yes
7	yes	Within 1 month	Anyone with knowledge	private	yes
8	yes	Within 1 month	Anyone with knowledge	private	yes
9	yes	When patient asks for it	Anyone with knowledge	private	yes
10	yes	Within 1 month	Anyone with knowledge	private	yes
11	yes	Within 1 month	Anyone with knowledge	private	yes
12	yes	Within 1 month	Anyone with knowledge	private	yes
13	yes	Within 1 month	Anyone with knowledge	private	yes
14	yes	Within 1 month	Anyone with knowledge	private	yes
15	yes	Within 1 month	Anyone with knowledge	private	yes

potential partner should receive sexual counseling as well as the patient.

Responses to the Questionnaire

Subject ratings on sexual topics that might be included in a counseling program by absolute and relative frequencies can be found in Table 6.

Each topic was rated as either: (1) Very Important, should definitely be discussed; (2) Important, should be discussed at some time; (3) Not Too Important, might or might not be discussed; or, (4) Unimportant, need not be discussed.

The topics of erection, urinary and bowel accidents, erogenous zones and mental orgasm were rated as "Very Important" by all subjects. The topics of ejaculation, orgasm, female sexual response, positions or methods for sexual activity and importance of communication in a relationship were rated by all subjects as "Important" to "Very Important". Fourteen of the subjects (93.3%) rated the topics of fertility and sexual anatomy and physiology of the female as being "Important" to "Very Important". Anatomy and physiology of sexual function in spinal injured males was rated as "Important" to "Very Important" by thirteen subjects (86.6%). Ten of the subjects (66.7%) believed the topic of marriage and divorce among spinal injured males to be either "Important" or "Very Important".

Table 6. Subject Ratings of Selected Topics that Could be Included in a Sexual Counseling Program by Absolute and Relative Frequencies

Topic	Very Important		Important		Not Too Important		Unimportant	
	number	percent	number	percent	number	percent	number	percent
Anatomy and physiology of sexual function in normal male	0	0.0	6	40.0	7	46.7	2	13.3
Anatomy and physiology of sexual function in spinal injured males	2	13.3	11	73.3	2	13.3	0	0.0
Methods to initiate or sustain erections	15	100.0	0	0.0	0	0.0	0	0.0
Ejaculation	11	73.3	4	26.7	0	0.0	0	0.0
Orgasm in the cord injured male	13	86.7	2	13.3	0	0.0	0	0.0
Fertility of spinal cord injured males	3	20.0	11	73.3	1	6.7	0	0.0
Sexual anatomy and physiology of the female	3	20.0	11	73.3	1	6.7	0	0.0
Female sexual response	14	93.3	1	6.7	0	0.0	0	0.0
Various positions or methods for sexual activity	14	93.3	1	6.7	0	0.0	0	0.0
Marriage and divorce among spinal injured males	44	26.7	6	40.0	3	20.0	2	13.3
Importance of, and how to improve communication in a relationship	12	80.0	3	20.0	0	0.0	0	0.0
Urinary and bowel accidents during sex and how to avoid these incidents	15	100.0	0	0.0	0	0.0	0	0.0
Artificial insemination	1	6.7	1	6.7	8	53.3	5	33.3
Spasms and sexual activity	1	6.7	0	0.0	9	60.0	5	33.3
Erogenous zones	15	100.0	0	0.0	0	0.0	0	0.0
Mental orgasms	15	100.0	0	0.0	0	0.0	0	0.0

Ten of the subjects (66.7%) rated the topic of anatomy and physiology of sexual function in the normal male as having little or no importance. Artificial insemination was also rated low, with thirteen of the subjects (86.6%) rating the topic as "Not Too Important" or "Unimportant". The lowest rated topic was spasms and sexual activity which was rated by fourteen of the subjects (93.3%) as being of little to no importance.

Five subjects (33.3%) suggested additional topics that should be included in sexual counseling. These topics were: psychology of sex in male and female relationships, how to handle catheters during sex, social aspects of sexuality, meaningful relationships and how to accomplish them, and dependency in a sexual relationship.

Statistical Analysis

Pearson correlation was the method employed to explore a relationship between education at the time of injury, age at time of injury, and level of injury with the ratings given to each of the sixteen sexual topics.

Education at the time of injury correlated significantly with the rating given on three of the sexual topics. The greater the number of years of education attained by a subject, the greater was the desire for information on the following topics. Education and the topic of anatomy and physiology of sexual function in the normal male had a correlation coefficient of .46 which

was significant at the .05 level. Education correlated significantly with the ratings given on the topic of female sexual physiology ($r = .70$) at the .01 level. The correlation coefficient for education and the ratings on sexual physiology of the cord injured male was .67 which was statistically significant at the .01 level.

Correlation between age at the time of injury and topic ratings was found to have no statistical significance.

Level of injury correlated significantly with the ratings of only one topic, artificial insemination. The correlation coefficient was .52 which was statistically significant at the .02 level. The lower the spinal injury level, the higher the subject tended to rate the topic of artificial insemination.

Analysis of variance was also used to explore mean differences in topic ratings by marital status at the time of injury. Analysis found there to be no statistically significant differences in ratings due to marital status at time of injury.

It was not possible to use analysis of variance to look at the variable of race due to the small sample size with 12 Caucasians and only one Negro and two Mexican-Americans.

Additional Findings

After completion of the questionnaire, several of the subjects noted that although they feel they now know

what is important in sexual counseling, they do not believe many newly cord injured patients would know. The subjects felt that some topics, such as communication, need to be presented to newly injured patients in terms of their importance in sexual relationships after injury.

CHAPTER 5

DISCUSSION OF FINDINGS

The subjects in the study are evidence that sexuality is not a dead issue with the cord injured male, but indeed, very much alive. Concurring with Hohmann (1972), the study showed that sexuality is of great importance and a major worry facing cord injured persons. Also in support of Hohmann (1972), the study showed the subjects to be eager for answers to their sexual questions and not inhibited in seeking answers.

The subjects were young (25 to 37 years). They were injured in activities not uncommon to spinal cord injuries--war, crime, work, and recreation. The average education at the time of injury was 12.1 years. At injury, eight subjects were single, two were engaged and five subjects were married. All subjects received physical rehabilitation, but none received any sexual counseling or information that was considered satisfactory. In fact, only three subjects received any counseling at all. Five of the subjects had children at the time of their injury, but none have had children since injury. None of the subjects' sexual partners received any sexual counseling, and four of the five subjects married at time of injury have undergone

a divorce. The study population was representative of the spinal cord injured patient in contemporary society as reported by other investigators (Talbot, 1971; Griffith et al. 1973; Hohmann, 1972; Winston et al. 1969; Romano and Lassiter, 1972; Comarr, 1962).

Sexuality was an early source of worry for all subjects. This is significant because it enforces the fact that sexuality is a major part of a person's total self-concept. After a spinal cord injury, a person's fear of being unable to function in the usual manner jeopardizes the viability of one's sexual self-concept.

Opinions relating to aspects of sexuality or sexual counseling revealed that all subjects believed that sexual counseling should be a part of the rehabilitative program and should be started within one month, or as soon as the patient begins to ask sexual questions. Contrary to Weber and Wessman (1971), all subjects felt that anyone could give sexual counseling as long as they had correct and thorough information. In concurrence with Hohmann (1972) all subjects preferred private, rather than group counseling. This preference may have been biased in that all subjects had received private counseling since their return to the community. All subjects believed sexual counseling should be available for sexual partners or potential partners, which was in agreement with several authors (Romano and

Lassiter, 1973; Weber and Wessman, 1971; Griffith et al. 1973; Hohmann, 1972; Mann et al. 1973).

Discussion of Statistical Findings

Of the sixteen listed sexual topics that could be included in a sexual counseling program, thirteen were rated important to very important by ten or more of the subjects. Three topics--anatomy and physiology of sexual function in normal males, artificial insemination and spasms and sexual activity--were rated unimportant or not too important by 60% to 93.3% of the subjects. While the latter three were unimportant to many, the topics should be available for discussion with those persons desiring this information.

Pearson correlation between education at the time of injury and the ratings on each sexual topic showed statistical significance for three topics--sexual anatomy and physiology of the spinal injured male, sexual anatomy and physiology of the normal male and sexual anatomy and physiology of the female. The less educated subjects saw these subjects as less important. However, the subject population was small and disparity between education at injury was also small. Therefore, the finding of significance by education at time of injury needs further study with a larger population.

Level of injury correlated significantly with only one topic, artificial insemination, at the .02 level. The higher the injury level, the less important this topic tended to be. However, five of the subjects already had children and these subjects rated this topic as unimportant.

The Negro subject and the one Mexican-American subject did rate the topics of communication and female sexual anatomy and physiology lower than the Caucasians, but still at the important level. The small sample size makes the validity of the data questionable on this point.

Education at time of injury affected the ratings on three topics, race affected two topics, and level of injury affected ratings on only one topic. Marital status at the time of injury and age at the time of injury did not have an affect on topic ratings. Almost all subjects rated almost all topics as "Very Important" or "Important". The fact that the study population was small and all subjects had received lengthy sexual counseling since return to the community may have affected their ratings on the topics.

Conclusions

As a result of the analysis of the entire questionnaire, it was found that sexual counseling should be a part of the rehabilitation process and should be conducted soon after injury by someone who is thoroughly knowledgeable with the topic. Counseling should include topics relating to

the physical, psychological and social aspects of sexuality of the cord injured person and his sexual partner. The subject-rated topics showed that spinal injured males feel sexual counseling should cover different aspects of sexuality, not only those relating to the neurophysiological aspects of sexuality.

Recommendations

The following implications for further study are suggested:

1. A study with a larger group of subjects under a similar format with a refined questionnaire.
2. A study with spinal cord injured males soon after injury, at one year after injury and again after two years post-injury, using a similar format.
3. A long term study to explore if spinal cord injured persons who are married at the time of their injury have less divorce when counseled than those who have received no counseling.
4. A study which evaluates the effectiveness of different approaches to sexual counseling.
5. Studies involving females with spinal cord injuries.
6. A study to explore what sexual partners or potential partners of spinal cord injured patients want to know in sexual counseling.

CHAPTER 6

SUMMARY

An area of concern for spinal cord injured males is that of sexuality. In the past, this subject has been more or less neglected. In the past few years, there has been an increasing awareness that the issue of sexuality must be dealt with if the injured patient is to receive total rehabilitation. This study was designed to discover what spinal cord injured males who had returned to the community felt was important in a sexual counseling program.

The theoretical basis for the study was based on Marmor's (1971) premise that sexuality is incorporated into one's concept of self at an early age and is a part of one's ego identity which by adulthood is a set characteristic. A spinal cord injury threatens this part of the self-concept. Sexual counseling should help protect the patient's sexual concept and help him to express his sexuality in whatever method is available and acceptable to him.

The study design was descriptive in nature. A patient biographical profile provided background information. A written rating scale of selected topics that could be included in sexual counseling was utilized to explore what cord injured males believed important in counseling.

Absolute and relative frequencies were used to analyze the importance of each topic. Pearson correlation was employed to explore correlation between topic ratings and the variables of education at time of injury, age at time of injury, and level of injury. Analysis of variance was used to explore mean differences on topic ratings by marital status at the time of injury.

Results of analysis indicated that all but three topics were considered to be important or very important by 86% or more of the subjects.

Education at time of injury correlated with the topics of sexual anatomy and physiology of the cord injured male and female sexual anatomy and physiology at the .01 level of statistical significance. Education correlated with sexual anatomy and physiology of the normal male at .04 level of significance. The lower the education of the subject, the lower they tended to rate these topics. Level of spinal injury correlated with the topic of artificial insemination at the .02 level. The lower the injury, the more important this topic became. Age at time of injury did not correlate significantly with any topic. Marital status at time of injury did not affect topic ratings.

The conclusion of the study is that sexual counseling is important to the spinal cord injured male and topics being included in a sexual counseling program should relate to the physical, sociological and psychological

aspects of sexuality. Patients should be asked about what they want to know in sexual counseling and given a chance to contribute data relating to what is important for the spinal cord injured patient in sexual counseling.

Recommendations for further study include a study with a larger sample, a study with cord injured males soon after injury, at one year after injury and again after two years, a long term study to explore if those patients that receive sexual counseling have less divorce than those who do not, a study on the effectiveness of various approaches to sexual counseling, a study involving females with cord injuries, and a study to explore what the sexual partners or potential partners of spinal cord injured patients want to know in sexual counseling.

APPENDIX A

QUESTIONNAIRE ON STATED OPINIONS ON SEXUAL COUNSELING BY SPINAL CORD INJURED MALES

PART ONE

Section One asks for biographical information and pertinent information relating to your spinal injury. To answer this section, put a check (✓) mark in the appropriate space, circle the correct answer, or fill in the blank with a response.

---

1. Date of Birth: _____

2. Race:

   Caucasion _____
   Mexican _____
   Negro _____
   Oriental _____
   Indian _____
   Other _____

3. Present Income:

   Below $5,000 a year _____
   $5,001 to $10,000 a year _____
   $10,001 to $15,000 a year _____
   Above $15,000 a year _____

4. Educational Background: Circle the highest year of schooling <u>completed at the time of your injury</u>.

   1 2 3 4 5 6 7 8 9 10 11 12 College: 1 2 3 4 5 6 7 8

   Other: (Please specify) _____.

5. Circle the highest year of schooling completed at the <u>present</u> time.

   1 2 3 4 5 6 7 8 9 10 11 12 College: 1 2 3 4 5 6 7 8

   Other: (Please specify) _____.

6. What was your age at the time you were injured? _____

7. How were you injured: (example: diving accident)

   _____.

8. To your knowledge, what is the level of your spinal injury?

   _____.

9. Are you completely paralyzed below the level of your injury?

   Yes _____; No _____

10. Do you have normal sensation below the level of your injury?

    Yes _____; No _____

11. Marital status at the time of injury:

    Single, dating no particular person _____
    Single, dating one certain person _____
    Married _____
    Engaged _____
    Divorced _____
    Separated _____
    Widowed _____

12. If you were married at the time of your injury, how long had you been married? _____.

13. Marital status at the present time:

    Single, dating no particular person _____
    Single, dating one certain person _____
    Married _____
    Engaged _____
    Divorced _____
    Separated _____
    Widowed _____

14. If you are now married, how long have you been married?

    _____.

15. How many children do you have? _____. What are their ages? _____.

PART TWO

Section Two asks for information about the help you may or may not have had in the area of sexuality from the time you were first injured until the present. Place a check (✓) mark in the appropriate space or fill in the blanks with the correct response.

1. After injury, did you go to a rehabilitation facility?

   Yes _____; No _____

2. Was the rehabilitation facility a:

   Private facility _____
   Veterans facility _____
   Other _____

3. How long were you there? _____.

4. Was the subject of sexuality a source of worry for you after injury?

   Yes _____; No _____

5. After injury, when did you first begin to have questions concerning sex?

   Immediately, one to two days _____
   One to two months _____
   Three to four months _____
   After four months _____

6. Did you ask any of the health workers for answers to sexual questions?

   Yes _____; No _____. If you answered "Yes", whom did you ask?

   Doctor _____
   Nurse _____
   Occupational or physical therapist _____
   Other cord injured persons _____
   Other _____

7. If the answer to Question 6 was "Yes" were your sexual questions answered to your satisfaction?

   Yes _____; No _____

8. Was sexual counseling available at the facility where you received rehabilitation? Yes _____; No _____

9. Did you receive any sexual counseling during your hospitalization or rehabilitation? Yes _____; No _____

10. If you received any kind of sexual information, who gave this information to you?

Doctor	____	Occupation Therapist	____
Nurse	____	Other Patient (s)	____
Physical Therapist	____	Other	____

11. If you received any sexual information how would you rate it?

Excellent	____	Below average	____
Above average	____	Extremely poor	____
Average	____	Did not receive any	____

12. If you received any formal sexual counseling, was it in a:

Private session	____
Group session	____
Receive None	____

13. Did your sexual partner receive any counseling?

Yes _____; No _____; Not applicable _____

14. Have you received any sexual counseling since you have been back into the community? Yes _____; No _____

PART THREE

Part Three asks for your opinions about certain aspects of sexuality and/or sexual counseling. Place a check (✓) mark in the appropriate space and feel free to comment on any question in the space provided.

1. Do you think sexual counseling should be included as part of the rehabilitation program? Yes ____; No ____

If "Yes":

2. How soon after injury do you feel sexual counseling should be begun?

_____

3. Who do you think should be the person to give sexual counseling? (More than one may be checked)

Doctor _____
Nurse _____
Occupation therapist _____
Physical therapist _____
Other cord injured persons _____
Any of the above as long as they know the answers _____
Other _____

4. Would you prefer to receive sexual counseling in a:

Private session _____; Group session _____

5. Do you think a sexual partner or potential sexual partner needs to receive sexual counseling along with the spinal injured person?

Yes _____; No _____; Do not know _____

COMMENTS:

Below are topics that might be discussed in sexual counseling. Place one of the following numbers next to each topic:

1=Very important, should definitely be discussed
2=Important, should be discussed at some time
3=Not too important, might or might not be discussed
4=Unimportant, need not be discussed

____ Anatomy and physiology of sexual functioning in the normal male

____ Anatomy and physiology of sexual functioning in the cord injured male

____ Methods to initiate or sustain erections

____ Ejaculation

____ Orgasm in cord injured males

____ Fertility of spinal cord injured males

____ Sexual anatomy and physiology of the female

____ The female sexual response

____ Various positions or methods for sexual activity

____ Marriage and divorce among spinal cord injured males

____ Importance of, and how to improve communication in a relationship

____ Urinary and bowel accidents during sex and how to avoid these incidents

____ Artificial insemination

____ Spasms and sexual activity

____ Erogenous zones

____ Mental orgasm

Other:

____

____

APPENDIX B

SUBJECT CONSENT FORM FOR PARTICIPATION IN A STUDY EXPLORING STATED OPINIONS ON VARIOUS ASPECTS OF SEXUAL COUNSELING BY SPINAL CORD INJURED MALES

I, Diana Sims, R.N., am conducting a study of paraplegic and quadriplegic males, under the direction of the Graduate College, at The University of Arizona. The main purpose of the study is to explore what paraplegic and quadriplegic males think is important in sexual counseling. It is hoped that this information will help medical workers to create sexual counseling programs for cord injured males that will meet patient needs.

The questionnaire you will be asked to complete is composed of three sections. Section One asks for giographical information and pertinent information relating to your spinal injury. Section Two asks for information about the help you may or may not have been given in the area of sexuality from the time you were first injured until the present time. Section Three asks for your opinion about certain aspects of sexuality and sexual counseling.

The questionnaire will require between 30 to 45 minutes to complete. Many of the questions are of a highly personal nature, and you may choose not to answer any particular question or withdraw from the study at any time. Your participation is completely voluntary. Should you decide not to answer every question or completely withdraw from the study, your care will in no way be affected, nor your relationship with any health worker or medical facility.

All confidentiality will be insured. For this reason, you are requested not to sign your name on the questionnaire nor put your return address on the stamped envelope which will be enclosed for return of the questionnaire. Each questionnaire will be given a code number. All data will be coded and computer analysis will be carried out on grouped data, not individual responses.

The investigator will be available to answer any questions you may have by telephone. If you consent to participate in this study as outlined above, please sign your name below.

Signature of Participant: _____

Date: _____

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