Professional Involvement in Sexuality Counseling for Patients With Spinal Cord Injuries

Paul P. Novak, Marlys M. Mitchell

Key Words: counseling, sex • rehabilitation • spinal cord injuries

A national survey was conducted to determine how occupational therapists and rehabilitation nurses conduct sexuality counseling in practice settings with spinal cord–injured patients. A review of the literature and results from the survey demonstrated a high priority concern for sexuality counseling in the total rehabilitation of the spinal cord–injured patient; however, many of the professionals surveyed did not conduct sexuality counseling as part of their job. This study provides data comparing the sexuality counseling approach taken by these two disciplines and identifies ways to eliminate the incongruities between recommendations made in the literature and actual clinical practice.

The literature has long advocated the necessity for sexuality counseling in the total rehabilitation of the disabled patient (Bardach, 1978; Conine & Evans, 1982; Isaacs & Delgado, 1974; Neistad & Baker, 1978; Neistad & Marques, 1984). The goal of sexuality counseling is to provide the patient with the information he or she needs to make a personal choice about sexual activity. The role of the individual providing sexuality counseling is to help the patient deal with fears, guilt, or lack of knowledge (Scalzi & Dracup, 1978).

The purpose of this study was to (a) determine the importance of sexuality counseling in the clinical setting, specifically with spinal cord–injured (SCI) patients; (b) determine the professional groups that take responsibility for the counseling; and (c) determine the methods and materials used to disseminate such information. Sexuality counseling is defined as advice and recommendations relating to the attitudes toward and expression of sexual practices. Included are explanations of the impact of disability on sexuality, a description of the techniques of foreplay, stimulation, and positioning; and a discussion of the corresponding feelings of the individual or the couple regarding such matters.

Review of Literature

The discussion of sex and sexuality is frequently neglected in the health care delivery system (Bardach, 1978; Evans, 1985; Neistad, 1986), although research studies have shown that physical disability does not decrease sexuality and the libidinous drive (Anderson & Cole, 1975; Conine & Evans, 1982; Latimer, 1981; Vemireddi, 1978; Wallace, 1980). Cole, Chilgren and Rosenberg (1973) contended that disabled clients rate sexual fulfillment as a high priority in their total rehabilitation; however, these clients receive little information or helpful assistance from health care professionals in adjusting to or overcoming their disability in this area.

Sexuality appears to play an important role in individuals' ability to cope with their disability. Weiss and Diamond (1966) stated that a positive correlation exists between patients' avoiding a realistic consideration of their sexuality and avoiding a realistic acceptance of their disability. Several authors (Berkman, 1975; Conine & Evans, 1982; Decker & Schulz, 1985; Evans & Conine, 1985; Wilberger, 1986) described a relationship between a person's sexuality and self-esteem and between a variety of disabilities and self-esteem (Conine & Evans, 1982; Yerxa, Barber, Diaz, Black, & Azen, 1983).

Many professions have realized the importance of sexuality counseling in the total rehabilitation of the patient. Sexual habilitation and rehabilitation require
a collaborative effort that transcends professional boundaries (Rehabilitation Literature, 1979). Support for collaboration has been provided by other studies (Conine & Evans, 1982; Wilberger, 1986). Engstrand (1975) and Rusk (1977) advocated that all treatment team members should be knowledgeable in sexuality counseling and that the patient should be able to choose an advocate from among the rehabilitation professionals.

Kigler (1982) stated that patients involved in a rehabilitation program have the right to use sexual rehabilitation services and should be encouraged to use them. An informed professional can use frank and understanding discussions to alleviate fears displayed by the patient. Evans, Halor, DeFreece, and Larsen (1976) stated that the following disciplines should be represented in a sexual education program for SCI patients: nursing, medicine, occupational therapy, physical therapy, social work, and psychology.

Occupational therapy views sexual functioning as an activity of daily living in which the patient needs assistance in achieving an optimal level of independence. Such achievement is important to the patient's productivity, self-esteem, and successful reentry into society (Andamo, 1980; Conine & Evans, 1982; Frieden & Cole, 1985; Neistad & Baker, 1978; Neistad & Marques, 1984).

The rehabilitation nurse’s responsibilities in sexuality counseling are to (a) identify and respond to the patient’s needs and (b) provide the patient with a trusting, open atmosphere in which his or her confidences will be accepted and respected. The patient should be aware that these channels of communication are open at all times (Hanlon, 1975; Latimer, 1981).

Chipouras, Cornelius, Daniels, and Makas (1982) outlined basic requirements for all sexuality counseling personnel, including occupational therapists: (a) adequate comfort level with one’s own sexuality, (b) nonprojection of one’s own morals onto the patient, (c) a basic knowledge of human sexuality, (d) awareness of one’s limitations as a provider of sexuality counseling, and (e) a willingness to refer patients to appropriate sources as necessary. However, Evans et al. (1976) stated that “the professional who has the best insights into the patient’s problem and has established, during the evaluation period, the closest working relationship with the patient and family should assume the responsibility of primary counselor” (p. 543).

Method

Two hundred professionals, 100 occupational therapists and 100 rehabilitation nurses who work with an SCI population, were surveyed. Using mailing lists provided by the American Occupational Therapy Association (AOTA) and the Association of Rehabilitation Nurses, we drew the sample from those professionals who identified spinal cord injury as the health problem they see most frequently and/or who identified their area of practice as spinal cord injury. Other professionals, physical therapists, and rehabilitation counselors were considered for inclusion; however, mailing lists for these groups were not available.

We developed a three-page survey to assess the degree to which the importance of sexuality counseling as emphasized in the literature is reflected in the clinical setting. Participants’ responses were selected from lists of alternatives presented in the survey. Parallel forms of the survey were constructed to receive parallel data from the two groups of professionals surveyed.

A cover letter, the survey, and a precoded, self-addressed, stamped return envelope were mailed to the professionals in the selected sample. Three weeks after the initial mailing, an identical mailing was sent to those who had not responded.

Data were tabulated and analyzed with reference to the following questions:

1. Is the importance that professionals in clinical practice place on sexuality counseling congruent with that advocated in the literature?
2. How do the professions assume responsibility for sexuality counseling?
3. Do methods of information dissemination vary among professions?

Results

One hundred and fifty surveys (75%) were returned. Of the 74 surveys returned by occupational therapists and the 76 surveys returned by rehabilitation nurses, 130 surveys (58 by occupational therapists and 72 by nurses) were appropriate for analysis.

Thirty (51.7%) of the responding occupational therapists reported having had some form of educational training regarding sexuality counseling whereas 28 (48.3%) reported having had none. Forty-nine (68%) of the rehabilitation nurses reported having had educational training in sexuality counseling whereas 22 (30.6%) reported having had none, and 1 (1.4%) did not respond to that question.

Occupational therapists reported that an average of 73% of their SCI clients were male whereas rehabilitation nurses stated that 77% of their SCI clients were male. Both groups reported that their largest counseling population age group was 20- to 30-year-olds, followed first by 16- to 19-year-olds and then by 31- to 40-year-olds. Both groups reported that the largest
percentage of their population was in the middle socioeconomic class, followed first by the low socioeconomic class, and then by the high socioeconomic class. Both groups identified the largest percentage of their counseling population to be high school graduates, followed first by the non-high school graduates, and then by the associate degree recipients. The findings correspond with literature reports that the typical SCI patient is the young athletic male 15 to 25 years old (Trombly, 1983).

Respondents for both professions indicated that sexuality counseling is a high priority concern in the total rehabilitation of the SCI patient. Chi-square analyses demonstrated no significant differences between professions in the priority ratings placed on sexuality counseling in the total rehabilitation of the patient with SCI (occupational therapists, 55%; rehabilitation nurses, 65%; \( \chi^2 [2] = 3.26, p = .20 \)).

Rehabilitation nurses reported a significantly greater involvement in sexuality counseling as a part of their jobs than did occupational therapists (\( \chi^2 [1] = 6.20, p = .01 \)). Occupational therapists reported serving a mean of 43 SCI patients per professional each year; rehabilitation nurses reported serving a mean of 63 patients per professional each year. Rehabilitation nurses reported approaching an average of 74% of the SCI patients with sexuality counseling; occupational therapists reported approaching an average of 48% of the SCI patients with sexuality counseling. There was no significant difference in responses of rehabilitation nurses and occupational therapists reporting frequency of sexuality counseling with their SCI patients. Fifty-eight percent of occupational therapists and 55% of rehabilitation nurses reported doing sexuality counseling consistently as part of their patient’s routine (\( \chi^2 [2] = 0.116, p = .94 \)).

Respondents were asked to indicate the methods for presentation of sexuality counseling (see Figure 1). It can be seen that responses on one variable, individual counseling, produced a significant difference (\( p < .01 \)) between occupational therapists and rehabilitation nurses, with rehabilitation nurses reporting greater use of this presentation style. Responses on two variables, significant other present and informal presentation style, also produced a significant difference (\( p < .05 \)) between occupational therapists and rehabilitation nurses, with the rehabilitation nurses reporting greater use of these presentation styles. Responses for the two variables of presentation style in the clinic and on the ward missed achieving a significant difference at the .05 level (\( p < .06 \) and \( p < .07 \), respectively), with rehabilitation nurses reporting greater use of an on-the-ward presentation style, and occupational therapists reporting greater use of in-the-clinic presentation style. No significant differences were noted between the two pro-

Figure 1
Sexuality Counseling Presentation Styles

![Sexuality Counseling Presentation Styles](chart.png)

*\( p < .05 \), **\( p < .01 \), tApproaching \( p = .05 \).
essions in the use of group sessions, formal lectures, and the patient's own home.

In settings where sexuality counseling was a professional team responsibility, respondents identified other team members involved (see Figure 2). Responses for the team member variable occupational therapists produced a significant difference ($p < .01$) between occupational therapists and rehabilitation nurses, with responding occupational therapists reporting greater involvement by their own professional team member. Responses for the team member variable rehabilitation counselors produced a significant difference ($p < .05$) between occupational therapists and rehabilitation nurses, with occupational therapists reporting greater involvement by this professional team member. Responses for the team member variable physical therapists missed achieving a significant difference at the .05 level ($p < .07$) between rehabilitation nurses and occupational therapists, with occupational therapists identifying greater involvement by physical therapists. No significant differences were noted between occupational therapists and rehabilitation nurses in their identification of the involvement in sexuality counseling of the following team members: physician, social worker, psychologist, psychiatrist, and rehabilitation nurse.

Analysis of responses regarding materials for disseminating information for sexuality counseling by occupational therapists and rehabilitation nurses produced no significant differences between the two groups. Materials included written materials, films, slides, tapes, or self-made materials.

Rehabilitation nurses reported conducting sexuality counseling follow-up interviews with their SCI clients an average of 37.2% of the time; occupational therapists, 28.6% of the time. The difference was not significant ($\chi^2 [1] = 0.16, p = 0.69$). Of those who reported conducting follow-up interviews with their SCI clients, a majority of the occupational therapists and rehabilitation nurses reported conducting these interviews on a yearly basis.

Professionals who did not identify sexuality counseling as an aspect of their responsibility attributed their noninvolvement to the fact that "someone else [was] doing the counseling" (70% occupational therapists; 90% rehabilitation nurses). Less frequently cited (22% occupational therapists; 28% rehabilitation nurses) was perceived lack of knowledge in the subject area. A majority of rehabilitation nurses and occupational therapists who do not do sexuality counseling with SCI patients identified the physician as the professional who fulfills this responsibility in their setting. Other professionals identified by rehabilitation nurses as performing this responsibility (in decreasing order) were psychologist, social worker, other rehabilitation nurse, occupational therapist, psychiatrist, rehabilitation counselor, and physical therapist. Occupational therapists identified (in de-
Discussion

Respondents for both professions, occupational therapy and rehabilitation nursing, indicated that sexuality counseling was a high priority concern for the total rehabilitation of the SCI patient. When these respondents were asked if sexuality counseling was practiced as a part of their job responsibilities, it was found that sexuality counseling is actually practiced by only 57% of the occupational therapists and 60% of the rehabilitation nurses. One factor that appears to contribute to greater involvement by rehabilitation nurses than by occupational therapists in sexuality counseling is the rehabilitation nurses' greater amount of daily contact time with the patient. More contact time affords greater opportunity to develop a comfort level that can facilitate a frank and open discussion of the patient's sexuality concerns. Moreover, since the rehabilitation nurse is involved in many of the personal hygiene aspects of the patient's care, such as bathing, catheterization, and skin care while the patient is in the acute stages of recovery, there is more time for communication between the nurse and the patient. The occupational therapist may begin therapy with a patient during the acute stage or after the patient's condition has stabilized medically; his or her contact with the patient is usually shorter and less frequent than that of the rehabilitation nurse. In addition, survey results indicated that occupational therapists present sexuality information more often in the clinic than on the ward. The highly structured and less private therapy environment provided by the occupational therapist in the clinic may not be as conducive to discussing the SCI patient's concerns regarding his or her sexual needs. Achieving a confident relationship may be more difficult and may require a stronger commitment by the occupational therapist.

Reasons given by respondents from both groups for noninvolvement in sexuality counseling with an SCI patient population fell into two major categories: (a) someone else was doing the counseling and (b) inadequate knowledge of the subject area. Additional data analysis revealed that of those respondents who indicated that someone else was doing the counseling, 44% also reported not feeling knowledgeable about sexuality counseling. It appears that for a substantial number of respondents, lack of knowledge is linked with relinquishing responsibility for sexual counseling to some other person perceived to be more knowledgeable.

It is important to note that if someone else is doing the counseling, there is no need to force the patient to accept additional services and counseling. However, each profession appears to have a unique perspective from which to share this knowledge, making both groups potentially well qualified.

Perceived lack of knowledge in the subject area of sexuality counseling is of concern because of its implication for education and practice in occupational therapy. Conine, Christie, Hammond, and Smith (1979) and Conine and Evans (1982) identified lack of knowledge as a primary reason for lack of clinical involvement by occupational therapists in the sexual rehabilitation of their disabled patients. Of the occupational therapists polled in the present study, approximately 51% indicated having some form of educational training regarding sexuality counseling. Of the occupational therapists polled, a majority identified as their highest academic degree completed a bachelor of arts or bachelor of science degree. Additional data analysis revealed the age range of occupational therapists who did not feel knowledgeable in sexuality counseling to be 29 to 65 years of age, with a mean age of 40.6 years. The length of time that had passed since these professionals became registered in occupational therapy was 4 to 31 years, with a mean of approximately 13 years. The lack of knowledge identified in the present study suggests that this subject area continues to receive relatively limited attention in academic or clinical preparation.

Occupational therapists in practice who do not feel knowledgeable in the subject area have the opportunity to acquire knowledge through resources available to them. A broad range of training activities is offered as continuing education at many universities and practice settings. Studies involving rehabilitation counselors indicated that in-service education is an efficient way to provide training in sexuality and disability counseling. Over one third of the rehabilitation counselors in one study believed that an in-house consultant on sexuality could provide needed training to staff members (Chipouras et al., 1982). Occupational therapists and other health professionals who need training in sexuality counseling should request in-house training from hospital administrators. We believe that in-service education in sexuality counseling should be included in staff development and is the responsibility of the setting that advocates quality patient care. Such education should be based on a foundation of education provided in the academic setting.

Figure 2 shows that occupational therapists and rehabilitation nurses appear to be in close agreement on the role of the physician and other team members in regard to sexuality counseling. The two polled professions identified the roles of the rehabilitation

The American Journal of Occupational Therapy
counselor, occupational therapist, and physical therapist in somewhat different ways; but it should be noted that the variant rankings are restricted to medical allied health professionals. Because of a close interchange of information among these professionals, the occupational therapist may be at a greater advantage to identify and delineate the role of the physical therapist, rehabilitation counselor, and other occupational therapists in sexuality counseling practices for the SCI patient. Without additional data it is difficult to explain the varying rankings with confidence.

The survey indicated that individual counseling and an informal, conversational manner are the presentation styles of choice for both rehabilitation nurses and occupational therapists engaged in sexuality counseling with SCI patients. In ranking other modes of presentation, rehabilitation nurses opted (in descending order) for having the significant other present, counseling on the ward, group sessions, formal lecture, and the equally used modes of counseling in the clinic or in the patient’s own home. Other modes of sexuality counseling chosen by occupational therapists (in descending order) are in-the-ward (chosen with the same frequency); a formal lecture approach; and counseling in the patient’s own home (chosen least often).

The differences between professions in methods of conducting sexuality counseling appear to be related to each profession’s working environment, which was discussed in a previous section. Methods of presentation by occupational therapists and rehabilitation nurses such as in the patient’s own home, group sessions, and formal lectures appear to be related to each professional’s personal judgment and approach to counseling in relation to the patient and not to environmental constraints.

A majority of occupational therapists and rehabilitation nurses surveyed identified written materials and films as their two most frequently used means of disseminating information about sexuality counseling. It appears that written materials and films are the most readily available commercial sources for information. Such materials can be obtained from a variety of national service organizations and private corporations. For example, the publication Who Cares? A Handbook on Sex Education and Counseling Services for Disabled People (Chipouras et al., 1982) offers a compilation of consultants and organizations, audio/visual/tactile resources, and books and journals on the subject of sexuality and disability.

Occupational therapists and rehabilitation nurses reported conducting follow-up interviews regarding sexuality counseling with SCI clients an average of only 28.6% and 37.2% of the time, respectively. These results point to a lack of continuity in the provision of care by both disciplines. The low percentages may be attributed to an inability of patients to return to the hospital setting for follow-up interviews or a reluctance of patients to discuss their sexuality concerns after discharge. If the patient’s contact with medical personnel is inconsistent while he or she is at home, the sharing of personal sexuality concerns may again become a threatening or embarrassing experience. The available home health care personnel may also be reluctant to discuss personal sexuality concerns.

Andamo (1980) recommends that the patient be contacted 6 months after discharge to monitor his or her functional level and to identify and respond to problems that may have arisen. The patient’s sexual partner should be involved in this process. Postdischarge follow-up should continue for at least 2 years. Thus, Andamo has defined a follow-up period which coincides with a finding by Masters and Johnson (1977) that recurrence of sexual dysfunction is most evident during the first 2 years after discharge.

During the transition from the rehabilitation setting or hospital to a home the SCI client needs support. This support takes the form of follow-up care by the medical personnel and understanding and acceptance by the family. This is the time when the SCI clients will have to come to terms with possible alterations in their roles and responsibilities in the family unit, their life-style, and the impact of the disability on their self-concept. It is a period when insecurities or questions arise that were not anticipated in the hospital. These need resolution so that the individual can progress toward higher levels of adaptation and independent functioning. We propose that sexuality counseling should not be terminated with discharge from the hospital but should continue until the SCI client has reached his or her highest attainable level of functioning.

Implications for Occupational Therapy

The occupational therapist addresses the patient’s functioning in activities of daily living, and the research has shown that an individual’s sexuality affects all areas of functioning (Conine & Evans, 1982; Yerxa et al., 1983). A therapist who advocates treatment designed to assist the patient in achieving the highest level of functioning but who does not consider the interdependence of a patient’s sexuality and his or her other areas of functioning in this treatment model is not practicing from an occupational therapy perspective of holistic care.

The therapist who advocates sexuality counseling as a high priority in the total rehabilitation of the pa-
tient but who does not feel knowledgeable on the subject should find ways to acquire this knowledge.

Additional analysis of data from this study shows that of all respondents (occupational therapists and rehabilitation nurses) who reported having had educational training in sexuality counseling, 71% conducted sexuality counseling. Those who had educational training but did not counsel clients may have refrained because of a lingering feeling of inadequate knowledge, lack of opportunity, or low comfort level in engaging in such counseling. Under any of these circumstances, it is the responsibility of the individual therapist, the occupational therapy curricula, and the health care facility to provide the student or therapist with the opportunity to obtain the relevant educational information and training. AOTA could assist by offering continuing education opportunities. However, the individual therapist must take the initiative to increase his or her knowledge.

Educational exchange in this subject area must first provide therapists an opportunity to develop an understanding of their own sexuality. Such an understanding will facilitate open and frank discussion of the patients’ concerns regarding their sexuality. Second, the impact of specific disabilities on an individual’s sexuality should be discussed. Third, actual evaluation processes and treatment/counseling considerations should be discussed.

It appears that the occupational therapy and rehabilitation nursing professions are in a relatively similar stage of development regarding sexuality counseling. A joint effort at national, state, and individual levels may be of benefit to both disciplines to make necessary changes in the educational and clinical arenas to provide better service delivery. Such efforts will alleviate the discrepancy between information available through research studies and the actual use of this information in clinical practice.

Future Research

The results of this study lead us to propose the following additional research. Patients should be surveyed regarding the benefits they feel they have obtained through their involvement in sexuality counseling and methods of information delivery and presentation style they view to be most informative and satisfying. It would also be useful to identify the criteria that the SCI client employs in choosing a qualified health care person for the discussion of sexuality concerns. The interrelationship between educational training in sexuality counseling and the practice of sexuality counseling in the clinical setting, which Cole (1975), Cole and Cole (1982), and we in the present study have begun to describe, needs to be explored in greater depth to determine if there are specific cause-and-effect relationships.

Acknowledgments

This paper was adapted from a thesis submitted by the first author to the faculty of the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for a degree of master of science in occupational therapy. This research was funded, in part, by a grant from the Smith Fund at the University of North Carolina at Chapel Hill.

References


Rehabilitation Literature, 1979, 40, 219. (Abstract)


---

**A book every researcher needs to read...**

**Scientific Inquiry:**

**Design and Analysis Issues in Occupational Therapy**

Kenneth J. Ottenbacher, PhD, OTR. University of Wisconsin-Madison

Bette Bonder, PhD, OTR. University of Illinois-Chicago

In this volume the authors discuss critical factors that affect the credibility of research. By examining the research conducted over the last decade in the field of occupational therapy, they focus on the strengths and weaknesses of research design and analysis methodology. They identify types of design that have the most application in daily practice, as well as the limitations and effectiveness of various analytical methods.

**Topics covered:**
- The limitations of traditional hypothesis testing in the behavioral sciences
- The four factors that should be considered in determining sample size—significance level, statistical power, analysis procedure, and effect size
- Research design factors that limit the practical application of findings
- Methods of applying research findings and procedures in practice environments
- Statistical methods for use with single-subject and time series designs.

**Member cost** $12.00  **Non-member cost** $16.00

Send check, money order, or purchase order to: AOTA Products, 1383 Piccard Drive, PO Box 1725, Rockville, MD 20850-4375. MasterCard and Visa holders: save time—order by phone. AOTA members call toll free, 1-800-THE-AOTA.