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Sexual Response in Women with Complete Spinal Cord Injury

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Sexual response in women with complete spinal cord injury cannot be understood without first defining sexuality. In the past, sexuality was viewed as having one purpose—reproduction. Today it is seen as an important aspect of health and personality functioning; it enhances the quality of life, fosters personal growth, and contributes to human fulfillment (Whipple & Gick, 1980). When the term *sexuality* is viewed holistically, it refers to the totality of a being. It encompasses human qualities, not just the genitals and their functions. It includes all of the qualities—biological, psychological, emotional, social, cultural, and spiritual—that make people who they are. People have the capacity to express their sexuality in any of these areas without necessarily involving the genitalia.

What the person and/or the couple view as their goal of sexual expression must also be considered. According to Timmers (1976), there are two commonly held views. The most common view is goal directed, which is analogous to climbing a flight of stairs. The first step is touching, the next step kissing, followed by caressing, vagina/penis contact, intercourse, and orgasm. The goal of both or one partner is orgasm. If the sexual experience does not lead to the achievement of that goal, then the partners do not feel satisfied with what they have experienced (Whipple, 1987).

The alternative view is pleasure directed, which can be conceptualized as a circle, with each expression on the circle considered an end in itself. Whether

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the experience involves kissing, oral sex, holding, or other physical contact, each is an end in itself and each is satisfying to the couple. There is no need to have this form of expression lead to anything else (Whipple, 1987). If one person in a couple is goal directed and one is pleasure directed, problems may occur if they do not realize their goals or do not communicate their goals to each other.

SEXUAL RESPONSE IN WOMEN

Little was known about the physiology of sexual response before Masters and Johnson published their pioneering research in 1966 (Masters & Johnson, 1966). They found that two principal physiological changes take place—vasocongestion (e.g., blood engorgement) and myotonia (e.g., muscle tension). Reporting their findings using arbitrarily chosen phases of excitement, plateau, orgasm, and resolution, Masters and Johnson reported that these phases correspond to the level of sexual arousal and describe typical responses.

Not all researchers or women agreed with Masters and Johnson's monolithic pattern and their report of one reflexive pathway in sexual response. Some women reported that they had orgasm from vaginal stimulation and some women reported an expulsion of fluid with orgasm, which Masters and Johnson said did not occur (Masters & Johnson, 1966). After listening to the reports of these women, Perry and Whipple designed research studies that led to their naming the Grafenberg spot and their documenting the phenomenon of female ejaculation (Addiego, Belzer, Comolli, Moger, Perry, & Whipple, 1981). Perry and Whipple (1981) hypothesized that there were two different nerve pathways involved in sexual response. One pathway, via the pudendal nerve, is the major sensory pathway from clitoral stimulation as identified by Masters and Johnson (1966). Perry and Whipple (1981) identified the hypogastric plexus and the pelvic nerve as the sensory pathways in sexual response in women when there is vaginal stimulation.

In a later study that was also designed to validate the reported experiences of women, Whipple, Ogden, and Komisaruk (1992) documented in the laboratory that women could achieve orgasm from fantasy alone, without touching their bodies. During this study, orgasm from both self-induced imagery and genital self-stimulation was associated with significant increases in blood pressure, heart rate, pupil diameter, and pain thresholds over resting control conditions. These two orgasm conditions did not differ significantly from each other on any of the physiological measures (Whipple, Ogden & Komisaruk, 1992). On the basis of these findings, it is evident that physical genital stimulation is not necessary to produce a state that is reported to be an orgasm.

SEXUALITY AND WOMEN WITH SPINAL CORD INJURY: LITERATURE REVIEW

There is a paucity of literature concerning female sexual response after spinal cord injury (SCI). Perhaps the reason for this is that the ratio of males to females with SCI is 4:1 and that it is much easier to study sexual response in males, who have external genitalia (Sipski, 1991). Based on the literature concerning female sexual function after SCI, it is clear that women with spinal cord injuries are capable of menstruating, conceiving, and giving birth (Whipple, 1990). Most of the current literature is not concerned with whether women with SCI have any sexual desire or response. For example, Billings and Stokes (1982) report that women with SCI, because their role can be *passive*, may enjoy intercourse and be perfectly capable of satisfying the male. Billings and Stokes (1982) also state that little is known about their capacity for orgasm.

Sandowski (1976) reported the following:

> Far less has been written about the female paraplegic, probably because her ability to participate in sexual activities is less affected than the male's. The female paraplegic can have intercourse in the usual position of the female lying on her back with the male facing her on top . . . With the help of an understanding husband, it is quite possible for the female paraplegic to satisfy his needs and for the couple to achieve a fairly normal sex life (p. 323).

As late as 1992, Szasz stated that in women with complete spinal cord injuries, "although vaginal lubrication may still occur in response to either touch or mental stimuli, there can be no orgasmic response arising from or detected in the genitalia" (Szasz, 1992, p. 178). He further stated that "whenever the injury is complete, genital signals cannot get to the brain to generate neuromuscular tensions" (Szasz, 1992, p. 180). Perduta-Fulginiti (1992) agrees that orgasm cannot be physiologically achieved. She further reports that "in all complete spinal cord injuries at the Sacral 4 segment and above, total vaginal and anal sensation are lost" (p. 109). Although Money (1960) acknowledged that orgasm was reported by people with SCI, he labeled these orgasms "phantom," a label that is still used today. As late as 1992, Perduta-Fulginiti reports that some women with complete SCI report orgasm of a nongenital nature, which have been labeled as "phantom," although they are described as having intense psychological pleasure and similar subjective physical sensations as detailed during the orgasm phase of the sexual response pattern. She suggests that visceral motor and sensory components of the autonomic nervous system may relay information between the cortex, the hypothalamus, and the genitalia (Perduta-Fulginiti, 1992). However, she does not identify the sensory pathways.

As early as 1976, Bregman and Hadley interviewed 31 women with SCI and reported that most of the women's descriptions of orgasm since their injury were very similar to those of women without disabilities. Three of the women

reported orgasms that were not different from the orgasms they experienced before their injuries (Bregman & Hadley, 1976). Berard (1989) discusses physiological responses based on interviews of 15 women with SCI and reports a correlation between richness of fantasy and fulfillment of sexual life. Berard (1989) does address orgasm and states that pleasure may be heightened by concomitant stimulation of an erogenous zone either above or at the level of injury.

Charlifue, Gerhart, Menter, and Whiteneck (1992) surveyed 231 women and noted that half of their subjects reported that they had experienced orgasms since their injuries. The stimulus was generally genital or a combination of genital and breast stimulation. They do not specify if these women had complete or incomplete injuries.

Kettl et al. (1991) surveyed 74 women, and 52% of their sample reported orgasm after SCI; however, half of these women stated that it was different after their injuries. They do not state if these women had complete or incomplete injuries.

Although it is claimed that women with complete SCI cannot achieve orgasm or that their orgasms are labeled as "phantom" orgasms, subjective reports of women do not support these contentions. Indeed, some women with complete SCI report that they can experience the psychological and even physical sensation of orgasm. In addition, Axel (1982) found that 56% of her sample experienced the same discomfort with their menstrual period as before their SCI, 22% had less discomfort, and 22% had more discomfort. Again, she does not state if these women have a complete or an incomplete injury. Having a spinal cord injury does not necessarily prevent a woman from being orgasmic or from having menstrual discomfort.

These psychosexual data are generally based on anecdotal evidence or information from questionnaires and interviews. This type of data collection and dissemination has inherent biases because it is based on subjective reports (Whipple & Komisaruk, 1993). Laboratory data to document these subjective reports are lacking.

CURRENT STUDIES

In 1992, the National Center for Medical Rehabilitation Research funded two studies that are addressing some of these psychosexual issues. Using a population of women with complete and incomplete injuries above the level of T6, Dr. Marca Sipski and colleagues are investigating "The Physiological Effects of SCI on Females" (M. Sipski, personal communication, September 1, 1992). In another study, Komisaruk, Whipple, and Richards are investigating the effects of vaginal and cervical self-stimulation on pain, spasticity, and sex-

ual response in women with complete spinal cord injury at or below T6. In addition to these physiological studies, supplemental funding was received for qualitative research to investigate additional understudied areas of sexuality in women with complete SCI. This part of the study is addressing the psychosocial, emotional, and relationship components, using a phenomenological approach and is described in the qualitative section.

QUANTITATIVE STUDY

Methods

The basic premise of this study is that after SCI the sensory, sensorimotor, and perceptual capabilities of the nervous system may be underestimated. The specific aims are to identify sensory, sensorimotor, and perceptual responses to vaginal and cervical self-stimulation (such as effect on pain, spasticity, and sexual responses) that are intact and potentially functional in women with complete SCI. The long-term objective of this study is to identify the actual capabilities of the nervous system after SCI so that they can be utilized to the fullest extent and thereby enrich the quality of life of women with complete SCI.

This study is designed to ask the following research questions. In women with complete SCI, are vaginal, cervical, and/or hypersensitive zone self-stimulation effective in 1) activating sexual response; 2) suppressing neurogenic or experimental pain; and 3) suppressing spasticity?

This study is also determining if there are differential responses depending on the level of SCI. Two of the nerves that carry sensory input from the vagina and cervix are the pelvic and hypogastric nerves. Because these nerves enter the spinal cord at different levels, their relative contribution is being determined by studying women whose levels of complete SCI are expected to either block or leave these pathways intact.

This study uses the same methodology used in previous studies from this laboratory (Whipple & Komisaruk, 1985, 1988; Whipple, Ogden & Komisaruk, 1992), with the addition of a disposable tampon stimulator used for vaginal self-stimulation and cervical self-stimulation. There is a pressure transducer embedded in the holder for the stimulator so that the amount of pressure the subject is self-applying can be monitored. A tampon is attached to a diaphragm with Velcro discs when the stimulator is used for cervical self-stimulation.

Results

The following are *preliminary* results of the sexuality data from the first 13 subjects. Five are controls without disabilities, four have a complete SCI

between the levels of T6 and T10, and four have a complete SCI between the levels of T11 and L2.

The mean age of the women with SCI is 39 years (range: 32–47 years). Seven of the women are Caucasian; 1 is African American. Five are married; one is living with a partner, and two are separated. The mean length of time since injury is 11.7 years (range: 2–21 years).

The *preliminary* physiological data are summarized in terms of pain thresholds, cervical and vaginal sensibility, level of arousal, blood pressure, and heart rate.

Pain Thresholds

The subjects in each group showed a significant increase in pain detection threshold (as measured with a Ugo Basile Analgesia meter [Stoelting, Chicago] on the fingers) from prestimulation to during the stimulation condition, in response to vaginal, cervical, or hypersensitive area self-stimulation. There were no significant differences among the groups within each stimulus condition by analysis of variance (ANOVA).

This is a major preliminary finding of the study; that is, evidence that genital self-stimulation exerts a perceptual effect after complete SCI at these levels. To our knowledge, this is also the first demonstration that cervical self-stimulation produces analgesia. (There was no increase in tactile thresholds.) The pain tolerance thresholds were also significantly increased, and there were no significant differences between any pairs of groups in response to each form of self-stimulation.

Based on this evidence in our sample to date, the existence of SCI did not significantly reduce the magnitude of the pain-blocking effect of vaginal or cervical self-stimulation.

Cervical and Vaginal Sensibility

All of the women tested in the control group perceived cervical and vaginal pressure. In the SCI groups, two of four women in each of the T6–T10 and T11–L2 groups perceived cervical and vaginal pressure to self-stimulation.

Of the women with complete SCI, seven of the eight reported that they experienced menstrual cramps. Three of these seven women said they experienced menstrual cramps as lower back pain, which was below the level of their injury.

One woman with complete SCI at T11–T12 experienced multiple orgasms from vaginal self-stimulation and from cervical self-stimulation during the testing, but reported that she did not feel the stimuli.

Arousal

There were no significant differences in arousal between any pairs of groups for any stimulus type (i.e., vaginal, cervical, or hypersensitive area self-stimulation) as reported on the visual analog scale.

Thus, under other conditions in which group differences were observed, it is unlikely that elevated levels of arousal could account for these effects. For example, pain thresholds during vaginal, cervical, or hypersensitive area self-stimulation were not significantly correlated with the magnitude of arousal reported during the corresponding type of self-stimulation.

Heart Rate and Blood Pressure

Heart rate and blood pressure increased significantly in the control group in response to vaginal and cervical, but not hypersensitive area, self-stimulation. These findings confirm our earlier findings (Whipple, Ogden & Komisaruk, 1992). In addition, this is the first demonstration, of which we are aware, that cervical self-stimulation in women increases heart rate and blood pressure.

Cervical self-stimulation increased heart rate significantly in the T11-L2 group, but not in the T6-T10 group. By contrast, cervical self-stimulation increased blood pressure significantly in the T6-T10, but not in the T11-L2 group.

These findings, taken together, suggest that a mechanism related to that underlying autonomic dysreflexia may be responsible, although the levels of SCI in this study were too low for the women to experience any crisis of autonomic dysreflexia.

There was no significant correlation between blood pressure, heart rate, or pain thresholds. Consequently, heart rate, blood pressure, arousal, and pain thresholds may be controlled by mechanisms that function independently of each other under the conditions of the present study.

Discussion

There are a number of possible mechanisms suggested by these data:

1. The spinal cord near the central canal could be undamaged but integrity untested.
2. The sensory input could bypass the level of injury ascending via the sympathetic chain and enter at a higher level, or an extramedullary

pathway via a cranial nerve, such as the sensory vagus, which enters the brain directly. This hypothesis is currently being tested in laboratory animals.

3. There could be humoral effects; however, the response is too fast, and some subjects could perceive vaginal and cervical pressure.
4. There could be a cognitive effect, similar to our imagery-induced orgasm results. However, some of these women report menstrual cramps and vaginal and cervical pressure in response to sensory stimulation.

Based on the present findings and the recent study on imagery-induced orgasms, the current concepts of orgasm and sexual response need reformulation. In the present study, two women with complete SCI reported orgasm induced by cervical and vaginal self-stimulation in the absence of perception of these stimuli as sensory stimuli per se. Previous studies documented increases in autonomic response and pain thresholds in response to imagery with no stimulation of any body region (Whipple, Ogden & Komisaruk, 1992) and in response to hypersensitive area stimulation in the absence of physical genital stimulation (Sipski, Komisaruk, Whipple, & Alexander, 1993).

Further research into the nature and mechanism of orgasm is warranted to advance our understanding of this significant physical and cognitive process. One ultimate benefit could be to improve the quality of life of people with SCI by making them aware of responses that have been underestimated in the past.

QUALITATIVE STUDY

The qualitative component of this study provides additional information about the subjects and their sexuality. Preliminary data from interviews with the eight women with complete SCI are summarized in the following sections.

Methods

Phenomenology, a qualitative research approach, permits emerging data to be described through the uniqueness of the experience of participants. This methodology was used to expand the depth of understanding of sexuality and relationship experiences. An Ethnograph (Qualis Research Associates, Corvallis, OR) computer program was used to analyze the content of tape-recorded semistructured interviews with the subjects. This analysis identified a trajectory of sexuality in women with complete SCI. For interview purposes, data were clustered in phases according to sexuality and relationship experiences: 1) prior to injury; 2) immediately postinjury; and 3) during the rehabilitation process until the present.

Results

Prior to injury, there were no clear commonalities in subjects' perceptions of sexuality or relationship experiences. All participants reported that they experienced coitus prior to their injury.

Immediately postinjury, participants reported a "shutting down and closing up" of their sexuality, or a shelving of sexual interest. On the basis of observed or assumed absence of genital sensation, women believed that physical sexual pleasure was no longer possible for them. Familiar sexual responses were perceived as unattainable. A cognitive awareness and conscious decision not to deal with their sexuality emerged from the data. We labeled this phenomenon "cognitive genital dissociation."

Energies were focused on maintaining or regaining salient physiological functions (mobility, bowel, and bladder). Sexuality was not perceived as being of high priority, although some concerns were expressed. Between 3 months and 3 years postinjury, participants experienced coitus. There was a stated curiosity of what the experience "would be like." The experience generally resulted in sexual dissonance, a comparison between pleasure (what was), and disappointment (what is). This experience activated for most women a lengthy sexual readjustment and reevaluation of the nature of sexual pleasure.

Beginning with the immediate postinjury period and continuing with the rehabilitative process, participants described a loss of their sexuality or a "sexual disenfranchisement." More graphically, they felt "robbed" of their sexuality, including sexual desirability.

A period of "sexual rediscovery" emerged following sexual disenfranchisement. For some women, significant life events (such as a 40th birthday), or situational events (such as a new sexual partner) were turning points. Postinjury (in some cases 7, 8, or 15 years), women who were engaged in unaffirming and destructive relationships tended to move toward relationships that were affirming or constructive. Affirming relationships characterized by open communication, creativity, and resourcefulness played a key role in positive sexual self-concept. In the period of sexual rediscovery, reciprocity in relationships was critical in the shift from negatively to positively perceived sexual readjustment.

There was also a reevaluation of the meaning of sexual pleasure. Exploration resulted in a self-awareness of alternative approaches to sexual arousal and, in some instances, orgasm. Four women reported experiencing orgasm, one with a T6-T7 injury, one with a T10-T11 injury, and two with T11-T12 injuries. Participants reported arousal or orgasm through breast, cervical/vaginal, and/or hypersensitive area stimulation. There were no consistently preferred sexual positions.

Participants were asked to comment on the extent and quality of their

postinjury sexuality education by health professionals. The overall quality was considered poor. Generally included with information on bowel and bladder functioning, the materials that were distributed were of poor quality, outdated, and usually targeted for men. The focus of female sexuality education was on giving, rather than receiving, sexual pleasure and on reproductive issues, such as fertility and conception. All women reported a clear preference for the formation of female groups to discuss issues of sexuality.

Discussion

A sexual trajectory emerged from our study, the major phases of which were, in sequence, cognitive dissociation, sexual disenfranchisement, and sexual rediscovery. The preliminary results of this qualitative study indicate the need for further sexuality research in these identified phases. Research is also needed to identify critical points for sexuality education and counseling in women with SCI with the goal of shortening the sexual adjustment process.

CONCLUSIONS

There is still much we do not know about sexuality and women with SCI. Nevertheless, positive steps are being taken to learn more about the physiological and interpersonal aspects of sexuality. Ultimately, these efforts will enhance the quality of life for women with SCI.

REFERENCES

Addiego, F., Belzer, E.G., Comolli, J., Moger, W., Perry, J.D., & Whipple, B. (1981). Female ejaculation: A case study. *Journal of Sex Research, 17*, 99–100.

Axel, S.J. (1982). Spinal cord injured women's concerns: Menstruation and pregnancy. *Rehabilitation Nursing, 7*, 10–15.

Berard, E.J.J. (1989). The sexuality of spinal cord injured women: Physiology and pathophysiology: A review. *Paraplegia, 27*, 99–112.

Billings, D.M., & Stokes, L.G. (1982). *Medical surgical nursing*. St. Louis: C.V. Mosby.

Bregman, S., & Hadley, R.G. (1976). Sexual adjustment and feminine attractiveness among spinal cord injured women. *Archives of Physical Medicine, 57*, 448–450.

Charlifue, S.W., Gerhart, K.A., Menter, R.R., & Whiteneck, G.G. (1992). Sexual issues of women with spinal cord injuries. *Paraplegia, 30*, 192–199.

Kettl, P., Zarefoss, S., Jacoby, K., Garman, C., Hulse, C., Rowley, F., Corey, R., Sredy, M., Bixler, E., & Tyson, K. (1991). Female sexuality after spinal cord injury. *Sexuality and Disability, 9*(4), 287–295.

Masters, W., & Johnson, V. (1966). *Human sexual response*. Boston: Little, Brown & Co.

Money, J. (1960). Phantom orgasm in the dreams of paraplegic men and women. *Archives of General Psychiatry, 3*, 373–382.

Perduta-Fulginiti, P.S. (1992). Sexual functioning of women with complete spinal cord injury: Nursing implications. *Sexuality and Disability, 10*(2), 103–118.

Perry, J.D., & Whipple, B. (1981). Pelvic muscle strength of female ejaculators: Evidence in support of a new theory of orgasm. *Journal of Sex Research, 17*, 22–39.

Sandowski, C. (1976). Sexuality and the paraplegic. *Rehabilitation Literature, 37*(11–12), 322–327.

Sipski, M.L. (1991). Spinal cord injury: What is the effect on sexual response? *Journal of the American Paraplegia Society, 14*(2), 40–43.

Sipski, M.L., Komisaruk, B.R., Whipple, B., & Alexander, C.J. (1993). Physiological responses associated with orgasm in the spinal cord injured female. *Proceedings of the American Academy of Physiological Medicine and Rehabilitation, 74*, 1270.

Szasz, G. (1992). Sexual health care. In C.P. Zejdlik (Ed.), *Management of spinal cord injury* (pp. 175–201). Boston: Jones and Bartlett Publishers.

Timmers, P.O. (1976). Treating goal-directed intimacy. *Social Work*, 401–402.

Whipple, B. (1987). Sexual counseling of couples after a mastectomy or a myocardial infarction. *Nursing Forum, 23*(3), 85–91.

Whipple. B. (1990). Female sexuality. In J.F.J. Leyson (Ed.), *Sexual rehabilitation of the spinal-cord-injured patient* (pp. 19–38). Clifton, NJ: Humana Press.

Whipple, B., & Gick, R. (1980). A holistic view of sexuality: Education for the health professional. *Topics in Clinical Nursing, 1*, 91–98.

Whipple, B., & Komisaruk, B.R. (1985). Elevation of pain threshold by vaginal stimulation in women. *Pain, 21*, 357–367.

Whipple, B., & Komisaruk, B.R. (1988). Analgesia produced in women by genital self-stimulation. *Journal of Sex Research, 24*, 130–140.

Whipple, B., & Komisaruk, B.R. (1993). Current research trends in spinal cord injuries. In F.P. Haseltine, S.S. Cole, & D.B. Gray (Eds.), *Reproductive issues for persons with physical disabilities* (pp. 197–207). Baltimore: Paul H. Brookes.

Whipple, B., Ogden, G., & Komisaruk, B.R. (1992), Relative analgesic effect of imagery compared to genital self-stimulation. *Archives of Sexual Behavior, 21*, 121–133.