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Sexuality and Sexual Health After Spinal Cord Injury: A Phenomenological Study of Women's Experiences

by

Margaret Anne MacCabe ©

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Master of Science

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Abstract

Although it is well recognized that postinjury sexual adjustment can impact overall adjustment to disability, research in the area of spinal cord injury (SCI) and sexual health often focuses only on men. Research focused on women is often superficial, looking only at issues such as reproduction, pregnancy, and childbirth. A phenomenological study was undertaken to gain subjective insight into what sexuality and sexual health issues exist for women after they sustain a SCI, what their experiences have been in addressing those expressed issues, and how they think sexual health promotion opportunities should be provided after SCI. In-depth interviews with 10 women with SCI were completed. Thematic analysis of transcripts revealed findings in the following areas: the impact of SCI on sense of self; expressed sexuality, and sexual health (SH) concerns after SCI; relationships after SCI; preferred methods used in coping with change after SCI; and interactions with helping professionals. Implications for future service provision and research are outlined.

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CHAPTER I

INTRODUCTION

Statement of the Problem

Everyone needs and has the right to be a sexual person (White, 1993). Sexuality helps define a person (Richards, Tepper, Whipple, & Komisaruk, 1997) and is inextricably tied to feelings of self-esteem (Drench, 1992; Kreuter, Sullivan, & Siosteen, 1996), attractiveness (Lanig, Chase, Butt, Hulse, & Johnson, 1996), and self-efficacy (Fitting, Salisbury, Davies, & Mayclin, 1978; Sipski & Alexander, 1997). The occurrence of a spinal cord injury (SCI) can have profound effects on a person's sense of sexuality, making vague once-familiar concepts of personal, social, and sexual interactions (Basson, 1998; Drench, 1992; Rieve, 1989; Rintala et al., 1997). In addition to this, it is well-recognized by professionals, as well as people with SCI, that post-injury sexual adjustment can have a significant impact on overall rehabilitation outcomes and well-being (Charlifue, Gerhart, Menter, Whiteneck, & Manley, 1992; Chicano, 1989; Drench, 1992; Fitting et al., 1978; Kettl, Zarefoss, Jacoby, & Garman et al., 1991; McAlonan, 1996; Nygaard, Bartscht, & Cole, 1990; Sawyer, Allen, & Reisin, 1983; Siosteen, Lundqvist, Blomstrand, Sullivan, & Sullivan, 1990).

Despite the acknowledgement that sexuality is an important area of clinical and academic practice in the overall rehabilitation of men and women with SCI, the bulk of existing information looks at sexuality issues of men only (Berard, 1989; Charlifue et al., 1992; Drench, 1992; Fitting et al., 1978; Harrison, Glass, Owens, & Soni, 1995; Kettl et al., 1991; Richards et al., 1997; White, Rintala, Hart, & Fuhrer, 1993). This may be due to the fact that women make up the minority of the spinal-cord-injured population (Drench, 1992; Harrison et al., 1995; Kettl et al., 1991; Nygaard et al., 1990; Richards et al., 1997; Whipple, Gerdes, & Komisaruk, 1996; White et al., 1993) and the fact that the sexuality concerns experienced by men with SCI (i.e., altered erectile function, ejaculation, and fertility) are much easier to observe and quantify (Charlifue et al., 1992; Fitting et al., 1978; Richards et al., 1997; Whipple et al., 1996).

Regardless of the reason, this dearth of information has left many women with SCI in a vulnerable position. Many are ignorant about their sexual and reproductive functioning and susceptibility to related health problems (Becker, Stuifbergen, & Tinkle, 1997; Charlifue et al., 1992; Nosek et al., 1995; Sawyer et al., 1983). Of those who state that they have sexuality concerns, many often perceive that they lack the ability to address those issues (Becker et al., 1997; Welner, 1997). Finally, women are often left feeling as though they do not have the right to be concerned about sexuality as long as their fertility is unaffected (Charlifue et al., 1992). This has led to a population of women who are unsatisfied with their sexuality (McAlonan, 1996), who experience disempowerment (Becker et al., 1997; Drench, 1992; Tilley, 1998), and whose holistic well-being and adjustment to disability are at risk (Berard, 1989; Charlifue et al., 1992; Nosek et al., 1995).

Existing information on the sexuality of women with SCI often fouces on physical functioning and disability management issues such as reproduction, pregnancy, and childbirth (Basson, 1998; Berard, 1989; Harrison et al., 1995;

Kettl et al., 1991; Nygaard et al., 1990). Furthermore, there is even less information available about the personal experiences that women with SCI have had pursuing optimal sexual health (Charlifue et al., 1992; Miller, 1988).

Statement of Purpose

Because of the above issues, and because of my personal experiences in pursuing optimal sexual health as a woman with SCI for the past 10 years, the focus of this study was to gain a greater understanding of the barriers and opportunities that women experience in pursuing an optimal sense of sexuality after SCI. In pursuit of this goal, I wanted to hear from women themselves about their perceptions and experiences in relation to the following objectives of learning about: the importance of sexuality and sexual health after SCI, the sexual health promotion opportunities that participants may or may not have received or had access to after their injury or diagnosis, the participants' opinions and feelings about those opportunities, and participants' suggestions on how effective sexual health promotion opportunities for women with SCI can be provided.

This was accomplished by taking a phenomenological approach, in which I tried to gain insight into the "lived experiences" of women with SCI in addressing their sexual health needs through in-depth interviews, or what I termed "conversations" (Beck, 1994a; Finlay, 1999; Morse & Field, 1995; Pallikkathayil & Morgan, 1991). The discussions that took place between the participants and myself are better qualified as conversations rather than interviews because of the mutual reciprocity and respect that was fostered throughout. Furthermore, in keeping with a phenomenological approach, the researcher is the major data-collection instrument (Pallikkathayil & Morgan, 1991), and therefore a reciprocal relationship must be developed in order to obtain the essential descriptions of a particular experience (Beck, 1994a).

It is hoped that the results of this study will assist helping professionals to broaden their understanding of what the common determinants of optimal sexuality are among women with SCI. In addition, it is hoped that the results will inform helping professionals in the task of creating and implementing sexual health promotion opportunities that are of high quality and that meet the needs that these women express (Hart, Rintala, & Fuhrer, 1996; Quigley, 1995; Tilley, 1998).

Research Questions

As a woman with SCI, I had originally made some cursory postulations about what issues were of importance to my peers. I do, however, recognize the potential for my own personal experience to influence the collection of data, the analysis of data, and the reporting of results. Because of this, I have been cautious and have not speculated about hypotheses. However, in keeping with a phenomenological approach, what is most pertinent is that the researcher make a conscious attempt to expose and heighten his or her awareness of personal perceptions, beliefs, and biases throughout the study, something often called bracketing or reduction (Beck, 1994a; Omery, 1983; Pallikkathayil & Morgan, 1991).

As this study was inductive in its approach, the goal was for the phenomena, as experienced by participants, to emerge naturally during data collection and analysis (Finlay, 1999; Morse & Field, 1995; Omery, 1983; Patton, 1990). Instead of hypothesizing, through personal experience and a review of pertinent literature, several guiding questions were formulated. The following questions provided me with a frame of reference as I progressed through the process of designing the and carrying out all phases of the study:

1. How important is sexual health to women after SCI?
2. What sexual health issues are important to women after SCI?
3. What experiences have women with SCI had in addressing sexuality and reproductive and sexual health concerns in rehabilitation and in their community postinjury?
4. What internal and external barriers and opportunities have women with SCI encountered in accessing sexual health promotion opportunities?
5. According to women with SCI, how should sexual health promotion opportunities be provided so that they are easy to access and use?

Definition of Terms

A very broad definition of sexuality was employed in this project, as sexuality is much more than the physical act of intercourse. Sexuality will be assumed to be an integral part of overall health, emphasizing a celebration of mind, body, and spirit (Chicano, 1989). The definition of sexuality used in this project will encompass biological, behavioral, emotional, psychological, social, cultural, and spiritual components (Chicano, 1989; Drench, 1992; Harrison et al., 1995; Kreuter et al., 1996; Richards et al., 1997; Rieve, 1989). The behavioral components of sexuality will include the ability to experience such activities as touching, kissing, any form of genital stimulation, and stimulation of other erogenous zones (Kreuter et al., 1996). The biological component of sexuality will be defined as the ability to experience all the stages in the sexual response cycle, as described by Masters and Johnson (1966): excitement, plateau, orgasm, and resolution. In addition to this, Kaplan's (1974) model of sexual response will also be used in defining the biological component of sexuality. It includes desire as a stage that precedes excitement and orgasm, an important precursor to sexual intimacy that that can be significantly impacted by disability (Kaplan, 1974). The psychological, emotional, social, and cultural components of sexuality will stem from developmental learning throughout life and through people's interactions with society and culture, as well as with significant others in their lives (Drench, 1992; Thorn-Gray & Kern, 1983). Psychologically, these experiences and learnings contribute to such things as sexual interest and satisfaction, perceived quality of life, self-esteem, self-worth, body image, and feelings of interpersonal attractiveness (Rathus, Nevid, & Fichner-Rathus, 1998; White, 1993). These influence the way people see themselves as sexual beings, the way they see themselves interacting with others, and the way they actually behave. The social component of sexuality will include the nature of intimate relationships (Kreuter et al., 1996); the learned concept of what it means to be masculine and feminine (Drench, 1992; Harrison et al., 1995; Thorn-Gray & Kern, 1983; White, 1993); and a person's cultural sense of what is right and wrong

(Rathus et al., 1998). These all contribute to our attitudes and beliefs, which, in turn, affect our behavior (Rathus et al., 1998).

For the purposes of this project, the term sexual health (SH) will be used according to the definition used by the World Health Organization (World Health Organization, 1975), that SH is "the integration of the somatic, emotional, intellectual and social aspects of sexual being in ways that are positively enriching and enhance personality, communication and love". SH will also include, but is not limited to the ability: to make informed decisions about one's sexuality and reproductive capacities, to develop healthy attitudes about sexuality and sexual behavior, and to respect one's own self and body, as well as those of others; the absence of sexually transmitted diseases (STD) and their sequelae; and the use of effective communication skills to have needs met. Where "optimal SH" is used, it will mean the achievement of the above factors that define SH.

The term sexual health promotion (SHP) will encompass sexual health education, which addresses presenting information to women with SCI about sexuality and/or disability; the clinical practice of assessing and treating physical dysfunction; sexual health counseling, which incorporates the emotional, psychological, and social aspects of sexual dysfunction; and advancing knowledge in SH through research.

Professionals who may have the opportunity to come into contact with women with SCI and could affect women's success in addressing sexuality and SH concerns will be referred to as helping professionals. This group of professionals includes, but is not limited to, doctors, nurses, occupational therapists, physical therapists, recreational therapists, social workers, psychologists, psychiatrists, religious pastors, health educators, and other counselors offering advocacy and support through adjustment to SCI. These professionals work in rehabilitation hospitals, acute-care hospitals, homecare settings, and facilities and advocacy organizations in the community at large.

CHAPTER II

REVIEW OF PREVIOUS RESEARCH

Effect of SCI on Women's Sexuality and SH.

SCI can have multiple and interacting effects on a woman's sexuality and SH. In terms of the physical effects of SCI on sexuality, several changes have been reported. Most women have been found to experience a cessation of menses for a short period of time following SCI in the range of 3-9 months (Berard, 1989; Charlifue et al., 1992; Drench, 1992; Fitting et al., 1978; Goddard, 1988; Lanig et al., 1996; Nygaard et al., 1990; Rieve, 1989; White, 1993). Many experience more bowel and bladder changes during their menstrual periods, including urinary incontinence, urinary tract infections, diarrhea, and constipation (Charlifue et al., 1992). Furthermore, because of the inability to move as one chooses and the lack of sensation, many also report greater difficulty in managing personal hygiene during their periods (Charlifue et al., 1992).

This same lack of physical ability and sensation for some can also be problematic and limit women in choosing birth-control options such as intra-uterine-devices and condoms (Becker et al., 1997; Berard, 1989; Charlifue et al., 1992; Drench, 1992; Welner, 1997). Also, because of the potential threat of formation of blood clots, many women with SCI can be limited in the types of oral birth control medications they can use (Berard, 1989; Drench, 1992; Welner, 1997).

Although ability to conceive, carry, and deliver a baby is unaltered for most women with SCI, pregnancy can heighten the risk and occurrence of disability-related health problems such as decubitus ulcers, blood clots, urinary tract infections, autonomic dysreflexia, bowel and bladder management problems, edema, fatigue, and loss of independence in activities of daily living (Basson, 1998; Berard, 1989; Charlifue et al., 1992; Goddard, 1988; Nygaard et al., 1990; Welner, 1997).

Sexual response can be altered to varying degrees by SCI (Fogel & Lauver, 1990; Goddard, 1988; Nygaard et al., 1990). Some of the potential changes in the sexual response cycle occur because of damage to the spinal cord affecting the efficacy of psychogenic and reflexogenic stimuli (Sipski & Alexander, 1997). The type and amount of effect depends on the level and completeness of SCI. Generally speaking, the more complete the injury, the more profoundly the impairment in the body's ability to respond to both psychogenic and reflexogenic stimuli (Fogel & Lauver, 1990; Kreuter, Sullivan, & Siosteen, 1994). Also, those women with higher-level spinal cord injuries are more likely to react to reflexogenic or touch stimuli, rather than psychogenic or thought-generated stimuli (Sipski & Alexander, 1997). In the arousal and plateau stages, lubrication can be affected, as can the ability of the breasts and genitals to become enlarged and engorged with blood (Sipski & Alexander, 1997). Blood pressure and heart rate may not elevate as quickly or as highly as it did before SCI. In terms of experiencing orgasm, about half of women with SCI report achieving orgasms of various types and intensities (Basson, 1998; Harrison et al., 1995; Kettl et al., 1991; Richards et al., 1997; Rintala et al., 1997), and about the same number report taking longer to achieve orgasm (Basson, 1998; Charlifue et al., 1992; Siosteen et al., 1990).

In terms of SCI's effect on sexual activity, most articles reported that women with SCI have less frequent sexual contact postinjury (Charlifue et al., 1992; Kettl et al., 1991; Kreuter et al., 1996; Sipski & Alexander, 1993). Only one article reviewed for this study postulated that women with SCI engage in more sexual contact than before injury, but offered no corroborating evidence (Drench, 1992). SCI-related factors such as necessity of relying on a partner or attendant care; spasticity (Basson, 1998; Berard, 1989; Drench, 1992; Harrison et al., 1995); limits in range of motion and mobility (Drench, 1992; Kreuter et al., 1996); dealing with bowel and bladder management (Berard, 1989; Drench, 1992; Fitting et al., 1978; Harrison et al., 1995); and inadequate vaginal lubrication (Berard, 1989; Goddard, 1988; Rieve, 1989) have been found to affect spontaneity and intimacy and to interfere with sexual activity (Charlifue et al., 1992; Harrison et al., 1995).

However, because of these interfering issues, many women with SCI also report enjoying a variety of methods of sexual expression besides intercourse more often than did their able-bodied counterparts (Kettl et al., 1991; Kreuter et al., 1996; Richards et al., 1997; Rintala et al., 1997). In fact, several sources found a varied sexual repertoire to be very highly correlated with sexual adjustment and satisfaction (Basson, 1998; Drench, 1992; Harrison et al., 1995; Kettl et al., 1991; Kreuter et al., 1994; Kreuter et al., 1996; Rintala et al., 1997; Siosteen et al., 1990). In using a variety of methods of sexual expression, some women reported that those body parts not paralyzed (e.g., the breasts, neck, and ears) are extrasensitive and that they can even be brought to orgasm if those body parts are touched and caressed (Lanig et al., 1996; White, 1993).

Although level and completeness of spinal cord injury can affect a woman's physical ability to experience the sexual response cycle (Sipski & Alexander, 1997) and to have voluntary control over her body, there does not appear to be a significant relationship between level of injury and subjective evaluation of sexual responsiveness, ability to achieve SH (Gerhart, Johnson, & Whiteneck, 1992; Willmuth, 1987). For example, both Harrison et al. (1995) and Kettl et al. (1991) found that although quadriplegics differed from paraplegics in terms of lower sexual activity and satisfaction, these differences were not statistically significant. Also, Fitting et al. (1978) found in a study of the subjective experiences of women with SCI that their feelings about sexuality were not correlated with their injury, and Kreuter et al. (1996) found that subjective sexual adjustment and quality of intimate relationships were unrelated to level of SCI. However, Charlifue et al. (1992) found that women with quadriplegia rated their sexual skills lower than did women with paraplegia.

The physical effects of SCI on sexuality and SH are much more predictable than the social and psychological effects that stem from them. It was consistently found that self-confidence, self-image, perceived sexual skills, and desirability are negatively affected by SCI (Drench, 1992; Kreuter et al., 1996; Lanig et al., 1996; Richards et al., 1997; Rieve, 1989; Rintala et al., 1997). Examples include one study in which 38% of women reported feeling better about themselves before injury (Charlifue et al., 1992), and another in which 33% had the same feeling about themselves after injury (Fitting et al., 1978). In yet another study, the most concerning change that women reported following injury was that they rated their bodies as only half as attractive as they once did before injury (Kettl et al., 1991). Furthermore, Harrison et al. (1995) found that women with SCI in general were more dissatisfied with their bodies than were able-bodied controls. Some postulate that this dissatisfaction may be partially caused by the body-changing effects of paralysis such as muscle wasting, loss of tone in the stomach, inability to avoid putting on weight in the stomach region, loss of independence, and loss of choice and control (Harrison et al., 1995; Lanig et al., 1996; White, 1993).

The social effect of disability on sexuality and SH seems to be intricately tied to the psychological effects. Throughout our life we are socialized to accept that women and men perform distinct and different roles (Cole & Cole, 1993; Drench, 1992). SCI affects how well women can fulfil those traditional sex roles, and findings suggest they can experience a loss of identity, they question their roles and femininity, and they feel unsatisfied with their residual identity (Chicano, 1989; Drench, 1992; Harrison et al., 1995; Quigley, 1995). In keeping with these prescribed roles, society places value on certain body parts and functions, as well as on characteristics such as independence and physical beauty (Drench, 1992; Hwang, 1997; Stohl, 1996; White, 1993). Self worth can be negatively affected when women with SCI are unable to fulfill these role prescriptions and conform to these criteria (Cole & Cole, 1993; Drench, 1992;

Fitting et al., 1978; Lanig et al., 1996; Rintala et al., 1997; Stohl, 1996). Furthermore, because society embraces a "body beautiful" image and values strength and power, many researchers reported that people with physical disabilities in general are seen as asexual and less attractive, and they have greater difficulty finding partners (Chicano, 1989; Fogel & Lauver, 1990; Hahn, 1981; Rintala et al., 1997; Stohl, 1996; Thorn-Gray & Kern, 1983; White, 1993).

Self-Reported SH Issues of Women With SCI

Women with SCI have reported several issues that are important and concern them in regards to sexuality and SH. First and perhaps most important, women still consider their sexuality to be an important part of their lives after SCI (Harrison et al., 1995; Kreuter et al., 1996; McAlonan, 1996; Rintala et al., 1997). However, although between 54% and 69% of women in many studies reported satisfaction with postinjury sexual experiences, they rated their satisfaction as lower (Charlifue et al., 1992; Fitting et al., 1978; Kreuter et al., 1996; Rintala et al., 1997; Siosteen et al., 1990). Several factors, both physiological and psychosocial in nature, have been mentioned in the literature as contributing to this lowered sense of satisfaction, and include lower self-confidence (Kreuter et al., 1996), spasticity (Goddard, 1988), limitations in ability to move (Drench, 1992; Kreuter et al., 1996), fear of rejection and reaction of others to disability (Richards et al., 1997; Sawyer et al., 1983), and lack of spontaneity (Kreuter et al., 1996). Many also report that their concerns are not necessarily different from those of able-bodied women, but are compounded by SCI, such as self-esteem issues (Fogel & Lauver, 1990; Kreuter et al., 1996; Lanig et al., 1996), self-image (Chicano, 1989; Fogel & Lauver, 1990; Lanig et al., 1996; Richards et al., 1997), feelings of unattractiveness (Chicano, 1989; Drench, 1992; Kreuter et al., 1996; Richards et al., 1997), lack of available partners (Rintala et al., 1997; Sawyer et al., 1983), and fear of rejection (Charlifue et al., 1992; Drench, 1992; Fitting et al., 1978; Lanig et al., 1996; Sawyer et al., 1983).

Fitting et al. (1978) found that 63% of women in their study reported that bowel and bladder changes interfered with sexual expression and contributed to the above-mentioned fears, and in another study by White et al. (1993), the most frequently mentioned concerns during sexual activity were bladder problems (72%) and bowel problems (57%). Others also acknowledged this as an expressed fear, but found that these fears and concerns about bowel and bladder function diminished with greater confidence in their ability to manage them over time (Goddard, 1988; Richards et al., 1997).

Many women with SCI, throughout their experience of disability, are concerned with giving as well as receiving pleasure, and the ability to respond sexually to a partner (Hwang, 1997; Richards et al., 1997; Sawyer et al., 1983). An example of this was the finding by White et al. that the third most cited concern after bowel and bladder function was the inability to satisfy sexual partners. Others surveying women with SCI also reported that educational topics of most interest to women with SCI are methods and techniques of achieving sexual satisfaction (Lanig et al., 1996; White et al., 1993).

One psychosocial issue frequently mentioned by women with SCI is a feeling of disenfranchisement for several reasons. Immediately after injury, they did not know what to expect from themselves or others in relationships and sexual activity (Richards et al., 1997). They felt that they had lost the right to be sexual persons (Charlifue et al., 1992; Richards et al., 1997). Furthermore, for many, sexuality and sexual functioning was never mentioned during rehabilitation, and they felt "left out" in comparison to males with SCI (Harrison et al., 1995, p. 691). Other examples of disenfranchisement include inaccessibility of doctors' offices, finding that doctors and clinic staff are unwilling to give extra assistance, and dealing with helping professionals who lack knowledge about SH needs of women with SCI.

In reflecting upon the process of adjustment to SCI, many women described an initial experience of dissociating from their bodies and sexuality, assuming that sexual pleasure was no longer possible and that no one would find them attractive (Lanig et al., 1996; Nosek et al., 1995; Richards et al., 1997). Because of this initial negative experience, women with SCI have stressed the need to be able to talk to other women with disabilities to learn about their experiences and accept themselves as sexual people again (Fitting et al., 1978; McAlonan, 1996). Women also described this adjustment process as a long one that generally occurs following their adjustment to disability in other areas of their lives (Kettl et al., 1991; Richards et al., 1997). Women also support experimentation, openness, and creativity in the rediscovery of their sexuality (Kettl et al., 1991; Lanig et al., 1996).

SHP Opportunities

The opportunities available for women to address postinjury sexuality and SH, both in rehabilitation and the community, appear to be unsystematic, with no agreement as to when these opportunities can be most effectively presented (Goddard, 1988; Miller, 1988; Nosek et al., 1995). There is, however, overwhelming agreement that many women with SCI are unsatisfied with information and support offered by helping professionals during rehabilitation. Women with SCI have been found to be twice as likely as men with SCI to have received unsatisfactory rehabilitation opportunities to address sexuality and SH (Lanig et al., 1996). Some women reported receiving no information at all (Lanig et al., 1996; White et al., 1993), and although many reported dissatisfaction with opportunities, they generally thought this was a vital component of adjustment to disability (Becker et al., 1997; Charlifue et al., 1992; McAlonan, 1996; Nosek et al., 1995; Richards et al., 1997). Women reported that what was provided was scant and focused on reproductive health only (Harrison et al., 1995; McAlonan, 1996). SHP opportunities were presented in conjunction with other rehabilitation topics such as bowel and bladder function, and this was criticized (Richards et al., 1997). In terms of preference for group versus individualized opportunities to address SH, people with SCI preferred one-to-one opportunities over group education/counseling because of individual needs and privacy (Cushman, 1988; Lanig et al., 1996; McAlonan, 1996; Miller, 1988), whereas another reinforced that group discussions are beneficial because of the opportunity to share experiences (Drench, 1992).

One opportunity highly endorsed by participants was Sexual Attitude Reassessment Seminars (SARS). Of those surveyed in one study by Drench (1992), 91% said that they would recommend the workshop to others like themselves; and in the pretesting of the proposed interview guide for this project, respondents who had been involved in SARS also were very pleased with their experiences (MacCabe, 1999).

In contrast, some have said that they were unprepared to receive information about various aspects of sexuality while in rehabilitation, that they were in a general state of information overload and interested only in learning basic survival skills at that point (Goddard, 1988; Hart et al., 1996; McAlonan, 1996; Richards et al., 1997). They were more accepting and came to recognize that they desired and needed information related to the various aspects of sexuality once they were functioning in the community again (Hart et al., 1996; McAlonan, 1996). In a study by Miller (1988), SHP opportunities were broken down into different types, and it was found that people with SCI were most interested in receiving information about sexual functioning while in rehabilitation, whereas peer education was best received by people in the acute-care stage of their injury.

Once women with SCI return to their communities, it appears that SHP opportunities are more satisfactory, yet not flawless. A majority of women in one study felt that their doctor was knowledgeable and comfortable working with them (Charlifue et al., 1992). However, if fertility was unaffected, other sexuality and SH issues were perceived as being undervalued by helping professionals

(Charlifue et al., 1992). Of those who were not satisfied, many women reported that doctors' offices are physically inaccessible, and staff often not knowledgeable about sexuality and SH in the context of SCI (Becker et al., 1997; Charlifue et al., 1992; Chicano, 1989; Nosek et al., 1995; Richards et al., 1997).

In addition to formal avenues for addressing SH issues, many women also sought out and talked with family, friends, and other women with SCI (Charlifue et al., 1992; Fitting et al., 1978; Kreuter et al., 1996). Furthermore, they often viewed counselors and educators as more credible if they themselves had a disability (Kreuter et al., 1996), because they viewed counselors with SCI as more knowledgeable about problems encountered by people with disabilities. An example of this endorsement was McAlonan (1996), finding that 50% of those in rehabilitation and 30% of those in the community were interested in peer-counseling opportunities.

Barriers to Achieving Optimal Sexual Health

Of the barriers that challenge women with SCI in the pursuit of optimal SH, the literature seems to have pointed to attitudinal barriers on the part of both women with SCI and society. Although it is changing, recent literature still reflects a lingering attitude that people with disabilities in general are less sexual than people without observable disabilities, and that unaltered ability to become pregnant and carry and deliver a baby equals unaltered SH (Charlifue et al., 1992; Chicano, 1989; Harrison et al., 1995; Hwang, 1997; Rintala et al., 1997; Sawyer et al., 1983; Stohl, 1996; Tilley, 1998; White, 1993). In addition, some researchers and professionals have subscribed to the notion that women are more passive in sex, and because they receive while men give, their sexuality and functioning are by nature less adversely affected (Berard, 1989; Drench, 1992; Harrison et al., 1995; Sawyer et al., 1983). These attitudes and beliefs are a barrier to advances in SH and SHP knowledge, access to SHP opportunities for women with SCI, and permission for women with SCI to have SH needs met (Becker et al., 1997; Chicano, 1989; Cole & Cole, 1993; Fitting et al., 1978; Harrison et al., 1995; Nosek et al., 1995; Sawyer et al., 1983). Physical access to and assistance in doctors' offices have also been mentioned as barriers to achieving positive SH outcomes (Becker et al., 1997; Cole & Cole, 1993; Nosek et al., 1995; Welner, 1997).

Women with SCI are inhibited in their search for SHP opportunities by the inaccessibility of facilities and doctors' lack of knowledge. They are additionally inhibited by previous negative health care experiences characterized by insensitive helping professionals, physical roughness of doctors, and feeling devalued, humiliated, and disrespected (Becker et al., 1997; Cole & Cole, 1993; Nosek et al., 1995; Welner, 1997).

Women limit themselves just by virtue of having a lack of SH knowledge and experience in being a sexual person with a disability (Becker et al., 1997; Nosek et al., 1995; Rintala et al., 1997). They may further lack the belief that they are susceptible to SH problems, such as STDs and unplanned pregnancy (Nosek et al., 1995). Contributing to this may be the lack of privacy and independence that many experience while in a rehabilitation setting at the time when they are first learning to interact with the world in their new body (Chicano, 1989; Harrison et al., 1995).

Preliminary Study by the Primary Investigator

A previous project with a similar focus received approval from the Ethics Committee of the Faculty of Physical Education and Recreation at the University of Alberta and was completed in March 1999 (MacCabe, 1999). In that project an interview protocol was pretested and incorporated into the interview guide for this study. The preliminary results of the interviews conducted suggested several things in keeping with findings from the literature. First, a common theme that emerged was that for some, sexual health and sexuality were not important issues during rehabilitation, but they became important soon after leaving rehabilitation centers. Second, some did not have sexuality and SH concerns because they perceived that they were no longer able to enjoy a healthy sexual life and sense of sexuality. They did not know that their SH and sexuality could be as important and fulfilling as it was before injury. Finally, there was a stark contrast in the reports from the male participants versus the one female participant although time since injury was similar. The males all reported receiving ample opportunity to talk and learn about sexual health and functioning, and the female reported that she had absolutely no opportunity to address sexuality issues in the broadest sense, until two years after her rehabilitation.

CHAPTER III

METHODS

A phenomenological approach was used in data collection and analysis to learn about the deeper meaning and essence of experiencing SH and sexuality as a woman after SCI (Beck, 1994a; Morse & Field, 1995; Patton, 1990). In the literature, phenomenology has been described in a variety of ways as both a philosophy, or a way of thinking about research, and a research method (Omery, 1983; Pallikkathayil & Morgan, 1991). In this study I have taken a more contemporary, American approach to the use of phenomenology. In the American form, the researcher seeks to understand the subjective reality of a person's experience (Caelli, 2000a; Finlay, 1999; Pallikkathayil & Morgan, 1991). The goal is to "allow the person's experience to speak so that it may be understood" (Caelli, 2000a, p. 370). Also, an American approach to phenomenology proceeds based on the belief that a person's experience and perception of an experience cannot be separated from the environment or context in which the phenomenon is experienced (Caelli, 2000a), and it respects commonalities as well as differences in the exploration of a given phenomenon (Caelli, 2000a; van Manen, 1997).

In contrast, a traditional European approach to phenomenological inquiry is led by the belief that a person's experiences can be examined and that an objective, universal reality can be uncovered (Caelli, 2000a). It seeks to challenge the participants to unravel their habits, experiences, and perceptions of experienced phenomena so that the phenomena may emerge as truths unbound to culture and context (Caelli, 2000a). As the context (e.g., participant's marital status at time of injury) and environment (e.g., where or whether a participant was exposed to a formal rehabilitation process) in which women experience SH and sexuality after SCI are of prime importance in this inquiry, and because women's subjective experiences of SH and sexuality after SCI have not been adequately attended to thus far in the literature, adopting an American approach to phenomenological seemed appropriate. Although I have primarily chosen an American approach to phenomenological inquiry, other well-known phenomenological traditions have been used here to "inspire" the primary method and inform my thinking as it has evolved throughout the study (Porter, 1998).

Data collection was mostly inductive, but was sensitive to literature reviewed previous to the undertaking of this study (Morse & Field, 1995; Neutens & Rubinson, 1997; Patton, 1990; Wilson & Hutchinson, 1991). Being an inductive approach, phenomenology relies on the participants as "experts on their own sexuality" (Richard et al., 1997, p. 273) and asks them to elaborate on and bring forth important themes and realities through their personal experiences (Caelli, 2000a; Cresswell, 1994; Neutens & Rubinson, 1997; Wilson & Hutchinson, 1991). This inductive approach was chosen because the topic of sexuality and disability lacks a consistently used theoretical framework for research (Gamel, Davis, & Hengeveld, 1993), and describing and understanding the experiences of women with SCI is a primary consideration in building that framework. Furthermore, if trustworthy and reliable theory and constructs are to be built in order to truthfully examine sexuality after SCI, then those experiencing the phenomenon must first describe and define those theories and constructs (Caelli, 2000a; Finlay, 1999; Porter, 1998)

Participant Recruitment Procedures

Two main methods and several sources were used to recruit participants for this study. First, the Canadian Paraplegic Association (CPA) in Edmonton, Alberta, agreed to be a participant source. A database that houses all of CPA's members was employed. The variables of age, gender, date of injury, and geographic locale were manipulated so that a very homogenous list of potential participants was produced (i.e., 43 women with SCIs of less than five years living in Edmonton and surrounding areas). These members received, via regular mail, an information letter about the project. It outlined the nature and purpose of the study and several alternative methods they could use to contact me if they wanted more information or wanted to participate (see Appendix A). Although CPA does have a large database, this method of recruitment did not prove to be effective, because the narrow inclusion criteria greatly reduced the number of women to whom I was able to mail the information letter.

Simultaneously, I also employed recruitment postings. I put up recruitment posters at the Steadward Centre for Professional and Personal Achievement (SCPPA; formerly known as the Rick Hansen Centre) and two of its satellite facilities. The SCPPA is a group of facilities in Edmonton that persons with disabilities access for, among other things, fitness and recreation opportunities. I also placed recruitment advertisements in the following publications that have a substantial reading audience of people with disabilities, in some cases specifically people with SCI: the SCPPA Newsletter for members; Total Access, a nationally distributed publication issued by CPA National; Spinal Columns, a provincial publication issued by CPA Alberta; SCITCS News Letter, a local publication issued by the Spinal Cord Injury Treatment Centre Society (SCITCS); and The Status Report, a provincial publication issued by the Premier's Council on the Status of Persons with Disabilities. Please see Appendix B for copies of the recruitment advertisements as they were to have appeared in the various publications.

Sample Description

At the outset of this study, I intended on talking to a minimum of five women with SCI and anticipated that the following factors would affect how many participants would be used:

1. The number of women who chose to participate through recruitment. Each year in Canada 900 Canadians sustain an SCI, and women comprise approximately 20% of that population (Canadian Paraplegic Association, 1999; Richards et al., 1997; White et al., 1993). Furthermore, sexuality and SH are anxiety-provoking topics of conversation (Charlifue et al., 1992; Thorn-Gray & Kern, 1983).

2. The desire to reach saturation. I wanted to collect enough data or do enough interviews so that by the time the last interview was completed, no new themes or information emerged.

I originally started recruiting participants using very strict criteria and focused on the recruitment of women with SCI who had been living with their injury or condition for less than five years, were between the ages of 18 and 45, and were living in Edmonton and surrounding areas. Marital and socioeconomic status were not used as inclusion criteria, because it was anticipated that this could delay the procurement of participants to the point where it would no longer be feasible to continue the study. The reason for restricting the sample was to gain information that was consistent, rich, and trustworthy. It is difficult to achieve this in a small sample group that is very diverse in their experiences in both the context of age and time since injury (Charlifue et al., 1992).

However, after doing the initial mail-out, I received only three inquiries from women who met the specific inclusion criteria originally set. Furthermore, after having conversations with the first three participants, it became apparent that they were still in the midst of coping and adapting to change, and some were still not really ready or comfortable in sharing their experiences around how or whether their SH and sexuality were affected by SCI. They seemed less candid and less able to reflect upon their feeling and experiences.

I did, however, receive a number of inquiries from several women as a result of the recruitment advertisements placed in the various publications. The only barrier to including them in the study was the fact that some of them had been living with their SCI for more than five years and were not living in the Edmonton area. In the recruitment advertisements, the publication editor, who was the same person for three out of five of the publications that posted the advertisements, cut out the inclusion criteria in order to make the advertisement fit the space in the publication. As a result, several women with SCI eagerly responded to the recruitment ad based on the assumption that they met the criteria to participate.

For three reasons, the decision was made to expand the inclusion criteria. First, the mediocre success of the initial mail-out led me to question the intrusiveness and effectiveness of the method of sending recruitment letters to CPA members' homes. I did not wish to intrude any further upon CPA members' rights to privacy, yet only three women responded to the original recruitment. Second, the conversations I had with the initial three participants with recent injuries were not informative, as previously outlined. Third, many other women from outside the Edmonton area with injuries of varied duration wanted to contribute to the study.

The inclusion criteria were expanded to accept participants who had been living with their SCI for up to 20 years, from any province across Canada. It was originally feared that using such broad criteria would make the sample too heterogeneous, and therefore difficult to accurately describe the phenomena being studied. Although the demographic characteristics of the participants were diverse, in many instances they shared experiences relating to sexuality and SCI. Also, in keeping with an American mode of phenomenological inquiry, it is not necessary to capture a person's description immediately after he or she has experienced a particular phenomenon (i.e., less than five years after SCI). Reflection and interpretation some time after an experience (i.e., 20 years after

SCI) can yield insight that is just as rich, valid, and meaningful (Beck, 1994a; Caelli, 2000a).

In total, 13 women inquired about the study, and 10 women chose to participate. In keeping with the phenomenological approach, the sample size is often not large because interviews conducted using this method are often quite lengthy and detailed (Morse & Field, 1995; Omery, 1983; Pallikkathayil & Morgan, 1991; Patton, 1990; Wilson & Hutchinson, 1991). Only three out of 13 studies that followed the same data-analysis method used in this study (Colaizzi, 1978) had sample sizes greater than 10 (Beck, 1994a).

Table 3-1 illustrates selected characteristics of the women who participated in this study. The description of this sample is necessarily broad in order to protect the anonymity of the participants. If described in further detail, many would be immediately identifiable. In terms of geographic locale, participants came from the provinces of British Columbia, Alberta, and Ontario. Participants were between the ages of 20 and 41 and had injuries ranging in duration from one year to 21 years. Four participants had children, with three having had children before their injury. In terms of marital status, at the time of the study two participants were single and had no partners, two were single but in committed relationships, one was single and was in an uncommitted relationship, one was unmarried and living with a partner in a committed relationship, and four were married. At the time of their injuries, six women had committed partners who stayed in the relationship for at least four years after their SCI, and the other four women were single at the time of injury. No participant indicated anything other than a heterosexual orientation.

Table 3-1

Selected Characteristics of Participants

Participant	Nature of SCI	Years injured	Description
A	C6-C7 quadriplegia, incomplete.	10	16 Y.O.A. at time of injury; no partner at time of injury; currently single, in a committed relationship; no children.
B	C4-C6 quadriplegia, incomplete.	4	30 Y.O.A. at time of injury; no partner at time of injury; currently single, in an uncommitted relationship; no children.
C	T5-T6 paraplegia, complete.	1	29 Y.O.A. at time of injury; partner at the time of injury; currently single, in a committed relationship; no children.
D	T7 paraplegia, complete.	21	18 Y.O.A. at time of injury; married, to partner at time of injury; 2 children, 17 and 19 Y.O.A.
E	C6-C7 quadriplegia, complete.	12	20 Y.O.A. at time of injury; no partner at time of injury; currently divorced, in a committed relationship; no children.
F	L4, L5, S1 paraplegia, incomplete.	10	31 Y.O.A. at time of injury; married at time of injury; currently divorced, no partner; 2 children, 8 and 16 Y.O.A.
G	T2-T4 paraplegia, complete.	2	18 Y.O.A. at time of injury; no partner at time of injury; currently single, no partner; no children.
H	Failed Surgery Syndrome, progressive.	6	33 Y.O.A. at time of injury; married, prior to injury; 1 child, 20 Y.O.A.
I	Cauda Aquina, due to herniated disc.	3	32 Y.O.A. at time of injury; married, prior to injury; 2 children, 4 and 6 Y.O.A.
J	Progressive degeneration of spinal processes.	5	Age at injury not disclosed; married, prior to injury; no children.

Note. Participants are not listed in any specific order. SCIs are listed as described by participants. Y.O.A.=years of age.

The types and nature of injuries reported by the participants also varied considerably. There were three women with quadriplegia, three with paraplegia, two with SCIs not caused by traumatic accident that could walk, and two with incomplete injuries that allowed them to walk somewhat, but with daily, chronic pain. They experienced various motor and sensory abilities and were independent to varying degrees in their activities of daily living. Of the 10 participants, five reported needing the help of someone else sometimes or all of the time to complete activities of daily living.

Data Collection

Semistructured, conversation-style interviews were conducted with the women. They were treated as reciprocal exchanges of information in which I also disclosed information about my experiences as a woman with SCI. This interview format was adopted in an effort to establish a sense of rapport, trust, and openness to make it easier for participants to disclose personal experiences and "tell their story" (Beck, 1994a; Fitting et al., 1978; Rathus et al., 1998). This interview format is also in keeping with a phenomenological approach which values the subjective experiences and themes from the viewpoint of the story teller (Caelli, 2000a; Finlay, 1999; Pallikkathayil & Morgan, 1991; Wilson & Hutchinson, 1991). As mentioned earlier, these interviews were necessarily interactive, and as such, more aptly termed "conversations" (Beck, 1994a).

Participants were given the choice of where our conversation would take place, as long as they felt that the location was quiet, convenient, and private. The intent in offering this option was to acknowledge that sexuality is a sensitive topic and address the need for increasing the sense of privacy, comfort, and control of the participant in order to ensure that participants would fully share their experience (Nosek et al., 1995). Of the 10 conversations, five occurred face-to-face, and five over the telephone. In those interviews that took place over the telephone, participants were asked to pick a private place and time when they knew they would be alone and unlikely to be uninterrupted.

Before starting our conversation, standard consent procedures were followed and permission to tape-record the interview was requested and granted by all participants. Certain core, open-ended questions were asked of each participant and where pertinent and appropriate, participants were prompted to elaborate (Patton, 1990). These initial core questions were based on the themes previously covered by other research projects of a similar nature (Charmaz, 1995; Cushman, 1988; McAlonan, 1996; Nosek et al., 1995; Wilson & Hutchinson, 1991), as well as the results of pretesting a previous version of these questions (MacCabe, 1999). However, in keeping with a phenomenological focus, I wanted to allow participants to describe and prioritize themes and important issues throughout our conversation, and I therefore tried as much as possible to let participants lead the conversation (Caelli, 2000a). The interview questions were responsive to the phenomenon as it unfolded (Finlay, 1999; Wilson & Hutchinson, 1991). They were unscripted for the most part, in an effort not to impose any presuppositions upon the participants' experiences (Finlay, 1999; Omery, 1983; Pallikkathayil & Morgan, 1991). Participants were asked simply to reflect upon and tell their story (Finlay, 1999; Morse & Field, 1995;

Neutens & Rubinson, 1997; Pallikkathayil & Morgan, 1991). I wanted to accurately and meaningfully describe the phenomenon through their experiences, rather than explore and verify it using existing theories and constructs (Omery, 1983; Wilson & Hutchinson, 1991). Therefore, as participants identified important areas and themes, I altered unimportant questions and explored new ones with the women in accordance with the priorities they set out in the conversation (Charmaz, 1995; Cresswell, 1994; Finlay, 1999; Morse & Field, 1995). For a copy of the interview guide as it evolved from the first interview to the last, see Appendix C.

The conversations were between one half hour and two hours in length, depending on the experiences and comfort of the participant with the topic. After the conversation, I gave each participant an opportunity to express concerns and have them addressed. This debriefing was done after each initial conversation and again after the information was validated with the participant. Participants were asked if they had any unanswered questions or comments and were offered several alternative opportunities to address questions or concerns.

Immediately after each interview, the tape-recorded conversations were replayed, and field notes were taken down to record the observations I made throughout the conversation and to identify emerging themes that stood out at the time. Notes were also kept on my own feelings and thoughts that I was conscious of throughout the conversation. This was a method of taking precautions not to bias the description of a phenomenon with prior knowledge or perceptions of the phenomenon (Beck, 1994a, 1994b; Finlay, 1999; Omery, 1983; Pallikkathayil & Morgan, 1991). A professional transcriptionist was employed.

Data Analysis

Thematic, inductive analysis was employed both while data were still being collected and while the data were being coded. In coding the data, a constant comparative approach was employed; and to ensure rigor, the conversations were analyzed in several steps (Beck, 1994a, 1994b; Colaizzi, 1978; Finlay, 1999). See Appendix D for an example of the thought process used in deriving the themes that emerged from the analysis of participants' transcripts. First, as already mentioned, each recorded conversation was reviewed immediately following the conversation for emerging themes that should be explored further with other participants (Finlay, 1999). Second, each participant's transcript was read over once in its entirety to conceptualize the whole experience (often referred to as gestalt) and to begin to understand all of the factors affecting that experience (Beck, 1994b; Finlay, 1999; Omery, 1983). Third, each participant's transcript was read over again line by line. At this stage, specific statements that illustrated a particular experience were identified, underlined, and labeled with a two- or three-word descriptor, so that I could identify common themes emerging among the different conversations at a later stage of analysis (Beck, 1994b; Finlay, 1999). In essence, I wanted to move from what participants said to what they intended by their words (Porter, 1998).

Fourth, I summarized each transcribed conversation into a short narrative, complete with quotes from the conversation I had with that respective participant.

The purpose in doing this was manifold. As part of a Collaizi (1978) approach to phenomenology, participants are often seen as co-researchers and included in analyzing and verifying the data collected and themes that emerge from analysis (Beck, 1994a, 1994b; Porter, 1998; Wilson & Hutchinson, 1991). To accomplish this, many researchers often give participants a copy of the transcript and use this as a tool in discussing the emerging themes and issues (Caelli, 2000b). This strategy has not been entirely useful, because participants often find it cumbersome and difficult to verify and analyze themes this way (Caelli, 2000b). In this study, some transcripts were as long as 75 pages, but the narratives were between three and seven pages in length, and easily digested and understood by the participants. In essence, it allowed me to verify my understanding of the participants' experiences as they intended them to be understood (Caelli, 2000a, 2000b; Finlay, 1999). It was a very useful tool for clearing up misconceptions about certain statements or experiences and further clarified emerging themes and similarities among participants (Porter, 1998; Wilson & Hutchinson, 1991). Furthermore, the narrative gave me an opportunity to present to the participants the experience as a whole picture and to find out from them if the phenomenon as I had described it was parsimonious (Beck, 1994b; van Manen, 1997). In other words, it allowed me to answer the following three questions, which were aimed at insuring rigor:

1. Was there anything missing in the narrative that was essential in fully defining their experience?

2. Did I include things in the narrative that were not important in describing their experience?

3. If I were to exclude any particular part of, or add to the narrative, would it still be the same experience?

(Beck, 1994b)

It also was used as an opportunity to overtly gain consent from participants to use specific quotations. See Appendix E for a sample of one of the narratives written and shared with a participant.

In the fifth stage of analysis, the transcripts were dissected, and statements and experiences that were similar from participant to participant were grouped together. To organize this process and ensure that rigor was practiced, index sheets were used, one sheet or set of sheets for each emerging theme (e.g., getting only reproductive information after SCI). The themes that emerged were placed across the top of the page. Under each theme a verbatim excerpt from the participant's transcript was placed next to other similar statements from other participants. The participant's identification number and the transcript line numbers identified each verbatim statement. If there were not at least three examples of a particular theme from each of at least three different participants, the theme was re-examined to see whether it should be combined with other themes or dropped altogether. (Berg, 1989; Morse & Field, 1995; Patton, 1990).

In the sixth stage of analysis, statements in the identified theme areas were once again reviewed. This time they were reviewed in order to more fully describe the phenomenon and to comprehensively understand all the different words used by participants in describing the phenomenon they had experienced (Finlay, 1999). Additionally, this stage assisted in deciphering to which parts of the literature I needed to compare these women's experiences in keeping with an inductive, phenomenological approach (Morse & Field, 1995; Patton, 1990).

Throughout the entire research process I attempted to practice triangulation in an effort to ensure that the study would trustworthy. Practicing triangulation was particularly important in this study because of my personal viewpoint as a woman with SCI. Although biases and preconceived notions may exist because I have experienced SCI, activities aimed at triangulating included the following: the use of memos, taking note of my own preconceived notions and thoughts, emotions, and experiences; taking down field notes, where I wrote down thoughts and observations about the conversations I with participants, immediately after talking with them; pre-testing the interview questions with others with SCI and with peers in the field of SHP; and verifying conclusions and themes with participants (Beck, 1994a; Finlay, 1999; Morse & Field, 1995; Pallikkathayil & Morgan, 1991). Furthermore, in following a phenomenological method, the researcher is consciously required to acknowledge and question their own prior knowledge of the phenomenon under study (Beck, 1994a; Finlay, 1999; Omery, 1983; Pallikkathayil & Morgan, 1991; Porter, 1998). I did this by consciously and consistently making note of my thoughts, opinions, and prior experiences throughout the conversations, the analysis, and writing of this study, to ensure that the results would meaningfully represent the participants' experiences as accurately as possible.

CHAPTER IV

DATA PRESENTATION AND ANALYSIS

As is often the case when the human experience of a particular phenomenon is explored, participants had experiences that were intertwined, some occurring simultaneously and some sequentially. In weaving the fabric that explains what it means to experience sexuality and sexual health as a woman after spinal cord injury, the following themes emerged from the participants' stories: the impact of SCI on sense of self, sexuality and SH concerns after SCI, relationships after SCI, coping with change, and interactions with helping professionals and modes of service delivery.

Impact of SCI on Sense of Self

Minority Status

A majority of participants experienced disenfranchisement after SCI. They recalled a feeling of being discounted or overlooked immediately after their injuries, during the rehabilitation process. They often felt left out because they were part of a small group of women among a disproportionately large group of men going through rehabilitation at the same time, a finding supported by other researchers (Charlifue et al., 1992; Harrison et al., 1995; Richards et al., 1997; Westgren, Hultling, Levi, Seiger, & Westgren, 1997). For some participants, they were the only women among many men. With reference to addressing sexual health throughout the overall rehabilitation process, these women felt much more attention was paid to men's SH and sexuality and that when topics were raised that often applied equally to women, the discussion was biased towards men and was much more detailed for men than for women. They also felt disadvantaged by the fact that men had a large network of peers with whom to discuss sexuality and SH concerns, whereas they often did not. This experience can be exemplified by the following comments from participants:

> We were definitely in the—what?—twenty percent, if that. . . . It's not just being a woman in a way. In a way, there were other minorities there too, because most of us were young too.

> When I was in the rehab center, there were four of us women, and there were tons of young guys who were struggling with this, and they were all talking about it amongst themselves.

> And because I went through rehab with guys, I never went through rehab with any women; . . . there was no one to tell me what to do or how to do it.

Participants also felt that this gender bias spilled over into the services and opportunities available to them in the larger community, again because more men experience SCI and make up the population of people with SCI. This experience of a bias toward male sexuality in SHP opportunities has been reported by others surveying women with SCI as well (Richards et al., 1997; Tepper, 1992). Two participants had the following to say about community services offered jointly to men and women with SCI:

> They have this annual—CPA puts it on. It's in [name of city]; it's like a forum, and they have six talks, and it could be on bowel management, bladder management, sexuality, physical activity, and injury or something. . . . So we went to this, and we sat through the whole talk, and not one time did they bring up women. . . . And another thing I found is, they were very—obviously erectile dysfunction, but "how can we get the men to reproduce again?" And I'm thinking, Okay, we carry a kid for nine months. . . . Can we have a little focus on us?

> I went to a research session, at an SCI conference here in [name of city], and there was a session on sexuality and SCI, . . . and it was all about erectile dysfunction, and I thought, I don't have a penis; that doesn't really help me much.

In addition to a gender bias, these women experienced different treatment by helping professionals (e.g., doctors, nurses, health educators) because they did not fit the "normal" client profile, as is illustrated by the comments of a participant who went to a prenatal class where she was the only woman with SCI:

> It's not like I wasn't allowed to join, but [laughs] it wasn't all that good for me because I wasn't allowed to be different, kind of thing. . . . But mostly it was just their discomfort. They were set up for a certain thing, and if something deviated from that, they weren't ready for that.

As a result of these experiences, participants often experienced frustration and resentment that, because they were women, they were afforded different and less satisfactory treatment than were men with SCI. They also felt that because they were part of a minority, a group of women who were not "typical" clients, helping professionals misunderstood and discounted their needs and experiences (Becker et al., 1997; Nosek et al., 1995). For example, when asked about her experiences in accessing services to deal with chronic pain in the community, one woman said, "The other thing too is that, 'Oh, it's all in your head,' because I'm a woman." Women felt that this treatment negatively impacted their ability to access needed services, both in a rehabilitation setting and in the community. Because they were different, they were given less attention, or in some cases denied access altogether.

Role Identification

Our sense of who we are as sexual beings is tied to much more than just our genitalia and sexual behavior; it is also related to work roles, gender stereotypes, and societal norms (Richards et al., 1997; Villeneuve, 1989). Participants in this study demonstrated the impact that these factors had on their sense of who they were as women and intimate sexual partners after SCI. After incurring SCI, five participants expressed a sense of anxiety that they no longer could fill many of the roles that they once did. This experience was related both to their role as an intimate partner in a sexual relationship and to the roles that helped them define themselves as partners and women in their overall experience of daily life, a co-relationship also described by other research articles reviewed for this study (Chicano, 1989; Drench, 1992; Harrison et al., 1995; Lemon, 1993; Quigley, 1995). One participant explained that the physical limitations of her SCI created a situation in which she could no longer physically demonstrate some of the same emotional and psychological supports she used to (e.g., a hug). In the following statement, she described the experience,

> Feeling weaker as a woman in a partnership stems from the physical limitations of spinal cord injury. Fulfilling physical, emotional, and psychological needs for both my partner and myself is complicated by disability. For example, although I can identify that he needs a hug, I can't always give it to him. Almost everything that I used to express physically now has to be rerouted and expressed by different means.

Other participants talked about the emotional impact of not being able to fill or fit into conventional, socially "normal" roles and stated that they experienced conflict because their new experience as a woman with SCI did not match their experience of life before SCI. This incongruency between pre- and post-SCI identification has been discussed by others as an experience in which familiar social roles are replaced by roles less socially and personally valued (Chicano, 1989; Drench, 1992; Harrison et al., 1995; Quigley, 1995; Villeneuve, 1989). For example, one participant in this study made the following comment about her social experiences as a woman with SCI:

> When I got out of the hospital, there was no one saying, . . . "These are your options." You just kind of got sent home kind of with, "This is your new life and job" kind of thing. And then I'd also moved to [city] to take part in [name of fitness program], so I was doing that every day. . . . And then I had met [partner's name], and then we got married and we moved, . . . built a house. It's not like I wasn't busy, but I just wasn't busy doing as everybody so-called, . . . like "What do you do for a living?" and I couldn't answer that. It's not like I wasn't busy, but I couldn't answer that with, "I'm a—"...And I found that . . . if you weren't in school or some famous athlete, they kind of looked at you like, "Wow! What do you do?"

A change in the roles participants identified with before SCI initially led to a sense of lost independence and a lesser experience of quality of life for some women in this study. In a study that looked specifically at quality of life ratings for women with disabilities or breast cancer, it was suggested that quality of life ratings were affected by functional independence (Tate, Riley, Perna, & Roller, 1997). This was also found in a study of men and women with SCI six months after injury, in which people reported experiencing sporadic emotional pain and depression because their abilities had become limited after SCI (Pilsecker, 1990).

Quality of life has also been described by others as a relationship where quality of life is impacted by the number and quality of social relationships experienced by women with disabilities (Tate et al., 1997). In this study, participants described the relationship in the reverse direction: Enjoyment of existing relationships was affected by lost independence and a resulting lower quality of life. This relationship between overall quality of life ratings and satisfaction in sexual relationships has been supported by others (Kreuter et al., 1994; Richards et al., 1997) and can be illustrated by the following statement:

> I've gone from being extremely independent and having my own job, my own money kind of thing, and now in a position where I have to rely on somebody to take me somewhere; I need help getting dressed. . . . There's a whole list of things that you just sort of can't deal with any more because it's too hard. . . . So you have to redefine your marriage. . . . But at the same time you're trying to redefine who you are as a person.

Many of these women commented that they found it necessary to redefine who they were as women with disabilities, renegotiate their roles in relationships, and problem-solve to decrease the anxiety and increase the satisfaction they experienced with the roles they filled. Others also reported that the change that SCI brought to the lifestyles and roles that were once familiar to a couple often causes a great deal of conflict and anxiety in the initial period after SCI (Cole & Cole, 1993; Drench, 1992; Persaud, 1986; Sipski, 1991).

Encouragement to Rediscover the Sexual Self

Many participants found that they needed and appreciated reassurance and support within the first year of their SCI in order to begin rediscovering themselves as sexual beings. They needed reaffirmation that they were desirable partners, that it was normal to be a sexual person after SCI, and that there were many opportunities to be "normal" on the horizon. This affirmation gave participants the permission and encouragement they needed to take risks in rediscovering their sexual self and to open up communication lines about their concerns. These participants' experiences reinforce the widely supported belief that helping professionals can have a positive impact on sexual adjustment if they legitimize and affirm people's sexuality after SCI (Becker et al., 1997; Richards et al., 1997; Rieve, 1989; Thorn-Gray & Kern, 1983; Villeneuve, 1989). The following statements describe vividly the impact of external encouragement for these participants:

> Well, the best part is that . . . they told me, "You are still . . . healthy, . . . so if you want to have sexual contact, if you want to have, like, a child, . . . it's okay. . . . Go for it. There is nothing that stays in your way."

> Uh, like, I, like, when she told me that if I needed to talk to her and I said, "Yes, let's make a meeting" and stuff like that, . . . I kind of enjoyed, enjoyed someone telling me . . . that it's possible. . . . Well, I just couldn't see myself doing it now because there's just no movement.

> No, and when I say I didn't need information about sex, I did need—I needed support somehow. . . . I didn't need to be told any of the mechanics, you know what I mean?

Awareness of Differentness

Body image can be defined as the way an individual perceives and feels about his or her body as different and apart from others (Weinberg, 1982). Of the women who participated in this study, a large majority (eight) had very positive perceptions regarding any self-image or body-image changes they experienced after SCI. However, many initially had a difficult time incorporating the changes that happened to their body after SCI into a new self-image of which they were proud, something not uncommon among women with SCI (Harrison et al., 1995; Kettl et al., 1991; Weinberg, 1982; Zwerner, 1982). Participants commented that a once familiar and positive concept of who they were was initially devastated by

SCI and that they continued to adapt and rebuild that self-image and sense of self-esteem:

> And then there's that whole realm of, I don't know, self-esteem. . . . I'm not the person who I was. . . . I used to weigh less than a hundred pounds. . . . That was hard. [laughs] I'm never going to be that small again . . . because I'll never be able to run again. . . . Gymnastics, none of it. It ain't gonna happen. So now I have to come to terms with that part of it.

> Self-esteem is enormous. I took it for granted before I was injured, and I do not take it for granted now, and I see lots of women in chairs who are struggling with that issue. . . . .Shaken is not the word; destroyed; shattered is the word, shattered. And I still struggle with that a little bit, although I feel just like me, for heaven's sake. . . . And it's more a matter now of how everyone else perceives me . . . than it is a matter of self-perception.

The above statement also illustrates that many participants continue to be aware of how their bodies are different in function and form from those of able-bodied women. This may be a source of anxiety and concern because of the still widely held belief that female worth is connected to physical appearance, the "body beautiful" image, and sexual marketability (Chicano, 1989; Fogel & Lauver, 1990; Rintala et al., 1997; Weinberg, 1982; White, 1993). As one participant put it, "I feel pretty good . . . other than . . . the odd day I'm on the way to shower, and you catch that glimpse of yourself naked in the mirror. . . . You're like, 'Who the hell is that?'" They know that they do not fit the "normal" image that is still so widely embraced by society-at-large and, as a result, are also conscious of how others perceive them. The following are examples of this experience:

> Self-esteem issue in regard to sexuality, sex appeal, healthy sexual relationships is really a big one; and the chair—the chair has a lot to do with that. . . . I can only really speak about my own experience. And I'm not really sure what my point is here, except that . . . it's mostly related to

> other people's ignorance about the chair. And you know what? With the people that matter, it isn't an issue. It dissolves very quickly as an issue. But everybody's afraid in the beginning.

> But there have been some comments that have stuck with me that people have said about my body that have just, to the core of my being. . . . My brother once said—and I have a great family; my family's been very supportive, but I was in a bikini a couple years ago, sun tanning on the deck, and my brother said to me, "Oh, your lower back is really bony." And, of course, I never see that, . . . ever. And now, because I never ever really still see it, I have this vision of, I'm like a stegosaurus or something. . . . And now I won't wear a bikini when he's around.

However, although these women were aware of how they are different, they have also come to perceive that their differences are part of who they have become as whole, successful women. They viewed their anxieties relating to their self-image as part of being human, not of having a disability. Many other researchers have also discussed these self-image and self-esteem issues as experiences that are complicated by, but not unique because of SCI (Chicano, 1989; Fogel & Lauver, 1990; Kreuter et al., 1996; Lanig et al., 1996; Richards et al., 1997). Although they recognize their differences, most of the women participating in this study did not dwell on them a great deal, as is illustrated by these comments:

> When I think about my self-esteem, yes, I liked having a waistline, and I liked having a body ten years ago, and I did. But I am who I am, so I feel good about who I am, and it doesn't matter shit what has happened to my body.

> As a person and as a woman, I still feel attractive. I don't really consider myself overly disabled. It's surprising to me that the only time I really do is when I'm with a group of disabled people, and I go, "I am one of these people. I really, truly am one of these people"—not that it's a bad thing or a good thing or whatever; it's just that this is who I am; this is what I am now.

> Sometimes I may have been a little embarrassed dining out in social situations], feeling like a two-year-old, like your parents are cutting your food up. Most of the time I don't care. I think it's just people and situations mainly. . . . if I was in that situation, able bodied, I'd be worried if my nylons had a run in them or something else. . . . This just happens to be that it's this. . . . I think I've handled it pretty well. I never really had a total downtime about it.

Sexuality and SH Concerns After SCI

Fighting Fires

The women who participated in this study described their sexuality as a concern that went on the back burner in the period immediately following their SCI. Most participants commented that they were just fighting fires as they were sparked, for several reasons, after their initial injury. First, they found their injury and its resulting permanency and impact on their daily life to be very overwhelming psychologically, a common occurrence mentioned by other researchers (Persaud, 1986; Smith & Bodner, 1993). They were able to accept and process only the information that they needed to physically survive on a daily basis. As these women described, their main concerns at that point revolved around just surviving:

> When I went as an outpatient, they gave me a binder to take home, and it did cover, you know, some information in there. . . . But that was so long ago, and it was at the beginning of this. . . . You kind of read through it all, but . . . you've just begun this . . . change, and it doesn't really all sink in. And so I can barely remember some of the stuff I read in there now, you know [laughs], because at the time you're just so overwhelmed with everything, and the change and having to, you know, do the cath routine and the bowel routine. Like, that's sort of the main concern for a while.

> To tell you the truth, at the time I was—like, even my mind was kind of in a shock still. . . . So the only thing was kind of survival for me, so in a way I did not really have so many questions in the rehab.

> The last thing on your mind [in rehab] is your awareness of yourself as a woman. . . . That was the last thing on my mind.

These women were also overwhelmed by the amount of learning, adapting, and problem solving they needed to do in a short period of time after their injury, a recurrent comment among people shortly after SCI (Goddard, 1988; Hart et al., 1996; McAlonan, 1996; Richards et al., 1997). So many basic issues needed to be dealt with that sexuality and SH just were not priorities. Weinberg (1982) also postulated that during the rehabilitation period, people with SCI consider any effort not focused directly on regaining independence or adapting to disability as a minor concern. Other studies also found that although SH and sexuality are still considered important, other areas of rehabilitation and independence are often deemed more important initially after SCI (Ide & Ogata, 1995; Richards et al., 1997). The participants in this study needed to address issues of: gaining independence in daily living tasks, finding accessible housing, finding a means of earning a stable income, juggling the therapeutic activities meted out by helping professionals, sorting out a medication program, and the list goes on. They were trying to regain control over their lives and were narrowly focused on independence, as is illustrated by the following accounts:

> In the beginning, I was . . . weak. . . . The injury affected me quite seriously, so I just needed to, uh, take some time to kind of get strength and just get moving.

> I was just so busy, and like, even if she [the sexual health nurse] flashed the idea again at me, it's like, six hours of therapy; I wanted to lay down; I didn't want to go to no more meetings. . . . When I left, I couldn't even lift my own legs; . . . I couldn't even get myself in the shower. . . . So I think I had way more concerns than—worrying—I had to worry about me before going to have sex or whatever.

> . . . getting some kind of a routine or whatever, if you will. . . . I would say that consumed me. I wasn't thinking any farther than I wanted to live on my own—and then kind of take it from there. . . . Yes, I don't think I was thinking any farther than that.

Furthermore, some women had very limited opportunities to discuss any issue with helping professionals, so this time was precious. This experience occurred for women who did not access the rehabilitation process. As these women related to me, on the rare occasions that they were afforded access to helping professionals, they had no time to ask questions about SH:

> You're rushed out so quickly. You wait for months to get in to see a specialist, and you've got like three minutes, so you've got to cover all this territory.. . . The last thing you're going to get into with your doctor when you know you've got two minutes is all these other issues.

> It took up so much energy sorting through the drugs, sorting through the weight of the—wading through the maze of physiotherapy or tortury, the WCB maze, . . . so every visit I had with my doctor—no wonder several doctors will only take a certain number of WCB cases. Every appointment—and actually, I had a diary that first three years . . . he had to fill out a form for this, a form for that. So every time I went, I was actually in his office at least an hour. And I had my list, and I was a prepared patient. I went prepared. I knew what I needed, I knew what I wanted, and I got what I wanted. . . . Did I ever have a second to ask a question about sex? Never."

Unconscious Incompetence

Of the participants, many recalled that during the period of time that they were in rehabilitation, they really had few questions about their sexuality and SH because they did not know what to ask. They were functioning in a social and physical body that was unfamiliar, and concepts of how that body would work and function were vague, an experience also described in a study by Richards et al. (1997). At this point in their lives, these women were moving through uncharted territory, and some had never been exposed to other people with any type of disability. They could not see in their mind's eye what they might experience in their social and sexual life or how these might be different from before their SCI, and, as a result, they did not know what questions to ask. The following statements illustrate how this ambiguity translated to few or no expectations about sexuality after injury:

> I did not really have so many questions in the rehab . . . because I, first of all, I didn't even know what to ask.

> [Pause] I can't really say I had any expectations. . . . I just had lots of blank spaces in my mind, . . . a lot of fervent curiosity.

> And at that time you don't know; you just think this is how it is until you—and again, going home to where I went—I had to go back to [home town], because that's where my parents were from. And there's no one in a wheelchair there. . . . So I didn't know that this was wrong, right, uncool, cool, I had options, until I went to the [name of facility] Center.

Managing Risk and Rediscovering Sexuality and SH

As one participant said, "I just had lots of blank spaces in my mind, . . . a lot of fervent curiosity." As participants moved closer towards resuming their lives in the community and began to live social and sexual lives in a more socially normative way, their curiosities turned into questions and concerns. Richards et al. (1996) also found that participants regained an interest in sexuality as they resumed more normal activities and interactions outside of rehabilitation. As this woman recalled, many participants' initial concerns revolved around basic fertility issues:

> Definitely one of the first questions in my mind was whether or not I'd be able to have children. . . . I remember asking that right in the emergency

> room . . . because I knew I was pretty much fucked. . . . I didn't know the details about spinal cord injury, but I knew this was very bad and probably for good.

The question "Can I still have children?" most often referred to participants' ability to conceive, carry, and deliver a child in comparison to the ability of able-bodied women to do the same. In addition to this, women had anxiety over how pregnancy would affect their now differently functioning bodies. However, for most, this anxiety subsided when they got straightforward answers to their questions. They merely wanted to be able to form a picture in their mind of what to expect of the future so that they could make informed choices.

In addition to being concerned about the ability to conceive, women had many concerns about controlling when or whether they conceived. The concern over birth control decisions began early after SCI, and it continues to be a serious concern for some, because options for contraception are limited, and each option poses different risks (e.g., blood clots, osteoporosis, undetected infection). Becker et al. (1997) also found that women experience a great deal of anxiety surrounding the lack of birth control options made available to women with disabilities. For some participants in this study, this concern had significantly interfered with enjoyment of sexual relationships. Again, these women wanted to both minimize the risks to which they exposed themselves (e.g., STDs, unplanned pregnancy, and SCI-related health risks associated with specific birth control options), and to enjoy their sexuality to its fullest capacity (Hart et al., 1996). For example, one participant who had been injured for almost 20 years at the time of our conversation explained the impact of having limited birth control options:

> I've never been able to use the birth control pill; I got a blood clot right away. . . . So it was always condoms and rhythm and condoms and rhythm. Anyway, I got pregnant, and it was only two years ago, and it was just—I hated it so much; it was just horrible. So that's when I had my tubes tied too. I just didn't want to have to deal with that any more. . . . Fear of pregnancy was always an issue with me, and it turned out to be real. . . . So I'm happy that I don't have to worry about that any more.

Another participant almost mirrored this statement in explaining her experience:

> My fear with the . . . pill is that whole blood-clot issue with the lack of circulation. And I had blood clots when I was in the hospital. I ended up with some of them, . . . so I've been on the pill for years, going, Okay, I'm just going to have a brain aneurysm tomorrow or something.

Whereas reproduction and fertility were addressed openly by helping professionals (e.g., nurses, doctors, occupational therapists), the sexual activities and intimate relationships that make reproduction and fertility a topic of importance were often less clearly addressed, as these two women described:

> Well, maybe more detailed information would be appropriate. Uh, it was more in general terms. I knew, okay, I'm okay and . . . But otherwise [it was] not really explained maybe how to deal with the issue.

> All the information about our functioning was very good and well done and everything. . . . It's just, they just left out the whole, . . . the actual sex part.

Many of the women in this study still had vague concepts of how their body might or might not work and how they could give and receive pleasure in a sexual relationship. They wanted to know more about how to adapt their repertoire of sexual activities, because many felt that their new abilities would not allow them to perform and function in the same manner as they had before SCI. In other studies looking at SH issues of women with SCI, it was also found that women needed more information than they received on topics such as orgasm, sexual positioning, and sexual aids (Lanig et al., 1996; White et al., 1993; Zwerner, 1982). The following statements illustrate this experience:

> It's kind of, now it's still like I haven't been there [had sex after SCI], so I don't know what's going to happen, and I can't [laughs], um, you know, how would it be, how would it be if I was in this situation?
>
> I guess the initial sort of physical how was a bit of an issue because I had no idea . . . how to deal with it or how it was going to be or how to even physically organize it or anything. So the first time that I actually put myself in the playing field, I actually rented a hotel room next door from my brother to make sure that he was there in case I needed him. . . . So I did struggle with how."
>
> So they said, "Yes, you can have sex again; and yes, you can have kids." So I was like, Oh, okay. And then . . . I would go home and learn about it; . . . it was like. Okay, so having sex . . . okay, I'm not going to orgasm. . . . How am I gong to do this . . . or how am I going to do that?

Furthermore, many were dealing with bowel and bladder paralysis and only beginning to learn about methods of managing that paralysis. They had many "what if" questions and anxiety relating to how they could successfully prepare for sexual activity and avoid or reduce the chance that embarrassing incontinence would occur. This anxiety over bowel and bladder control has also been found by other researchers, because loss of control over bodily function is part of the self-image change with which women with SCI are forced to come to terms and problem-solve (Berard, 1989; Closson, Toerge, Ragnarsson, Parsons, & Lammertse, 1991; Drench, 1992; Fitting et al., 1978; Harrison et al., 1995;

Weinberg, 1982; Westgren et al., 1997; Willmuth, 1987). The following woman's recollection illustrates how her initial fear of bowel incontinence caused her anxiety:

> When I first started having [sex]—because I heard that could stimulate your bowel, it could whatever, and I was like, Oh, my God! Are you serious?

They also wanted to know about how to maintain a balance between having some sense of normal intimacy and spontaneity and addressing their disability-related needs, as illustrated by this statement:

> I think the only thing that they mentioned was, I think, trying to cath before. But I mean, it's also quite hard because how do you sometimes know, you know? And from nowhere it comes and you go like, "Oh, excuse me, I should cath," and you know.

In attempting to adapt to changes and conceptualize a new reality, many experienced a great deal of anxiety and fear of the unknown prior to re-experiencing sexual contact with partners after SCI. In another phenomenological study of sexuality after SCI for women, this experience was also common (Richards et al., 1997). Like the women in the previously mentioned study, the participants in this one were afraid of how they might function and react in a sexual encounter and of how their partners might react to this new reality. It was scary for them because this would be a new experience for both partners. They were afraid the experience would be less satisfying. These women wanted to both maximize their enjoyment of their relationships and minimize the risk that sexual intimacy would result in a negative experience, as exemplified by this recollection:

> It was a big thing. It was very scary, actually. . . . I was scared that he wouldn't be aroused, basically, and I think he was scared he would hurt me. . . . But it worked, thank goodness [laughs].

Relationships After SCI

Impact of Disability on Existing Relationships

Of all the issues that were brought up by the women in this study, one of the most frequently discussed was how the disability that resulted from their SCI impacted the relationships in which they were involved at the time of injury. On a very basic level, just the quality of everyday life impacted how much some participants were able to contribute to and enjoy the intimate relationships they had, a finding supported by other studies (Kreuter et al., 1994; Kreuter, Sullivan, Dahllof, & Siosteen, 1998). In fact, in one of these two studies on global quality of life and satisfaction partnerships after SCI, pain was the only medical complication that significantly impacted quality of life (Kreuter et al., 1998). For three women in this study, quality of life was directly related to their experiences of chronic pain or altered sensory perception. These participants found that the pain they experienced affected their level of frustration, tension, and anger throughout the day. They also found that they would then direct their tension, frustration, and anger towards significant others in their life. This affected their ability to be emotionally and physically close to partners. The following two statements vividly illustrate the impact that pain had on quality of life and, in turn, quality of relationships with others:

> It's like that one nerve that I do have left, you're standing on it, so get out of my face. You get to a point, and you can't help it. You're in so much pain; nothing helps. The medication doesn't dull it enough to get through it. All the other techniques that you might have tried, like heat, ice,

> relaxation, whatever, that's not cutting it either. . . . And it's like, I have one nerve left, and you're standing on it. Get out of my face. You snap at everybody and everything, and it's like, "Don't even touch me!" So yes, it makes it really tough.

> When the pain is so bad, I'm just talking through gritted teeth, right? [Through gritted teeth] "Get in the car right now!" So that was the big difference, and that was probably the biggest hurdle.

As in any relationship, both giving and receiving pleasure remained an important part of these women's sexual relationships. Others have also found that ability to satisfy a partner is of high importance in sexual experiences with partners (Charlifue et al., 1992; White et al., 1993; Willmuth, 1987). However, some experienced anxiety in comparing their desirability and ability to perform after SCI to their abilities before, and they feared that their partners were doing the same. They were worried that in addition to this, because their new repertoire of sexual activities were more limited in some ways than their previous repertoire, their partners would no longer find them attractive and desirable. This fear has also been described by other authors (Drench, 1992; Kreuter et al., 1996; Lanig et al., 1996; Richards et al., 1997; Rieve, 1989), who said that this perception of being less desirable and capable in a sexual relationship feeling can lead to feelings of inferiority, weakness, and isolation (Lemon, 1993; Richards et al., 1997; Weinberg, 1982). This experience can be illustrated by the following recount of the first time one participant and her partner of one year had the opportunity for sexual contact after SCI:

> We were nervous...Fortunately, he was young enough that he probably could have got it up no matter what. [laughs] And we were nervous, yes...I think I—yes, I know I was nervous then...He wouldn't want me.

These women initially found the limitations imposed on their sexual relationships by their disabilities to be overwhelming and frustrating. For a few, it meant the dissolution of relationships. One participant was in a relationship with another individual with SCI, and the dual impact of two people with physical limitations trying to achieve physical intimacy was just too difficult:

> Even to this day, we still have deep feelings for each other, but just the frustration of two disabled people trying to have sex, if you want to call it that, . . . was just overwhelming.

Eventually, however, participants found that in order to again enjoy a satisfactory relationship with their partners, they had to take the time to redefine the roles that each partner played in sexual relationships and let go of some of the conventional definitions of "good sex," a strategy supported by the literature on regaining a satisfying experience of sexuality after SCI (Weinberg, 1982). For example, one participant explained that in her current relationship, there is less of a focus on orgasm as the end result, and more focus on just enjoying what feels good:

> To be frank, when I first met [partner's name] and everything, he was concerned about that, . . . because he was thinking, . . . "My mission in life is to make this quad orgasm." . . . And I was like, "You're taking all the fun out of it because I don't orgasm, and if I do, it'll be a miracle, and yahoo." But . . . it goes with the way I am: Just let me enjoy what I'm doing, the way I do it. And you enjoy yourself . . . because if I'm having a good time, leave me alone! You don't hear me complaining—so don't try and fix a problem that's not there, for me.

Others have posited that spontaneity in sexual encounters is often decreased or eliminated for people with SCI, often due to the necessity of preparing for sexual activity and the loss of independence in activities of daily living (Charlifue et al., 1992; Harrison et al., 1995; Lemon, 1993; Perduta-Fulginiti, 1992; Weinberg, 1982). For four participants this was the case: They felt that their disability decreased the amount of spontaneity and closeness they once enjoyed in their sexual relationships with their partners. The necessity of preparing for sexual activity, whether it be bowel and bladder management or managing pain tolerance during sex, decreased the amount of pleasure these women derived from sex. For one participant, the fact that her husband could never be sure of her pain level made initiating sex and maintaining closeness very difficult:

> And then with my husband, I know we've hashed this out a million times, but he's also afraid to initiate anything for fear of hurting me. . . . So he's in that, "Do I? Don't I? What kind of day is she having?" kind of thing. So it's been hard. . . . It puts a lot of strain on the marriage, in that part of it. . . . It's just that closeness; you almost feel disconnected in a lot of ways.

For another participant, being physically dependent on others for assistance was also a source of concerns, because a third person (i.e., a personal care assistant) was injected into the private life she once had (Lemon, 1993). This third person eliminated the spontaneity and privacy that she used to enjoy with her partner:

> Well, now I'm living just with my mom, and, uh, . . . we [she and her partner] just became good friends, so there really . . . is not any sexual contact . . . yet, um, [that] I have experience with.

These women also spoke of independence in regards to trying to strike a balance in their relationships between accepting the help that their partners were offering and maintaining their own independence. The women were very aware of the potential caregiver/care receiver relationship that could evolve and were eager to avoid this relationship. This was also found in the literature, where the conflict between being in a loving partnership and being in a caregiver/care receiver relationship with the same person created a lot of stress and frustration for both partners (Rieve, 1989; Sipski, & Alexander, 1992). The women in this study feared that falling into these roles could put an unmanageable strain and burden on their relationships. They did not wish to experience the guilt of being a burden, nor did they want to be source of burnout and resentment for their partners. For those women who had more physical limitations due to their SCI, they struggled more with how to strike that balance than did other women who could more easily maintain their independence. The following statements demonstrate the tension and anxiety that was and is experienced by these women:

> Sometimes he likes lifting me into the van instead of me getting in the driver's seat [by myself], . . . and I'm like, "Why—?" And then a few other things. He likes putting my shoes on. . . . I always say, "You know, . . . why don't you let me do it while I can do it? because if we're together in twenty, thirty years, there's a good chance I won't be doing this, . . . and you'll be doing it. And then it won't be fun; . . . it'll be "Put my damned shoes on.'"

> I'm trying to work on a long-term relationship here, and I want to know what's going to happen when I'm sixty and someone needs to wipe my butt. What do you do? And how do you not cross the line between helper and partner?"

> I hated my husband at one point. . . . He's trying to make things easier for me, so he's trying to do things for me. And that only irritated me. . . . He thought he was being helpful because he doesn't want to see me in pain. Yet I saw it as a threat. . . . And there's that guilt trip too that I'm a burden.

> As far as being paralyzed goes, really, he claims it's not really an issue to him because he doesn't have to take care of me. He says he wouldn't like to be my attendant if I were a quad or something. . . . And I say, "I wouldn't

> want you anyway." . . . But there are lots of times where he does have to help me when we're traveling and things like that, or when I have an accident or stuff like that. But it's never—no, it's not really affected our relationship, because he's never signaled in any way that this bothers him. . . . But, God, I wouldn't want to push it any further, you know? [laughs] Yes, it's never really been an issue. But I think that that's been probably a lot of effort.

Dating and Mating

The concept of establishing new relationships after SCI was one that created anxiety for participants in this study. They simply were afraid that they would not be able to find partners who chose to be with them based on their value and desirability as a partner, both in general terms and sexually. One woman in this study had a partner who remained in the relationship for a very short time after her injury and had these thoughts when faced with the prospect of finding a new partner:

> I thought it had been okay because I had somebody there, but after that it's kind of like, kind of went all downhill from there because it's, like, who'd want to do that with me, you know?
>
> I was with him before. . . . And now it's like, try and find somebody that will be there and understand my situation. . . . Like, how to, how to do it [laughs], . . . like intercourse and stuff like that.

Two women even went so far as to attempt to push away partners shortly after their injury because they questioned the viability of their relationships and were concerned that they were only going to be a burden on their partners and hold them back from achieving happiness. One participant told the following story about her relationship with her partner, only days after her injury:

> I was thinking fairly coldly at the time about my options and stuff . . . and what was left for me and this kind of thing, and I was thinking, obviously a

> lot of people were getting hurt, like my family. . . . And I was thinking, Minimize the hurt. This guy's young and . . . he's not hurt, and he can walk. . . . So literally, he can walk away; he can go. If he can do it, he should probably.'

In addition to this, these women feared rejection because of their disability and because of the fact that their bodies moved and functioned differently than those of many able-bodied women, an experience that has been discussed and examined by other researcher as well (Lemon, 1993; Richards et al., 1997; Rieve, 1989; Sawyer et al., 1983; Weinberg, 1982; Yoshida, 1994). Because of this fear of rejection,some participants mentioned that they were reluctant to disclose certain characteristics of their disability (e.g., incontinence, lack of independence in personal-care activities, etc.) for fear that these characteristics would cause a potential or new partner to turn away from them. This internalized perception that they deviate from the norm has been mentioned by other researchers as a common factor that negatively impacts the pursuit of new relationships after one incurs SCI (Chicano, 1989; Fogel & Lauver, 1990; Kreuter et al., 1998; Lemon, 1993; Rintala et al., 1997; White, 1993; Yoshida, 1994). One participant spoke of how she had not yet had an able-bodied partner and related her concerns about this prospect:

> That's right, and that's a big issue. I have not been intimately involved with an able-bodied man since my injury, and I think about that quite a lot, because the issues, the spinal cord injury issues, the spinal cord injury complications that people who have spinal cord injuries take for granted and understand, I haven't addressed that with an able-bodied lover, and I think about that. I wonder if my able-bodied lover would have a lot of problems, etc., with all the usual bladder-bowel stuff and all the rest of it.

However, although these women were afraid of rejection, they also did not want to be in a relationship based on charity or pity, as this participant stated:

> I don't know if I could have gotten into a relationship if this had happened before I met my husband. . . . I would have been more afraid of pity. . . . It's "You're only here because you feel sorry for me." Or that, as crazy as it might sound, that sympathy story.

As a result of these concerns, these women were reluctant to pursue new relationships and selective in choosing with whom they would risk pursuing an emotionally and physically intimate relationship. This self-distancing due to fear of rejection has also been seen by other researchers (Lemon, 1993; Weinberg, 1982).

Supportive Partners

Those women who had supportive partners in their lives at the time of their injury, or very shortly after, adjusted to their disability in terms of SH and sexuality with much less anxiety than did those who were single at the time of injury. Supportive relationships have been found by others to positively impact overall adjustment to SCI (Kreuter et al., 1998). Women in this study who had established intimacy and trust in a relationship felt safe and supported in "trying on their new social and sexual body." They had less anxiety in adapting sexually, and the trial and error method of sexual rediscovery was easier, as this participant explained:

> I've been with my husband—we got married in '88, so we were together almost twelve years by the time I walked or rolled out of there. So we were in a fairly—actually, we were at a very good place when I injured in terms of the intimacy between us....he was very supportive.

As the above statement illustrates, questions that arose for women with supportive partners caused less anxiety because they could answer them and work through issues together in a safe environment, a finding of other researchers as well (Rieve, 1989). These statements echo that experience:

> All the information about our functioning was very good and well done and everything. . . . It's just, they just left out the whole, . . . the actual sex part. [laughs] . . . It was okay with me, yes, because I had a partner. . . . But I think it's not an okay thing in general.

> It was very shortly after my injury that I moved to [city] and met [partner]. And then we just learned off of each other. So nothing was really, . . . I never really ever thought about it a lot . . . because I just assumed I would have sex again.

Having a supportive partner early on also seemed to positively mold these women's self-image. Richards et al. (1996) supported this finding that being reaffirmed by a partner and feeling desirable contributes to an improved sense of self among women after SCI. When participants in this study were questioning their own desirability and coping with a life-altering change, their partners reaffirmed them, as this woman's partner did:

> You know, my husband and I just tried again and kept at it. . . . You know, he's not been any different, so that's sure made a difference as well, you know. He doesn't treat me any less—you know, like I'm less of a person because of what's happened. You know, I'm still the same [laughs] to him, so, I mean, that's probably a big factor in how I feel too.

Coping With Change

Proactive Frame of Mind

No matter what method was used in coping with sexuality and SH after SCI, most of the women who chose to participate in this study proceeded with a proactive mindset. They described their disabilities as one part of the way they lived their lives, but not as something that defined who they were and what they could do. One participants illustrated this concept in regards to her sexuality and SH:

> I think in my head and in my own mind I just decided, I don't care what kind of pain I'm in. There's certain things that I'm going to do regardless. I am going to have a healthy, active sex life, and I'm going to dance. . . . And I just kind of came to that place.

They did not allow their disability to control them and viewed their SH and sexuality as something for which they were responsible and capable of affecting. Their locus of control was internal, in that they more often viewed themselves as having the power to affect their circumstances and surroundings. This locus of control concept (Lefcourt, 1982) was reported by only one other study, in which the specific relationship between sexual locus of control (i.e., whether or not an individual perceives they have the power to address their concerns) was significantly related to sexual satisfaction and adjustment in men with SCI (Linton, 1990). No other studies were found relating to problem-solving capabilities or locus of control orientation of women with SCI regarding SH and sexuality. When asked to describe how her sense of control over her own SH and sexuality changed after SCI, one participant said:

> I don't really let anything limit me, other than the obvious things that do, but I don't say, "Oh, I don't think I can do that"

Participants described themselves as feeling successful in pursuing sexual well-being because they were problem focused, and when they had concerns about their SH, they actively sought out assistance and information. The following statements exemplify this proactive orientation:

> That was me asking the questions; it wasn't something that was offered to me. It was me going to my GP, saying, "What do you know about this procedure?" And that's sort of the way it's been with me.

> So I did struggle with how [to have sex]. But I just started asking everybody.

Furthermore, these women employed a multitude of strategies and creativity in coping with changes and overcoming barriers, as this woman described:

> We actually had the Baptist Church house manse for almost a year, this great big, rambling old house with a huge back yard. And so it was a really nice main floor. And I did have a flight of stairs, which I didn't tackle for the first four months. We had a bathroom on the main floor. So I lived on the couch. . . . I lived on the couch, and when we wanted to make out, we did it on the couch.

> So again, we were on the couch, he [the baby] and I. He slept on the floor in a little—I had one of those bassinets that I could drag with a handle. . . . It zipped down, so I actually had him on a—I had a trunk, and he was on top of this. He was right at my level, so I could actually roll over, . . . throw my boob in his mouth, and he'd go back to sleep. It worked really well.

> So finally we settled on, I take Tylenol with codeine, and I take it at night generally when I'm just off the planet. I use the TENS unit as much as I can; I go see an acupuncturist every once in a while when I can afford it. . . . And it does help. It can turn an intolerable day into, "I can cope today."

As they honed their creative problem-solving skills, these participants found that their anxiety and frustration decreased when they were faced with a new barrier:

> Ten years into it, I've learned what to do to make my life functional . . . and have a quality of life. I do have reoccurrences that are kind of—I have learned—I have this motto, and I have learned that "This too shall pass."

Participants did not wait for anyone else to offer information or assistance first, because they were skeptical that they would receive beneficial assistance or any assistance at all from helping professionals. These women assertively asked for support from helping professionals they trusted and actively sought out peers to share with and learn from, as these women described:

> I have found people who have . . . used morphine for years. But those people I sought out, I found them on the Internet. I asked the questions. . . . There is nobody to tell you that—it was a fluke I found out about the methadone program. . . . I have my own CPS book, so I can go in and I can check the drugs myself. . . . And a lot of this has been me asking for it; it's nobody volunteering to give it to me.

> I knew she was active, so as soon as I realized that I was about to become active, I went to her and said, "I need to talk about this." And then I started saying, "I need to talk to some of the nurses about this," and then I went to the OT and to the social worker and etc.

> We have this little group out here. There's [peer]; . . . then there's about three other wheelchair users in the area, but they're all fifty, sixty-plus, but we still get together once a month for coffee. And I'm the only woman there, so I sit there and I listen. . . . And then I just started speaking up and asking questions like "How do you guys—?" Not with all the men, but there's one guy. He's old, but he's very open minded, and I just ask him: "Do you and your wife still have sex? because you're this old—" and they've been married [a long time], but he got a virus, and so he's only been in a chair for maybe less than ten years. So I want to know how it changes their relationship . . . because I'm trying to work on a long-term relationship.

Peer Support

In reflecting back on how they coped with changes to their abilities, functioning, and self-image, the women who participated in this study reported a variety of methods they preferred to use in addressing their concerns. However, all participants mentioned the ability to share with and learn from peers as their most valuable and trusted coping mechanism. Tepper (1992), also found that people with SCI most frequently mentioned peers (66% of the time) as the people with whom they would be most comfortable talking about sexuality concerns. Participants in this study who were exposed to other women with SCI soon after their injury reported having less anxiety in coping with changes and more self-confidence in their desirability and ability to problem-solve. They experienced this decreased anxiety and increased self-confidence because the peers they met were able to paint a picture of the future and clear up ambiguous concepts of sexuality and SH after SCI. As this participant expressed, even the simplest reaffirmation that her sexuality was not over made a huge impact:

> When I met [name], . . . I met her shortly after I was injured. It was the same thing, where I had never met anybody who had a disability like mine. And I really had a poor concept in my head of how life was going to be. And to see this person functioning—and she had makeup on—she had earrings on, and I wanted to know, how did she get it on?

By relating their experiences and strategies for problem solving, women with injuries of longer duration could affirm the experiences of newly injured women. Other researchers have also found that exposure to other women with SCI helped newly injured women to accept themselves as sexual beings again and believe that sexual relationships could be satisfying after SCI (Fitting et al., 1978; McAlonan, 1996; Richards et al., 1997). This reaffirmation encouraged the women in this study to take the risks associated with rediscovering their selves and sexuality, as this participant explained:

> The first thing I learned from a woman in a chair who I knew was sexually active is that you can survive the most mortifying experience. Her partner was able bodied and therefore was not privy to all of the spinal cord injury issues—bladder, bowel, all that stuff, . . . dealing with it. But she went through it, and she survived it, and she told me that it was okay. . . . And she told me that she achieves orgasm, and that was incredibly exciting to me. And so I really got nothing but encouragement from this woman.

Those women who were going through adjustment to SCI together at the same time found that they had more confidence because they "fed off of one another" and felt as though there was no problem that could not be solved as long as they could rely on one another, as this participant explained:

> Meeting another girl quad [like me] was just another total eye opener. It just felt like me and [friend] against the world. If we couldn't do something, we would help each other, . . . and there wasn't an eye blinked or anything like that. So, yes, nothing learned in rehab; all learned from other injuries.

In addition to the confidence and camaraderie that was experienced by women who went through this period of adjustment in their lives together, women also appreciated learning vicariously from others who were at slightly different stages of rehabilitation. In hearing about other peers' experiences, they learned about problem-solving strategies that they were able to use later when they felt ready to address an issue or when an issue confronted them. The benefit of sharing and learning from others in a group setting was also a common finding by other authors (Drench, 1992). One participant explained that a benefit of vicarious participation in small peer groups is that "other people will say things that you might be going through that you aren't ready to talk about."

Furthermore, participants in this study preferred speaking to peers about SH and sexuality concerns over speaking to any helping professional (e.g., doctors, nurses, occupational therapists, health educators). They felt that peers understood them better, and because they often had lived the experience, these women had less anxiety in communicating openly and disclosing concerns to other women with SCI. Because of real-life experience, they viewed peers as more credible and knowledgeable than helping professionals. Other researchers also reported that women in their studies felt similarly about peer support (Kreuter et al., 1996; McAlonan, 1996). They felt more comfortable talking with other women with SCI and did not feel as though they would be seen as odd or judged negatively if they talked about their concerns. The following statements from participants illustrate this experience:

> I think [peer] said it best lately: It's just kind of nice to have somebody who understands what you're saying.

> And again just . . . being able to talk to somebody . . . in your age group or something with the same injury as you have and just kind of share. . . . You can relate to that other person and say, "Well, you are in the same shoes as I am, . . . so just talk to me. How do you deal with this issue?" . . . Otherwise the healthy [sic] people don't really know, so even if you are talking to your friends, well, they are healthy [sic], so . . . they can't really direct you.

> So it came with talking. And even talking, I went through rehab with a fellow, and we would be very candid with each other: "What do you think is going to happen when this?" or "What do you think—?'

> So meeting [peer] was great, because we learned off each other; we taught each other things; we understood each other right down to the core of disability, I think.

Another reason that these women wished to share experiences with peers was simply to learn more about how to maximize their enjoyment of their sexuality and to know how most other women with SCI problem-solve around SH and sexuality. This seemed appropriate, given the finding of others that achieving sexual satisfaction is a topic of interest often mentioned by women with SCI (Lanig et al., 1996; White et al., 1993). When asked to specify the concerns she wanted to discuss with peers over the years, one participant said:

> I just want to know more, and I think I just want to know—I want to know about other people's experiences—because I want to know, . . . you want to know if you're doing it right, if there's other ways to do it better.

In seeking out and sharing with peers, participants seemed to be striving to normalize their experience of sexuality and SH after SCI. It was and is important for these participants to create a schema or a reference point to which they could compare themselves:

> I only want the one-on-one. I don't really trust the written word because I never know who's written it, and it's usually somebody who doesn't have a disability. So my preferred method is someone with a disability, and it could be male or female. I like talking to them both because you want to get it from both sides—and probably because I was also in a relationship with a male [peer]. So yes, I would prefer it to be one-on-one and prefer it to be an injured person.
>
> And I think it's like with anything else; you ask other people what they have been doing and different things, and this is probably the best way to find out what is in a way the best way or what is the usual way or something.

Although many prefer to talk with peers about sexuality and SH after SCI, not many get the opportunity (Tepper, 1992). Most of the women in this study had very limited exposure to other women with SCI, due to the fact that few women sustain SCI in comparison to men. Furthermore, there are even fewer women living with SCI who are willing to share their experiences, as these participants described:

> So, yes, it's very frustrating and even—I ran into a lady. She's a parent, . . . has two children, and I just wanted to ask her a million questions but didn't get the feeling that it was comfort—you know some people, you just meet them and you go, "Okay, I can ask you how you cath; I can ask you how—" I wasn't getting that vibe from her. But just the fact that I was like, Wow! Or who's your doctor? Who talks about these things with you? Even birth control.

> I'm very interested in educating myself, and I do not have women around me that I can talk to. . . . I'm really interested in talking about it and in having other people that want to talk about with me.

In recalling the sexuality and sexual health barriers that these women experienced immediately after their injury and throughout their lives since injury, they craved the opportunity to speak to someone, as one participant said, "who's been there, done that, or is thinking the same thing." For those who had little exposure to peers, they felt as though they lacked the encouragement and guidance they needed at a time when no one else could answer their questions credibly or point them in the right direction:

> And I would have liked that very much, yes, . . . especially somebody who had—because that was what I was focusing on, was being a mom, . . . that I wanted to be a mom, and I would have liked to have seen somebody doing it or telling me, "It's okay; it's not going to be that horribly difficult" or whatever.

Another participant even wished that her husband and she had been afforded interaction with other couples going through similar struggles:

> I think they [partners] need it as much as we do. . . . They also need to be somewhere where they can say to someone else, or even hear someone else say, "This is what we've been through. This is where we went, and this is what works."

On the rare occasions that they were able to meet a peer, it was an experience not to be wasted. When asked to describe this experience, one woman said:

> I had one girl come and visit me. I did not know her, and I think maybe it was just part of CPA, something that she did. She was from a different city, and she came in and talked to me, and because I'd never really been around people in wheelchairs, . . . to see a woman in a wheelchair, I could have kept her for a week.

Age and Stage of Life

Many participants reported that their age and their stage of life affected how they coped with SCI and what impact SCI had on their sexuality and concerns about their sexuality and SH. For example, two participants explained that they were injured at a time when their self-identities were undergoing tumultuous changes:

> Emotionally, I feel weaker as a woman. A large part of that is, again, the age thing because I think at thirty things change for women; I think at thirty things changed for me. And my outlook on sort of sexuality, the opposite sex, interaction, intimate relationships changed dramatically from the time from my late twenties to when I was thirty. And, of course, my injury didn't make that any easier; . . . complicated it and compounded it.

> I know for myself, . . . I was sixteen, so at sixteen you're going through all sorts of weird crap and trying to decide who you are and what you like about yourself and what you don't, and then all of a sudden you have a spinal cord injury, and that just compounds all the other upheavals that are going on at that time.

These women were confused in trying to identify whether their emotions and reactions to the events in their life were linked to their age, to the fact that SCI had radically impacted the way that they knew life to be, or both.

Participants also commented that, depending on what part of "life cycle" they were experiencing, their sexuality and SH concerns differed, and the weighting or importance of those concerns changed. This finding was supported by Pilsecker (1990), who found that an increased dissatisfaction with life and anxiety in coping when SCI interrupted the life plans of an individual who had not yet finished accomplishing life goals, or alternatively who had not yet come to terms with giving up on unreachable ones. For example, one participant rationalized why she had not experienced a lot of anxiety about sexuality and SH after her SCI:

> In my mind I'm thinking, . . . I've had my kids already. . . . I've got a, you know, a boy and a girl, and, um, being married, you know, already, . . . maybe that makes things different. . . . Somebody that might . . . be single and not had a family yet or not had a relationship yet, you know, it might have been different.

Another participant explained that pregnancy and parenthood were distant concerns when she was injured at the age of 20 and single, but now that she was in a committed relationship at 32, questions about it were closer to the front of her mind:

> I've thought about it. I would have to say in the last couple years it's been on our minds a bit; it's been on my mind: Can I have it? Will they C-section, and have quads had babies?

Other participants talked about the anxieties, desires, and concerns they had as part of the process of growing and changing throughout life, an experience described by other researchers also (Charlifue et al., 1992; Chicano, 1989; Drench, 1992; Fogel & Lauver, 1990; Kreuter et al., 1996; Lanig et al., 1996; Richards et al., 1997). They viewed SCI as cursory to their experiences and concerns:

> Interviewer: And how about body image? Did that change for you?
> Participant: Yes, just over the years though. But I think that would have happened with age anyway—
> Interviewer: Yes.
> Participant: —in that sense. Now I'm thirty-two; I'm not twenty any more.

> Again, it has a lot to do with where you're at in life. . . . I'm thirty-four, and this is my sexual prime. So I have needs coming from inside of me that <u>have</u> to be addressed. I don't have any choice in the matter.

<u>Trial and Error</u>

To quote a participant, the second most often preferred method of problem solving and rediscovery in regards to sexuality and sexual health was "just by doing it." Other women with SCI in previous studies have also mentioned this as a method of rediscovery that they support (Kettl et al., 1991; Lanig et al., 1996). Simply put, participants saw this as a natural way to come to terms with and get answers for themselves about how they and their partners could adapt to any new changes in their sexual life. One participant recalled that this process occurred in the first couple of years after her injury:

> He was sensitive, and he was understanding, and he was gentle, and I guess through trial and error I just learned to try all sorts of different positions until I was comfortable. And there were times where I'd just say, "Ain't happening! Bye-bye!" [laughs] And he was okay with—he was very supportive.

In describing how she used the trial and error method, one participant stressed the importance of open communication as a criteria for success:

> When you first started doing the deed with him, he was very concerned: "Is this okay?" or "Is that okay?" And then there was just communication

> the whole way through: "This works for me" and "What would be good for you?" and "This is what I can do for you, and this is what I can't do for you.'"

As the above statements suggest, this method again seemed to go hand in hand with the presence of a supportive partner soon after injury, when these women felt safe in trying new things and felt safe enough to risk having a negative experience:

> You know, my husband and I just tried again and kept at it, . . . you know, so it wasn't— . . . he's not been any different, so that's sure made a difference.

Take-Away Resources

The third most often preferred method of coping with changes in sexuality and SH mentioned by the women in this study were resources they could take home with them after rehabilitation or help that they could access without having to physically go to a facility or helping professional. A majority reported that they had not received enough of this type of support in coping with their sexuality and SH immediately after SCI. They acknowledged that if they had been presented with sexuality and SH information and sources of support during that time, they would not have used it then, because they were still in the midst of "fighting fires." However, a few felt that they would have come back to the information at a later time, once they were back living in the community. They wished they had something to refer to and rely on once they had more questions and concerns and were ready to cope with and rediscover their sexuality and sexual health. The following statements from participants illustrate this desire:

> If somebody just had—whether or not I would have heard it at the time or not is another issue, but even, "Here is a list of people, when you're ready, if you're ready; this is their numbers. If you have questions, they're going to be able to answer them.'"

> Or even maybe—like, I am not quite sure if there exists like, let's say, a book or something . . . you can read; . . . even just have a name of the book or something: "This is what you can get." . . . You know, "Read it, and it answers many of your questions." But as I said, I don't know if there is such a book or something; just to have maybe a little newsletter or . . . some information to rely on.

> But written material I think is really good. . . . The whole birth control stuff they gave us and everything was very helpful. And they did the same thing with footcare and this and that. I don't think you should only do it that way, but I think it does allow the person to go back to it. . . . I think another thing that would have been good is somebody you can call with these questions. . . . You can ask your physiatrist, but at least here in [province], the distances are so far that most of us only—unless you live in the city, most of us only go every couple of years. . . . And there are questions.

The types of "take-away" resources mentioned by participants included the following: credible websites with bulletin boards on which to post questions, helping professionals in the area of sexual health that you can call, a bureau of peers who are willing to share their problem-solving strategies and experiences, a list of books on specific topics to which women can refer, and newsletters or regular articles on the topic. The literature, although generally supportive of offering a range of opportunities to meet individual learning needs, did not specifically support or reject the idea of offering written or take-away resources.

Interactions with Helping Professionals and Modes of Service Delivery

Access to the Rehabilitation Process

It was truly a surprise to find that half of the women in this study had never experiences the SCI rehabilitation process. The incidence in this study is much higher than that reported in the literature reviewed for this project. Tepper (1992) reported that only 17% of participants did not receive SCI rehabilitation, and Gerhart et al. (1992) found one third of participants had the same experience. Of Four participants in the current study had access only to an acute-care hospital setting, where they were stabilized after surgery or traumatic accidents and then sent home. One other woman completed her SCI rehabilitation in a general rehabilitation hospital with one other male, along with people recovering from strokes, hip replacements, and other conditions not related to SCI.

For these participants, their SCIs were not deemed serious enough to warrant admission to a rehabilitation facility, although two women asserted that they lamented not being able to take advantage of that process. Gerhart et al. (1992) followed women with incomplete SCI through the coping process, and also found that these women had just as significant problems post-SCI as those with permanent, severe, high-level SCIs, and that they needed just as much support to cope. The women in the current study felt that they were denied access because their injuries did not fit the usual definition of SCI:

> And I guess maybe because it wasn't a car accident or another type of accident, it's sort of overlooked for the rehab part of it. . . . Just kind of like, "Okay, well, that kind of failed, but get used to it." I actually had a doctor tell me to get over it, get used to it; it was only going to get worse.

> So my point of contacts have been all the way along the line doctors. . . . So they should be armed with information to tell people who have spinal cord injuries or back injuries (a) who CPA is, who they serve; and (b) that there is this [sexual health] option. I didn't even know that I qualified to be served by CPA until [counselor] told me I did, and I just phoned them out of desperation for some help because they were idiots where I was living. And again, I was caught in this embroiled fight of whether I was actually a

> spinal cord injury. Figure that one out. . . . So there's a whole bunch of us who never make it [into rehab], so we miss all those . . . entry points.

Women Left out of the Information Loop

As the above quotations suggest, many participants (five) in this study felt that they were left out of the information loop because they did not go through the formal rehabilitation process and were not able to access rehabilitation professionals or even speak with other peers going through similar experiences. They did not get the opportunity to talk to SH professionals, and SHP opportunities were not made available to them, even in the community of helping professionals to whom they did have access (e.g., general practitioners in a regular doctor's office).

Participants also felt that they missed out on valuable information and educational opportunities because they were part of a minority of women in a population that is 80% comprised of men (Harrison et al., 1995; Westgren et al., 1997; Whipple et al., 1996; Zwerner, 1982). Those who attended a rehabilitation facility felt that women's sexuality and SH were forgotten and overshadowed by that of men:

> That's the other thing: There's so very few women that sometimes it seems like it gets missed almost; . . . whereas guys, there's like four or five or six of them, and they get them in one room, and they're talking about erectile dysfunction and fertility, and they've got all the gadgets out and everything, and they've got all this stuff for guys. And they get all kinds of information, and women get so little, it seems like.

> I went to one class, but they talked in quite general terms, because it was for men and women at the same time. So they didn't really go into much detail; they just in general kind of described the sexual health, but not . . . particularly for, let's say for females, how does it work.

This is an all-too-common occurrence that has been reported by many researchers and women with SCI (Harrison et al., 1995; Tepper, 1992; Whipple et al., 1996). Tepper (1992) found that women were twice as likely as men not to have received any information or support regarding their sexuality or SH after SCI. Perhaps the lack of attention paid to women's SH and sexuality is not only due to the fact that they are part of a minority, but also linked to the subtle belief pervading society that women continue to be less sexual than men, the passive receivers in sexual intercourse (Weinberg, 1982; Whipple et al., 1996).

Given their lack of peers, these women also experienced isolation and a feeling that they were going blindly through this experience of SH and sexuality after SCI alone. One participant made the following statements about this experience:

> Nobody sort of explains to you that the desire's still there, but it's like, forget it! This is going to hurt, and I don't want to be there. . . . It's like struggling between the two.
>
> So it's been hard. And there's nobody to say, "This, that, or the other thing might help." Or even anyone to sort of sound it off with.
>
> I mean, literally, I have sat down and cried because there's nothing that they can do.
>
> And where do I turn? You're not getting any support from the medical community. You have no idea what resources are out there for you. . . . And so you're sort of left . . . on your own.

Reproduction and Fertility Talk

Half of the participants commented that helping professionals generally did a very good job of educating them about how their basic reproductive functioning might or might not change. They were basically advised that their reproductive functioning would be unaffected by their SCI and that they would need to make some choices about birth control; then the conversation stopped there if they did not pursue it further themselves. One participant called this "plumbing talk," and the following participants described their exposure to this information:

> The doctors gave me, you know, a basic, . . . "You know, you're not going to feel, you know, sex, but you can still get pregnant," and, you know, very technical.

> They approached me first. Um, I had a head nurse talking to me. She was talking to me on several topics, and beside the topics she was talking also about sexual health. So she said, um, that, um, actually, the functioning in my body is the same as it was before. I might not for some time experience, let's say, my periods, because the body's in a shock. But, um, in a while they will come. And, um, I can, let's say, conceive a baby and have a baby, so there's not a problem.

> Now, I did find from the nursing end of things, they were very knowledgeable about women's issues; whether it was menstruation or birth control or catheterization, any of those things, they were very good. . . . [Sex] was left out. . . . They just said everybody's different, that kind of thing [laughs]. . . . They addressed reproduction though. And birth control. . . . They said, "An IUD will most often give you an infection. It's probably not a good idea." And they warned about effects of the pill. Yes, they went through all that.

The participants did mention that this was their first area of concern soon after injury, and it was important and valuable information to have received:

> I think she was a nurse, but she had her own, like, little office. . . . I don't know exactly what she was, but she talked to me about it, about babies and stuff like that, because my main concern was, "Will I be able to have children?" So she kind of helped me out with that.

> ...I knew this was very bad and probably for good. And so I was projecting—I tend to do that—I was projecting really about the relationship, about everything. And I asked very quickly whether or not I'd be able to have kids, and they reassured me very quickly about that, which I was glad about.

However, as has been the case in other studies on this issue, it seems that perhaps ability to conceive and deliver babies has been equated with sexuality; and as such, for many, only reproductive functioning was addressed under the guise of sexuality (Harrison et al., 1995; McAlonan, 1996; Weinberg, 1982; Zwerner, 1982). Tepper (1992) found that sexuality is often treated superficially, and similar experiences were reported by participants in this study. Although they reported feeling a sense of relief and normalcy after learning about their reproductive functioning, this cursory information was not particularly useful to them in addressing any emotional issues around sexuality or issues pertaining to rediscovery of physical intimacy and sexual functioning after SCI, as this participant described:

> Social Work didn't tell me very much. Social Work told me, "You're going to function as a normal, healthy woman, [name of participant]," meaning "Use birth control." And what else did they tell me? "If you have any more questions, come on back and ask me." It was pretty lame. It was very weak; they're pretty weak. The best help I got was from one nurse, who really explained to me and talked to me just very openly about it.

Generic Modes of Service Delivery

Only half the participants reported receiving any formal SH education, and that half were very vocal about their opinions on what they received. They did not receive the formal opportunities very positively because they perceived them as very generic and not attentive to individual needs or readiness to share and learn about SH or sexuality after SCI. In addition, these women often experienced formal SHP opportunities in lecture-style, mixed-gender settings. They felt very uncomfortable in large groups, especially when they were a minority among men, a finding also uncovered by other researchers (Tepper, 1992). Participants here felt as though the environment actually closed down communication lines, rather than opening them up. They felt the lecture style environment was not conducive to creating a feeling of safety and comfort. In recalling these lecture, participants described them in the following way:

> They talked in quite general terms, because it was for men and women at the same time. So they didn't really go into much detail; they just in general kind of described the sexual health.

> It was an embarrassing thing. We went as a joke kind of thing, or we joked our way into going. It was mostly—I think there was another woman there and me and a bunch of guys kind of thing, and we sort of joked our way into going. We went, and then we were all kind of embarrassed; . . . it was upsetting.

Furthermore, three women from two different provinces who went through rehabilitation at three different times (1980, 1992, and 1995) recalled that they had all seen the same explicit video of people with disabilities engaging in a variety of sexual activities with their partners. The following two participants vividly recalled the experience:

> It was sex class. But that was for everybody to go—that was sort of like a class on a Wednesday afternoon. . . . But it was just awful [laughs]. . . . It was a tape of disabled people having sex, and it was very uncomfortable. . . . Having a video is fine. I've got nothing against videos; I just don't want to see people having sex.

> There were these little weenie continuing-education kind of classes that were going on at the rehab center. One of them was entitled Sexuality. I

> went to it, and they showed me a movie that was made around 1902. . . . Completely irrelevant to me; it made no sense to me whatsoever.

All three described their shock in viewing the video at a time when they were still trying to build a positive concept in their mind of being a sexual person after SCI. The video was disturbing to them because the people with disabilities in the video did not meet their familiar standards for beauty, sex appeal, and desirability; yet at the same time they themselves belonged to that population which they rejected (Cole & Cole, 1993; Drench, 1992; Lanig et al., 1996; Rintala et al., 1997; Weinberg, 1982). The video did not meet their needs morally or educationally or their readiness to address sexuality and SH (Levitt, 1980; Mihelich Hogan, 1982).

Finally, as these opportunities were presented in the same format as other "self-care" classes, they perceived them as "just another lecture they had to attend." Richards et al. (1997) also reported that women did not like having sexuality included with other self-care lectures. They did not feel as though these opportunities were of added value; nor did they feel that they were offered any choice in the matter. As a result, participants discounted the value of these sessions, as these participants expressed:

> Because I was just so busy, and like, even if she flashed the idea again at me, it's like, six hours of therapy; I wanted to lay down; I didn't want to go to no more meetings.

> There are a few people who kind of go and ask and volunteer to, um, talk about the stuff. But otherwise it's like, "Yes, I have to be here. I don't really feel good. I don't want to be here." . . . So that's kind of how you feel.

Readiness and Individual Needs

Many participants were not ready to address sexuality and SH in the period immediately following their SCI. While in rehabilitation, several participants related that they had been too busy "fighting fires" and just were not able to process or accept a lot of the information when it was presented to them. When asked when is the best time to address sexuality and SH needs after SCI, participants were uncomfortable in committing to a time frame. Most thought it was a very individual process that could not be rushed or slowed down, but a process of which helping professionals needed to be keenly aware, as one participant opined:

> I certainly feel that whoever's on the theoretical rehab team—your doctors, your therapists, your nurses, etc., your friends, your family—that an awareness of, I want to say the reawakening of every physical issue from shaving your legs to your bowels to your bladder to your psyche to dressing, everything, there needs to be a custom-made, as much as possible, a custom-made strategy where somebody is paying a lot of attention to the timing of when an individual is ready to accept or discuss this issue, and that somebody needs to be really sensitive to that, to the timing aspect, and to the supportive, caring offering of wellness.

What many participants did agree on was that they were all more likely to have been ready, and definitely had more of an interest in SH and sexuality once they began to resume some semblance of a normal life in the community and realized the potential permanency of their disability. Others have commented on this readiness and advocated that this is the best time to expose men and women with SCI to sexuality information and education (Hart et al., 1996; Kettl et al., 1991; McAlonan, 1996; Richards et al., 1997; Smith & Bodner, 1993; Tepper, 1992; Westgren et al., 1997). In this research project, the women were better able to reconceptualize their sexuality and come up with questions once they were interacting with others in more socially normative ways than they had when they were "patients." These women described that experience:

> As you are [leaving] . . . rehab, you start to deal with different, um, information; and just, you are outside, you are between people, so you see how the people react to you. . . . I mean, that's probably the most important part, that you actually learn, This is what I am going [to do]; . . . now I have some questions.

> Maybe later on when the patient is getting ready to be discharged, maybe in the second half of the rehab, uh, when you start to think a little bit more about, Okay, I'm finishing here in the hospital. I'm going out there to the world, . . . and about the future. This might be a good time when you should be exposed to, um, the classes about it and maybe have the people from Sexual Health then coming and talking to you.

> So probably at the point where I came to a place where I knew I was looking at being—when I was being assessed as a permanent injury, that would have been the ideal point for someone to—and I would have been most capable and able to hear, "These are some things that . . . ."

Negative Encounters With Helping Professionals

Most participants have had negative experiences with professionals who were supposed to help them in adjusting to and managing their disabilities. For some women, these experiences happened very soon after SCI, and they molded and solidified their perception of helping professionals. One participant had this to say about the bedside manner of the doctor who performed surgery on her back:

> Well, you know, of course, uh [laughs], it was all quite shocking, because I didn't, you know, expect this to happen to me; and, uh, it was, uh, like an intern doctor that actually came in the day after surgery and kind of bluntly told me, you know [laughs], "This is how it's going to be. You're won't feel, you know, sex." . . . The doctor who did the emergency surgery, I'm sure he did a fine job on the surgery, but the poorest bedside manner I've ever

> had is Dr. [name of doctor.] . . . But, uh, he was terrible, like, to say the least, as far as, you know, a bedside manner. . . . I was not impressed [laughs] with him.

When participants received assistance from helping professionals in the community, they also encountered situations where their different needs were not fully accommodated or acknowledged. Women talked about having experienced situations where their emotional and physical experience of SCI was made more difficult by the way they were treated by helping professionals. Some felt that their needs were undervalued and discounted by helping professionals and that they experienced humiliation and disrespect, a regular complaint of women surveyed in other studies (Becker et al., 1997; Charlifue et al., 1992; Cole & Cole, 1993; Welner, 1997). One participant was dismayed that when she finally was emotionally ready and found enough courage to ask for help, she was set back by the treatment she received:

> It took everything I had to say to my doctor, "I am losing bladder control. This really, really bothers me." And it took me a long time to say that to him and to be told, "It's only stress." . . . The one thing I was told all along was, "If you have any problems with the loss of bowel or bladder control, that is one of the key points that you're looking for which means that there is nerve damage." . . . So I had to come to a place where I could actually say the words that I'm losing bladder control, . . . and it was brushed off.

When physical barriers (e.g., high examining tables, x-ray tables, mammogram machines) made it difficult to access health care services and they needed extra assistance, participants were treated in a manner that made them feel vulnerable, exposed, and humiliated, as this woman described:

> I've had a few horror experiences here. . . . What were they doing? Must have been doing an X-ray or something, but it was so embarrassing; it was just so embarrassing. The women didn't know what they were doing.

> They had to lift me on a table, and you usually get on the table and then take your top off. And they made me take my top off first in my chair first, and then I felt totally just— . . . And then they lifted me on the table, and they were fumbling, and they couldn't get my legs up. And you're dealing with your body; you know they're looking at your body. And it was terrible, and I just thought [sighs], Not good, not good.

They felt as though helping professionals either did not know how or did not want to assist them if they had needs differing from the usual clientele they assisted. Others have also experienced this when trying to access community-based services (Becker et al., 1997; Charlifue et al., 1992; Nosek et al., 1995; Richards et al., 1997). These two statements describe this experience:

> And sometimes they're willing to help and learn, and sometimes they seem almost reluctant to. . . . I think that [laughs] the health-care system is not as good as it used to be. I'm noticing attitudes from staff, really. . . . I think you get way more of a—it's not their fault. They're not equipped in the first place . . . say, to get you up on an X-ray table or something. It's not their fault that they're not equipped, but I think more and more they're feeling like "This isn't my job to help this person." . . . If you are the deviant client, I think, more and more, I feel anyway, I'm getting more and more of these attitudes of . . . "It's not my job to deal with this person because it's different than the norm."

> They were nice to me, but they just sort of stuck me at the back of the room and never really addressed—I would ask them a question: "Do you think this might be any different for me?" And they would just say, "We don't know" kind of thing. . . . It's not like I wasn't allowed to join, but [laughs] it wasn't all that good for me because I wasn't allowed to be different, kind of thing.

As these women have accessed or tried to access the assistance of helping professionals after their initial injury, repeated demonstrations of ineptness created for these women a perception that helping professionals lack the knowledge, skills, insight, and professionalism to be of any help to them. As a result, they had very low confidence in them and viewed them as lacking credibility, as can be seen in the following experiences:

> I've had a doctor since tell me that it was completely unnecessary for me to have had my tubes tied or a hysterectomy being that there is nothing wrong with my back that would have ever prevented me from having more children. And when I asked him what he was basing this on, because he had not seen my X-rays, had not seen my medical files, nothing; that was his . . . his opinion, his belief.

> I had one therapist who I really don't know what UFO she got off, but she said, "Why don't you tie some fishing line around your arm [laughs], onto the cane? And then if you drop it—"

> I have even had—two times I have had to go to emerg in [town], and both times different doctors argued with me that I wasn't a quadriplegic—doctors— . . . He goes, "You're not a quad because you can move your arms." And I'm like, Oh, I'm just going to die here.

The end result of these negative experiences was that trust and comfort were not established between participants and helping professionals. Communication lines were actually shut down, because they often avoided interacting with the helping professionals because of the perception that it would be a waste of their time or that they would be judged negatively. Other researchers looking at SH issues and barriers to achieving SH have also reported that their participants avoided community-based services and refrained from seeking the help of helping professionals because of very similar negative experiences (Becker et al., 1997; Charlifue et al., 1992; Chicano, 1989; Nosek et al., 1995). The following participants explained their feelings and experiences regarding their decisions about interacting with helping professionals:

> I think my biggest concern has always been the judgment issue. If I ask these questions, . . . do I think this person can give me the answers I

> need? Trust for me is a big thing. You sort of have to feel comfortable. . . . And it's taking that risk to ask that question.

> So asking for help for different issues can sometimes be not an option because of the way you'll be perceived. And that sort of makes it more difficult.

> Well, first of all, you know, he comes in and he was—you know, I have all these questions, of course, and they're in a big rush and didn't want to answer: "Well, I'll have my intern talk to you, you know, later. I don't have time for your questions," you know, and that put me off because, you know, well, I need to know what's going on here, you know.

> Even my family doctor here on the island, who doesn't have any spinal cord background, . . . I don't even bother . . . because I just think, I'm the doctor here. . . . I just figure I know me better than he does.

Expectations of Helping Professionals

The participants also had some strong opinions about how and which helping professionals could best assist them as they coped with their sexuality and SH after SCI. In reflecting on their experiences immediately after injury and over the years in the communities in which they lived, 7 of 10 participants mentioned that they either appreciated or wished that helping professionals had been proactive, taking the first step in opening up communication lines. One participant recalled that she felt encouraged to pursue her sexuality and SH concerns:

> The nurses that knew me and realized that what I wanted was, "I'm about to go out and get involved in this, and I need to know about it," . . . they came to me. There were actually two of them. They came to me and were really encouraging and really supportive. . . . But they went on. They didn't just answer my questions and walk away; they voluntarily got involved and were supportive in trying to help me to figure it out.

The participants felt that proactive helping professionals gave them permission to be sexual and have concerns, and encouraged them to share and ask questions about SH and sexuality. It helped them in establishing the trust and rapport they needed to feel safe in opening up to ask sensitive and potentially embarrassing questions. Others also supported this type of proactive encouragement to ask questions and rediscover by helping professionals, and it is often called permission giving (Becker et al., 1997; Levitt, 1980; Rieve, 1989; Thorn-Gray & Kern, 1983).

They also felt that because they experienced a great deal of "unconscious incompetence" during the time shortly after their injury and often did not know what questions to ask, it should have been the responsibility of helping professionals to be aware of this. They thought that helping professionals in rehabilitation should have been armed with and proactively offering information to them, as these individuals described:

> At the time when I was in rehab, since I didn't really know what to ask, . . . not realizing that I am injured and I will be in a wheelchair [permanently], . . . I obviously didn't have too many questions, but I think, um, rehab should be prepared for conditions like this. Like, what if the patient doesn't really know, like, how is it going to be when he or she gets out to the real world?

> Everything [laughs], everything. I just wanted them to tell me everything I needed to know basically.

Finally, some participants recalled that they were approached only once about the topic of SH and sexuality, and when they turned down the offer of information and support, the topic was never brought up again. Many felt that they were not ready to hear and accept offerings of support and information when they were presented the opportunity, or at that point in time had not been presented with a sexuality or SH concern that was important to them. This woman explained that the timing was off when she was approached about sexuality, and this has shaped her opinion about offering wellness to women after SCI:

> The whole issue of sexuality, I remember them doing an initial interview with me when I showed up at the rehab center, asking me fifty questions, probably forty-eight of which I couldn't answer. And one of them was about sexuality. I didn't have a clue, so it has a lot to do with timing.
>
> I think every aspect of rehab has to be offered again and again and again and again and again and again and again, until the individual is ready to hear and understand. Especially—that's especially important with people who are not outgoing, who are shy, who are frightened, who are ill, who are psychologically damaged. . . . Somebody has to be prepared to be accountable for asking and answering the questions for those people who don't know how to ask and answer them.

As a result, several women felt that sexuality and SH should be brought up on more than one occasion during rehabilitation to account for the readiness of the individual and to reinforce that sexuality and SH are just as important as every other aspect of adjustment after SCI. Tepper (1992) also supported offering sexuality information and support on more than one occasion and suggested that at least four sessions should be dedicated to the topic.

In addition, many participants felt that more time needed to be allowed during rehabilitation to address sexuality and SH issues. Participants felt that the opportunities they had were too short, were presented in too little detail, and left them with many unanswered questions. When asked what she would have changed about how sexuality and SH were addressed during rehabilitation, one participants said:

> I didn't get to spend much time. . . . Yes, yes, more information and stuff, yes; . . . like, even the questions that I asked them about children and just the actual . . . caring for the child, having the child, um, conceiving the child. Just more questions...because it was just like a brief half an hour that I had with her, . . . so I didn't—everything that I know is from experience [laughs]. . . . More time, . . . more information. That's about it.

Participants also felt that the range of options available to meet their specific learning needs and readiness were limited. Therefore, they advised that a number of options be formally presented to women on a number of topics so that individual needs could be met. For example, topics mentioned included carrying and delivering babies; birth-control options; self-care; self-image, self-esteem, and attractiveness; adapting sexual activity to mediate for chronic pain; how partners might react and are affected by SCI; bowel and bladder management around sexual activity; arousal, lubrication, and orgasm; and strategies for adapting sexual activities. Types of opportunities mentioned that would meet different learning and readiness needs included one-to-one discussions; small-group (fewer than 10) discussions and presentations that include peers from the community; small-group (fewer than 10) sessions that are presented separately from other "self-care" sessions; resource lists of books, credible websites, contact information for services in the community, and contact information for helping professionals in rehabilitation facilities; and newsletters that devoted to different sexuality and sexual health topics of interest to women with SCI. Offering a comprehensive range of options to address individual learning and information needs was also supported in the literature by other helping professionals and people with SCI (Levitt, 1980; Tepper, 1992).

Women who had missed out on the rehabilitation process or who did not have sexuality or SH concerns until they left rehabilitation hospitals were quick to add that inclusive opportunities for addressing sexuality and SH needs must be made more readily available than they already are. They felt that it is also the responsibility of general practitioners and obstetrician/gynecologists to ensure that community clinics proactively, not reactively address SH care needs, because that may be their only point of contact with helping professionals. They felt that these helping professionals need to become better educated about SCI, or at least aware of referral services, and need to be ready to problem-solve to accommodate the different needs of women with SCI, an expectation of women interviewed for other studies as well (Becker et al., 1997; Nosek et al., 1995; Richards et al., 1997). These participants described this expectation succinctly:

> So, okay, what would I change? I guess I'd just have more education [of helping professionals], because you're going to have us popping up everywhere, and we do need help getting up on tables, and we do need help spreading our legs and all this kind of stuff [laughs].

> So my point of contacts have been all the way along the line doctors and . . . GPs. So they should be armed with information to tell people who have spinal cord injuries or back injuries (a) who CPA is, who they serve; and (b) that there is this option. I didn't even know that I qualified to be served by CPA until [a CPA counselor] told me I did, and I just phoned them out of desperation for some help.

Limiting and Delimiting Factors

Before discussing the implications of this study for service delivery and further research, it is important to present the study limitations to provide a lens with which the reader may follow the discussion. There are two types, limiting and delimiting factors.

Limiting Factors

Several inherent characteristics of this study were outside the control of the investigator and may have affected the collection and analysis of information. First, the topic of sexuality and SH, regardless of context, is sensitive and has the potential to provoke anxiety (Charlifue et al., 1992; Thorn-Gray & Kern, 1983). This may have impacted potential participants' decisions about whether or not to discuss their sexuality and experiences in achieving satisfactory SH (Rathus et al., 1998). In essence, this may also have decreased the number of available participants for the study. Furthermore, social desirability (i.e., halo effect) may have influenced participants, causing them to disclose less or different information from the full truth if they thought the principal investigator was judging them (Kreuter et al., 1996; Willmuth, 1987). As principal investigator, I was cognizant of this, and in formulating the initial core interview questions, I worked extensively with other professionals in the area to decrease the likelihood that the questions would elicit feelings in the participants that they were being judged. Furthermore, in establishing the researcher/participant relationship, I focused more on establishing a trusting, egalitarian, peer-based relationship, rather than a relationship where a perceived imbalance in power or status could influence how candid the conversation was.

Conversely, volunteer bias may affect the trustworthiness of the study due to the fact that the sample for this study was self-selected (Willmuth, 1987).

Those who respond to volunteer recruitment campaigns tend to be more open than the general population and may even exaggerate when describing their experiences (Rathus et al., 1998). Because of this, those who agreed to become participants may not be representative of all women with SCI. I attempted to address the issue of social desirability and volunteer bias by using value-neutral terminology in the project description and recruitment notice, and throughout the interviews. Because the conversations I had with participants varied greatly in their length, candor, and detail, it is hoped that issues surrounding volunteer bias and social desirability were suitably addressed.

When a participant chose to do a telephone interview, I lost control over half of the interview setting. In other words, there was no control over the distractions or factors influencing discussion on the participant's end of the telephone line. For the most part, this was not an issue, however. One participant had several dogs in close proximity to the telephone, but because this was part of her normal environment, the dogs were more of a distraction to me than they were to her, and their presence did not seem to affect her comfort or openness with me. I attempted to proactively address this issue by setting up all interviews in advance, and asking participants to pick a place and time for the interview where they knew that they would have uninterrupted privacy (Morse & Field, 1995; Neutens & Rubinson, 1997).

As a woman with SCI, I may have placed inherent bias on the trustworthiness of the results of this study. I may have unknowingly influenced the way the study was designed, the way participants were interviewed, the themes I saw emerging, and the way the results were synthesized into this thesis. Because it has been a constant and valid concern, I have frequently mentioned attempts to raise my own awareness of this bias and to temper it through the use of several triangulation methods. Furthermore, participants were included in the analysis and verification of emergent themes at several junctures along the way, and the experiences that they spoke of were often in keeping with the findings of other researchers.

Delimiting Factors

Due to methodology decisions made by the principal investigator, the results and usefulness of this study may again have been affected in a number of ways. In choosing to use an unstructured interview format, I voluntarily gave up some control over consistency and increased the probability that I might miss gaining some information relating to participants' experiences. To facilitate consistency in interviewing and insure that important issues were not missed, I used an interview guide (Patton, 1990). What must be remembered in this study is that, in keeping with a phenomenological method, the interviewer naturally draws out important information from participants, and it is the participants who set the priorities in the conversation. Furthermore, consistency across participant accounts is not necessarily the goal in this type of research, because it proceeds based on the assumption that there is no absolute truth that can be examined outside the context in which it is perceived or experienced. Therefore, as the social context in which participants experienced the phenomena of sexuality and SH after SCI was varied, so too would be there experience of it. Also, I chose very consciously to conduct *conversations*, rather than structured interviews, specifically in an effort to increase comfort with an anxiety-provoking topic, to increase rapport and trust, and to increase the likelihood that participants would feel safe enough to disclose their experiences honestly and fully.

Using an interview format may have been perceived by some participants as compromising anonymity if they were concerned about their voice and/or physical identity being known to the principal investigator. For this reason, I gave participants options to protect their identity even more than standard consent and interview procedures do, such as the option of doing a telephone interview instead of a face-to-face interview.

Other researchers in previous studies have focused on premorbid sexual behavior, satisfaction, and relationships (Richards et al., 1997), and it was regrettable that I did not do so in this study. It would have been useful to compare pre- and postmorbid experiences of sexuality, SH, SHP opportunities, and relationships of these women, especially in deciphering how closely their experiences were tied to their experience of disability or whether their experiences were moderated by premorbid experiences. A few participants did talk about their pre-SCI experiences, however; and where it emerged as a theme, it was described in this study.

Several other themes linked to SH and sexuality were not explored in any depth in this study. One area not pursued was an accounting of participants' sexual activities, preferences, and the frequency with which they engaged in such activities. Although other studies have obtained this data, they employed different research methods than I did, and gained this information through the use of surveys that asked multiple choice and forced choice questions specifically about sexual behaviors of respondents (Tepper, 1992). Because of the method I chose, I let participants prioritize and lead the conversation, and I consciously gave up the ability to ask very specific questions of this nature. However, because the participants in this study did not focus on specific sexual activities and focused instead on relationships, coping with change and ambiguity, interactions with others, emotions, and psychological experiences, perhaps specific sexual activities were not the primary concern of the group of women whom I interviewed.

Another experience not mentioned by participants was that of abuse, sexual or otherwise. Although others have tackled this in their research (Tilley, 1996), it did not emerge as important in this study. While this may be because of the shame and stigma that often surround abuse, it could also be the case that abuse was not something the participants in this study experienced. Again, in accordance with a phenomenological approach, since the women I interviewed did not bring it up, other than to say that they would not stay in relationships where they were pitied, it is assumed that abuse was not an experience that the women in this study deemed important enough to mention.

Although brief definitions of sexuality and SH were given to participants in the information letter they received prior to participating in the study, I did not follow that up by defining it again for them, or asking them to give me their definition of SH and sexuality. Furthermore, in several conversations, participants seemed to use a very narrow definition of sexuality. In other words, they equated sexuality with the physical act of intercourse, other sexual activities that often surround intercourse, and the ability to orgasm and perform sexual activities. Conversely, other participants, particularly women who had been living with SCI for at least five years, seemed to use a more broad definition of sexuality and SH. They seemed to reflect over their journey in adjusting to SCI, and expanded upon the physical definition of sexuality and sexual health to include emotional, social, and spiritual components, such as body-image, self-esteem, being cherished and valued by partners, satisfaction with the life roles they enacted, and feeling as though they fit into the world they lived in as "normal" women. This diversity in definitions among participants could have impacted the consistency with which they framed their thinking as we talked throughout the conversations, and thus may have impacted the trustworthiness of the results (Willmuth, 1987). However, in an effort to let participants define themes and priorities in a phenomenological inquiry, I did not want to force a definition of sexuality and SH upon participants that was not theirs. It was also not the aim of this study to necessarily uncover patterns in behavior or attitude, and as such it is not assumed that the divergence among participants with reference to definitions of sexuality and SH should be cause for great concern.

CHAPTER V

IMPLICATIONS, SUGGESTIONS, AND SUMMARY

Implications for Service Delivery and Clinical Practice

Although a textbook could be written on how to improve the SHP opportunities available to women after SCI, only improvements related to the experiences of participants in this study will be discussed here. While the women in this study were mostly satisfied with the support they received surrounding reproduction and fertility, they indicated dissatisfaction with the amount of attention paid to almost all other areas of their sexuality and SH, and the lack of choices offered that met their needs. In order to more comprehensively address the SH needs of women after SCI, several strategies need to be integrated into a comprehensive plan for offering valuable SHP opportunities in rehabilitation settings:

1. Offer gender specific support that is detailed and offered in women-only settings, no matter how few women might potentially benefit from it.

2. Separate issues of reproductive capacity from with sexuality, as marriage of these two issues may propagate the myth that women's sexuality is less impacted by SCI than that of men (Perduta-Fulginiti, 1992; Weinberg, 1982; Whipple et al., 1996; Zwerner, 1982).

3. Offer choices that respect individual learning styles, morals, and readiness so that women with SCI can have their specific needs addressed in a way that makes them feel positive about themselves and sexuality, and encourages them to rediscover their sexuality (Levitt, 1980; Mihelich Hogan,

1982). Choice and control should be reflected in both the topics covered and the modes of service delivery.

4. Offer SHP more than once to address the timing and readiness issues which participants addressed.

5. Prepare helping professionals for probability that they will meet women who do not know what questions to ask, and encourage them to proactively offer support, information, and affirmation surrounding SH and sexuality.

Many participants of this study also commented that they were not ready when information and support were offered and that they tended to have more questions and interest in SH and sexuality once they left a rehabilitation setting. Also, a large portion of participants did not enter a rehabilitation facility at all and, as a result, were not introduced to the rehabilitation process. Because participants experience the above phenomenon, it is suggested that formal opportunities for addressing SH be offered in an outpatient setting, perhaps as outreach from the rehabilitation team when they do post-discharge follow up. For those who do not access formal rehabilitation, community health care providers and SCI organizations should be made aware that these opportunities exist, and they should be able to refer patients to them.

Given the negative and traumatizing experiences that some participants have had in accessing SHP, a better effort should be made to increase the SCI knowledge and professional skills of community helping professionals around SCI and to change attitudes toward the responsibility to provide accommodations and service (Gamel et al., 1993). Further, they need to be made aware of the perception that many women may have of their inability to help and should work towards eliminating that stereotype by being proactive and willing to learn about and accommodate differences and by treating women as partners and experts in achieving their own health outcomes. Community providers also need to be prepared to serve a large number of people with SCI who have never accessed any formal supports after injury (i.e., rehabilitation hospital) or who have just begun to rediscover their sexuality and are unaware of their needs, options, and abilities (Gerhart et al., 1992).

Finally, there was an overwhelming support from participants that peer support is both highly valued and sorely lacking, in rehabilitation settings and in the community at large. For those in rehabilitation settings, peer support from those with sexual and relationship experience needs to be offered to provide women with credible support and affirmation at a time when their sexual identity and future is ambiguous (Tepper, 1992). For women living in the community, peer networks need to be better facilitated by advocacy and service organizations, because it was reported that there are few opportunities to meet and derive support from other women coping with similar issues. As these women have few opportunities to interact with peers in their daily lives, these opportunities are viewed as extremely valuable.

Suggestions for Further Investigation

After reviewing the literature and going through the learning trajectory that one always does in qualitative research, there are now several suggestions for further study. First, in terms of practicing triangulation and further insuring rigor, using a combination of qualitative research tools might be valuable. For example, a combination of journal writing, interviews, and analysis of web-based bulletin boards could be employed to add to the richness of a description of the phenomena experienced.

To further develop the idea of how women experience sexuality and SH after SCI, this study could easily be followed up with a grounded theory study (Glaser & Strauss, 1967), in which the phenomenon is further explored and themes are expanded on in such a way that theory to explain the phenomenon is generated. This then would expand the knowledge base and allow other researchers to further attempt to replicate and hypothesize about what specific factors impact the experience of sexuality and SH after SCI.

There are several questions that were not answered in this study or through a review of the literature that warrant further investigation. First, future research could focus more on comparing pre- to postmorbid experiences and attitudes towards sexuality and SH, so that a more complete picture can be painted of the impact of SCI on sexuality and SH. Second, not one research article discussed the experience of being a lesbian with SCI, and no participants in this study indicated anything other than a heterosexual orientation. It would be interesting to see if there is a difference between heterosexual and homosexual women in the pursuit of optimal SH and sexuality. Third, future investigations need to look at the quality of relationships between women with SCI and their partners. In looking at the literature on the impact of SCI on heterosexual partnerships, the studies reviewed seldom mentioned partnerships where the woman had SCI. Those that looked at this milieu most often looked at the health and well-being of female partners of men with SCI (Kester, Rothblum, Lobato, & Milhous, 1988) or at the relationship issues of men with SCI (Yoshida, 1994). When a mixed-gender approach was taken in examining partnerships after SCI in two studies, only 20% of participants in these studies were couples in which the woman had SCI (Kreuter et al., 1998; Kreuter et al., 1994). Although this is representative of the distribution of women versus men with SCI, it was disappointing that there were no comprehensive studies focusing solely on partnerships in which the female has SCI and the impacts that that has on the partnership. Furthermore, in the above-mentioned studies, researchers even acknowledged the questionability of any conclusions about partnerships in which women had SCI, simply because the sample of male able-bodied partners in their studies was so small (Kreuter et al., 1998; Kreuter et al., 1994).

Summary

Although research and practice in the general areas of SH and SHP are no longer in their infancy stage, attention to the SH and sexuality of women with SCI is lagging behind. In order to empower women with SCI to take responsibility in achieving satisfactory SH, they need to be included in strategic planning of SHP opportunities in rehabilitation and community settings. Women with SCI need to be seen as experts in their own right and encouraged to speak freely and candidly about their experiences. In order for research and resulting practice to be meaningful and useful, women with SCI themselves must establish themes and set priorities for achieving their own SH and well-being and, as a result, improved quality of life.

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APPENDIX A

INFORMATION LETTER FOR PARTICIPANTS

(Printed on University of Alberta, Centre for Health Promotion Studies letterhead)

Title of Project: Exploring the Experiences of Women with Spinal Cord Injuries in Addressing Sexual Health Issues During and After Rehabilitation

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April 27, 2000

Dear Participant:

I am completing a Masters of Science degree in Health Promotion at the University of Alberta, and would appreciate your help with a small study to learn more about the experiences that women with spinal cord injuries (SCI) have had in having their sexuality, sexual health and relationship needs addressed, both during and after rehabilitation. Sexuality and sexual health are a major part of who a person is, and for some people, these can be affected by SCI. There is not a lot of information in this area for women with SCI, and it is an area that we need to learn more about.

While you read this information letter, it might help to understand what I mean when I talk about sexuality, sexual health, and sexual health promotion opportunities. What I mean by the word sexuality is "the ability to develop warm, sensitive and intimate relationships with others". It can include the ability to be physically and emotionally close to a partner, and to do the things that are enjoyable for you and your partner. Your sexuality is also the way you feel about your body and yourself as a woman. It is also the way you feel about the relationships you have with other people in your life.

When I use the term sexual health, I mean your ability to make informed choices about your sexuality and reproductive health. This includes knowing how to get your needs met if you have questions and concerns about your sexuality and reproductive health.

Sexual health promotion opportunities includes many things. It includes any information you have gotten about sexuality and/or disability. It also includes any time that you have gotten treatment for an emotional or physical problem with your sexuality or sexual and reproductive health.

In my study, I will be interviewing women between the ages of 18 and 45 who have had SCI for five years or less. I will ask you about the following things:

Any concerns and questions you have had about your sexuality and sexual health during and after rehabilitation;
Any sexual health promotion opportunities you may have received or had a chance to use;
How you felt about those sexual health promotion opportunities;
How you think the sexuality and sexual health needs of women with SCI could be best addressed.

Although you will not benefit directly from this research, your experiences and thoughts could improve future sexual health promotion opportunities available to women with SCI. Also, if questions come up about your sexuality and sexual health, this may be a good chance to have them answered.

My study will consist of a one-hour tape-recorded interview that can be done over the telephone or at a place that you feel is comfortable and private. After this first interview, I may need to contact you again for more information or to make sure I have understood you correctly. This second interview should take less than one more hour.

Although quotes from your interview may be published, they will be anonymous. Your identity will remain anonymous, and I will use a number in place of your name. The information from your interview will be kept in a locked file cabinet that only I have access to. The interview information will be kept for a period of at least seven years after the study is completed, and after that, it will be destroyed. All information will be held confidential except when professional codes of ethics and/or legislation require reporting. At any time during the interview you have the right to refuse to answer any and all questions, and you can stop your participation at any time, without penalty or negative effects. You may also prohibit the use of your information, again without penalty or negative effects.

Although there is no physical risk to you if you get involved in this study, you may be reminded of unpleasant experiences and feelings. If you do have questions or concerns that you want answers to, I can provide you with the opportunity to speak with someone who works in sexual health care.

A research paper will be written, called a thesis, reporting the results of all the interviews conducted. I will provide you with the chance to read any quotes I use in my thesis so that you can decide whether or not I can use them in my writing. You are welcome to a finished copy of my thesis, and can get a copy from me.

If you would like to participate in the study, but do not want me to know your telephone number or name, you can call me at the number above, and we can set up a time that you can call me to do the interview.

If you have questions or concerns, please feel free to contact me or my Thesis Supervisor, Elizabeth Taylor, using the information at the beginning of this letter. If you have concerns about how this project is being done, you may also call Dr. Helen Madill, and her number is also on the front of this letter.

Thank you for your time and consideration in this important project.

Sincerely,

Margaret MacCabe

Encl.

APPENDIX B

RECRUITMENT ADVERTISEMENTS

Request for Research Participants: Exploring the Experiences of Women With Spinal Cord Injuries in Addressing Sexual Health Issues During and After Rehabilitation

When a woman becomes spinal cord injured (SCI), life changes! I am a student completing a Masters of Science degree in Health Promotion at the University of Alberta. As part of my degree requirements, I am interested in learning more about the experiences of women with SCI with SCIs of less than 5 years in getting sexual and reproductive health needs met during and after rehabilitation. I will be doing interviews of about one hour, either over the phone or at locations of the participant's choice. I will also follow up this interview with another one of about an hour to verify the information I get in the first interview. Questions will only be as in depth as the participant chooses them to be. As a participant, your identity will remain anonymous, and you will be assigned a number in place of your name. Any quotes used will also be anonymous. If you would like to participate, but do not want to give out you name or phone number, arrangements can be made where you call me at the number below to do the interview. Also, if you wish to stop the interview at any time you may do so, and direct that your information not be used. You will also be provided with information and the names of people to contact in case you feel the need to talk to someone after the interviews are completed. The information you give will be used in the writing of a research paper, and to make recommendations about how sexual health services can best be provided for women with SCI. If you are interested in participating in this important study, please call and leave a message at (780) 492-8661, or email me at mmaccabe@ualberta.ca.

APPENDIX C

INTERVIEW GUIDES

Interview Guide 1 (Used from February-April 2000)

1) Tell me about yourself (to gain rapport, increase comfort and ease into conversation):
- Marital status, now, and at time of injury
- Family composition
- Age and gender
- Onset of disability
- Nature of disability

Objective One: to gain insight into the importance of sexual health and sexuality after SCI.

2) I'd like to talk a little bit about the thoughts and feelings you had about sexuality while you were in rehabilitation.
   a) When you were in the hospital, what thoughts did you have about your sexuality and relationships?
   b) Tell me how you felt at that time?
   c) Before you knew that sexual health services were available, tell me what expectations you had about your sexuality?
   d) Once you left rehab, how did those thoughts change, if they changed at all?
   e) Once you left rehab, how did your feelings change about sexuality, if they changed at all?
   f) Once you left rehab, how did your expectations change about sexuality, if they changed at all?

3) Tell me a little bit about what questions you had during and after rehab about sexuality and relationships that you wanted answers to.
   a) What was the most concerning or important to you?
   b) How did it make you feel to have those questions in your mind?

Objective Two: to gain insight into what sexual health promotion opportunities women with SCI receive after injury or diagnosis.

4) Now I'd like to know about the kinds of people you have talked to about sexuality and relationships during and after your rehab.
   a) Who spoke to you while you were in rehab about sexuality and relationships?
      i) What were those experiences like?
      ii) When did it happen?
      iii) Where did it take place?

        - iv) What did you think about it?
        - v) How did it make you feel?
    - b) What kinds of people have you spoken to since rehab about sexuality and relationships?
        - i) What were those experiences like?
        - ii) When did it happen?
        - iii) Where did it take place?
        - iv) What did you think about it?
        - v) How did it make you feel?
    - c) If no one spoke to you first about sexuality during rehab, tell me how you found out about sexuality and how your disability affected it?
        - i) Who did you make a point of talking to while you were in rehab, or after rehab? (for example, a professional person, a partner, a friend, or another person with a disability).
        - ii) When did you decided that it was time to find out about your sexuality?
        - iii) What made you decide to contact the people you did?

5) I'd like to hear a little more now about what you learned about sexuality and your disability?
    - a) What did you learn?
    - b) When did you receive this information?
    - c) How did you happen to learn about it?
    - d) What did you think about what you learned?
    - e) How did this information make you feel?

Objective Three: to learn about the opinions and feelings of women with SCI about the opportunities they may or may not have used or had access to.

6) What is your opinion about those sexual health services that you used or knew were available?
    - a) What did you expect from the sexual health services available to you?
    - b) What was the best about them?
    - c) What are some of the things that you disliked
    - d) What are some things that you thought could have been done better?

Objective Four: to learn from women with SCI how to provide sexual health promotion opportunities that are easily accessible, taking into account various barriers that are internal and external to women with SCI.

7) Now I want to find out about the things that made it more or less difficult for you to get answers to any sexuality and relationship concerns you may have had.
    - a) Tell me about what made it easy for you to get answers to your questions about relationships and sexuality?
    - b) How could it have been made easier for you to have those concerns answered?

    c) Tell me about what things made it difficult or uncomfortable for you to find out the answers to your questions about sexuality and relationships?

8) I would now like you to think about how you think sexual health services should be provided to women with SCI.
    a) In your opinion, when is the best time or stage to discuss sexuality and relationships after SCI?
    b) What is the best way to get answers to questions about sexuality?
    c) What is your preferred method of having questions about sexuality and relationships answered?
    d) How can others best address sexuality and relationship concerns of women with SCI?
    e) In terms of different people, whether they're professionals or peers, or any variety of people that come to mind, who would you be most comfortable talking to about sexuality and relationship concerns?
    f) What types of people would you be uncomfortable talking to?

What other comments or questions do you have to ask me? What have I left out or missed that you think is really important?

Interview Guide 2 (Used from April-September 2000)

1) Tell me about yourself (to gain rapport, increase comfort and ease into conversation):

- Marital status, now, and at time of injury
- Family composition
- Age and gender
- Onset of disability
- Nature of disability
- What do you do?

How has SCI changed the way you live your life?

Objective One: to gain insight into the importance of sexual health and sexuality after SCI.

2) I want you to think about your sexuality and close relationships like a pie with four parts: an emotional part (feelings about yourself, your competence, attractiveness-feelings about your partner, how you think they feel about you, how you think others see you); a spiritual part (feelings of belonging and connections with others, closeness); a physical part (the way our bodies look, feel and work on their own, with others, etc.), and an intellectual part (the knowledge base we have and share with others, the level at which we relate to others, what we know about ourselves). How did these parts of the pie changed for you after your injury/diagnosis?

3) Tell me a little bit about what questions you had during and after rehab about sexuality and relationships that you wanted answers to.
   a) What was the most concerning or important to you?
   b) How did it make you feel to have those questions in your mind?

4) I'd like to talk a little bit about the thoughts and feelings you had about sexuality while you were in rehabilitation.
   a) When you were in the hospital, what thoughts did you have about your sexuality and relationships?
   b) Tell me how you felt at that time?
   c) Before you knew that sexual health services were available, tell me what expectations you had about your sexuality?
   d) Once you left rehab, how did those thoughts change, if they changed at all?
   e) Once you left rehab, how did your feelings change about sexuality, if they changed at all?
   f) Once you left rehab, how did your expectations change about sexuality, if they changed at all?

Objective Two: to gain insight into what sexual health promotion opportunities women with SCI receive after injury or diagnosis.

5) How was rehabilitation/community care geared towards your needs as a woman?

6) I'd like to hear a little more now about what you learned about sexuality and your disability?
    a) What did you learn?
    b) When did you receive this information?
    c) How did you happen to learn about it?
    d) What did you think about what you learned?
    e) How did this information make you feel?

7) Now I'd like to know about the kinds of people you have talked to about sexuality and relationships during and after your rehab.
    a) Who spoke to you while you were in rehab about sexuality and relationships?
        i) What were those experiences like?
        ii) When did it happen?
        iii) Where did it take place?
        iv) What did you think about it?
        v) How did it make you feel?
    b) What kinds of people have you spoken to since rehab about sexuality and relationships?
        i) What were those experiences like?
        ii) When did it happen?
        iii) Where did it take place?
        iv) What did you think about it?
        v) How did it make you feel?
    c) If no one spoke to you first about sexuality during rehab, tell me how you found out about sexuality and how your disability affected it?
        i) Who did you make a point of talking to while you were in rehab, or after rehab? (for example, a professional person, a partner, a friend, or another person with a disability).
        ii) When did you decided that it was time to find out about your sexuality?
        iii) What made you decide to contact the people you did?

Objective Three: to learn about the opinions and feelings of women with SCI about the opportunities they may or may not have used or had access to.

8) What is your opinion about those sexual health services that you used or knew were available?
    a) What did you expect from the sexual health services available to you?
    b) What was the best about them?
    c) What are some of the things that you disliked
    d) Given the opportunity, what would you have changed?

Objective Four: to learn from women with SCI how to provide sexual health promotion opportunities that are easily accessible, taking into account various barriers that are internal and external to women with SCI.

9) Now I want to find out about the things that made it more or less difficult for you to get answers to any sexuality and relationship concerns you may have had.
    a) Tell me about what made it easy for you to get answers to your questions about relationships and sexuality?
    b) How could it have been made easier for you to have those concerns answered?
    c) Tell me about what things made it difficult or uncomfortable for you to find out the answers to your questions about sexuality and relationships?

10) I would now like you to think about how you think sexual health services should be provided to women with SCI.
    a) In your opinion, when is the best time or stage to discuss sexuality and relationships after SCI?
    b) What is the best way to get answers to questions about sexuality?
    c) What is your preferred method of having questions about sexuality and relationships answered?
    d) How can others best address sexuality and relationship concerns of women with SCI?
    e) In terms of different people, whether they're professionals or peers, or any variety of people that come to mind, who would you be most comfortable talking to about sexuality and relationship concerns?
    f) What types of people would you be uncomfortable talking to?

What other comments or questions do you have to ask me? What have I left out or missed that you think is really important?

APPENDIX D

SAMPLE OF THOUGHT PROCESS USED IN DATA ANALYSIS ONCE INTERVIEWS HAVE BEEN COMPLETED

- Step 1-Gestalt
  - Read each entire transcript.
  - Go through them again, underlining statements where participants described a particular process, experience or opinion.
  - Also underline statements that seem to reoccur within and between transcripts.
- Step 2-Labeling
  - Label the statements with 2-3 word descriptor, so similar statements can be grouped together later.
  - In this instance, many participants seemed to mention that they were unprepared to address sexuality immediately after injury.
- Step 3-Sticky notes
  - Going through the transcripts again, I write the statements and their short labels that I have previously highlighted onto recipe card-sized sticky notes.
  - As I do this, I again check the statement against the transcript to see if the statement still fits with the descriptor I originally gave it, or if another descriptor I used elsewhere seems to fit better.
    - At this point I also go back to participants to verify that the statements fit with the labels or themes I have assigned to them.
- Step 4-Clusters of sticky notes
  - As I go through the transcripts a fourth time, I now pull out and group together the sticky notes that have similar descriptors like the following:
    "sex on the back burner"
    "fighting fires"
    "survival mode"
    "overwhelmed"
    "no time or energy for sex"
    "no time for concerns about sex"
- Step 5-Index sheets
  - At the top of a blank page, I leave half of it empty, and begin putting the similar sticky notes onto the page(s).
  - In the blank space, I write all of the descriptors so I can examine them all at the same time, looking for a thread of similarity running through them.
- Step 6-A theme is born
  - It turns out that seven participants mentioned this issue, and the theme is accepted, as it meets the criteria I set out earlier (i.e. at least three participants had to bring up this issue, before it would be accepted as valid).

- Here are a few examples of similar statements, with the descriptor in brackets:

  "...when I went as an outpatient, they gave me a binder to take home, and it did cover, you know, some information in there...but that was so long ago, and it was at the beginning of this...you kind of read through it all, but...you've just begun this...change, and it doesn't really all sink in, and so I can barely remember some of the stuff I read in there now, you know [laughs], because at the time you're just so overwhelmed with everything, and the change and having to, you know, do the cath routine and the bowel routine. Like, that's sort of the main concern for a while." (sex on the back burner-just fighting fires-overwhelming change)

  "To tell you the truth, at the time I was—like, even my mind was kind of in a shock still...So the only thing was kind of survival for me, so in a way I did not really have so many questions in the rehab..." (trying to survive and become independent)

  "So I don't think I spent a lot of time thinking about it, because things happened fast. I had my rehab; I was focused on that...That kind of consumed me. The whole bowel thing was quite the...getting some kind of a routine or whatever if you will...I would say that consumed me...I wasn't thinking any farther than I wanted to live on my own...and then kind of take it from there...Yes, I don't think I was thinking any farther than that." (fighting fires-just focusing on surviving and becoming independent)

  "...when I left, I couldn't even lift my own legs...I couldn't even get myself in the shower...I had way more concerns than—worrying—I had to worry about me before going to have sex or whatever." (fighting fires-survival mode)

- Now I look at the descriptors and pick one that seems to best summarize the experience that the participants spoke of: Fighting Fires stands out the most.

❖ <u>Step 7-Comparing themes</u>

- After going through all the index sheets and deciding upon theme titles, I go to the index sheets where less than three participants shared an experience, and I look to see if that experience fits in with any of the other themes.
- If an experience does not fit, I discard the theme. For example, only one participant thought it was really important to offer basic AIDS education to women after SCI, and this did not really fit into any other theme, so it was left out.
- Finally, I compare all valid themes to one another looking for threads of similarity again, and I group similar themes together into categories. "Fighting Fires" fit best into "Sexuality and SH Concerns After SCI".

APPENDIX E

SAMPLE NARRATIVE

C95 Narrative

At the time of our interview, C95 was 20 years old, single, and had no dependants. Only 2 years earlier in a motor vehicle accident she sustained a complete spinal cord injury at the levels T2-4. So C95 really is new to the experience of SCI and is just beginning to feel out who she is as a woman with SCI. In short, C95 seems to still be in a process of comparing her abilities and identity now to the way she lived, thought, and interacted with people before her injury.

Initially after her SCI, C95 did have a partner, and at first she was comforted by the thought of having a close partner who would understand and be there through such a life-altering event. Because of this, she was not overly concerned about sexuality and relationships. However, this partner faded quickly from the picture, and this stirred up new anxieties and questions for C95. Was she still desirable? Who would want to do "that" with a paralyzed person? How could she really be an intimate partner if she couldn't do things the way she used to?

While in rehab, C95 was only approached once by a sexual health nurse and spent about half an hour talking. The nurse covered what another participant has called "the plumbing talk," reassuring C95 about her reproductive capabilities. She also went a little further to suggest strategies for adapting sexual activities to maximize success and enjoyment in rediscovering sexuality, but this was brief. C95 had more questions after this and wished that she had had more opportunities to learn more. She would have also preferred that the nurse offer a few more structured learning opportunities, such as videos, written information, or discussion on specific topics. However, even this one encounter was very reassuring to C95, because it reconfirmed that she was desirable and sexual and that this was not a part of life that was over. Also, she was relieved to learn that conception and motherhood were just as likely to happen to her after SCI as they were before, depending on her choices.

Although she said that she wished more time and information had been given in regards to sexual health during her rehab experience, C95 admitted that she was more ready to take in the information after she left rehab and was back in the community interacting with the people she used to. During rehab, she was just fighting fires and was almost completely focused on learning to be independent. Because of this focus, she was often very fatigued and just didn't care about sex.

In reflecting back on her experience in rehab, C95 had high expectations for health professionals around her. In terms of sexual health, she expected them to have the knowledge and expertise to fully assist her in adapting to disability. She expected that they would tell her all that she needed to know in order to properly adapt, make decisions for herself, and understand how things might or might not work after SCI. She was pleased that sexual health was included in her total care plan. She said that it was easy to ask questions because the service providers were readily available and right there in her rehab facility, and they made the first contact to discuss sexuality.

Although opportunities to address sexual health were naturally occurring in rehab, now C95 said that the greatest barrier to achieving sexual health was meeting with others in the community who have SCI or who have the ability to answer her questions, especially because she lived in a rural community. Additionally, C95 had not yet been in an intimate relationship since her SCI and had no concept of how her own body might function, how she might interact with a sexual partner, or even how a partner might respond to her. What this created was a series of "what ifs" and "hows" that are only beginning to be answered.

At this point in C95's life, what seems the most important and concerning to her seems to revolve around being a desirable partner to someone else, being choosy about who she will get close to, and eventually being a good parent to children who may enter her life. Although these concerns are not uncommon in the able-bodied population, they are definitely amplified and complicated by SCI.

Below are some quotations from our conversation that I liked and may want to use in writing my thesis. Behind each quotation in brackets is a description of the idea or theme that I think it represents. Each quotation will be used exactly as it appears here, unless you direct otherwise.

"I thought it had been okay because I had somebody there, but after that it's kind of like, kind of went all downhill from there because it's, like, who'd want to do that with me, you know?" (Illustrates how it is easier to cope when a partner is there to support you, and also shows anxiety about being a desirable sexual partner to others)

"I was with him before, . . . and now it's like, try and find somebody that will be there and understand my situation, . . . like, how to, how to do it [laughs], . . . like intercourse and stuff like that." (Illustrates anxiety about finding a partner who will understand and accept disability)

I: "What is the most concerning or important to you?"

R: "Um, probably just the actual performance, . . . just the actual, you know, . . . how would I be intimate, you know? How would I react in that kind of situation?" (Illustrates concern over "how to" and "what if" questions)

"Well, I was just right at the [hospital], and she kind of, not forced it on me, but kind of, she flashed the idea at me." (Illustrates the preference that health professionals take the responsibility to start the discussion about sex and that they are not pushy about it)

"But what makes it hard is to meet people. . . . Like, who do I talk to? I don't know who I talk to. I mean, I live in [town]." (Illustrates lack of resources and peers in the community to share with and ask questions of)

"Probably I think it would be easier if I was out of rehab for one thing. . . . Because I was just so busy, and like, even if she flashed the idea again at me, it's like, six hours of therapy; I wanted to lay down; I didn't want to go to no more meetings. . . . Just didn't care." (Illustrates that sex was on the back burner during rehab; you were just in survival mode)

"When I left, I couldn't even lift my own legs. . . . I couldn't even get myself in the shower. . . . I had way more concerns than—worrying—I had to worry about me before going to have sex or whatever." (Illustrates the "fighting fires" or survival mode concept)