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# “Don’t Think Paralysis Takes Away Your Womanhood”: Sexual Intimacy After Spinal Cord Injury

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## MeSH TERMS

- interpersonal relations
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- women

Sexuality and intimacy are important components of health and well-being. Issues surrounding sexuality and intimacy are equally important for men and women living with physical disabilities, including spinal cord injury (SCI). Yet, women’s sexuality after SCI remains largely unexamined. This article presents the findings from an in-depth qualitative investigation of the sexual and reproductive health experiences of 20 women with SCI in or around Detroit, MI. Findings echo existing literature documenting the sexual consequences of life after SCI and suggest new areas of inquiry important for better addressing sexual concerns across the lifespan. Specifically, findings suggest a need to consider the variable effects of SCI on sexual intimacy in relation to a person’s developmental trajectory, the appropriate timing of sexual education, the need to expand conceptualizations of sexual intimacy, and the ways SCI may affect sexuality in later life.

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In 2008, the American Occupational Therapy Association (AOTA) classified sexual activity as a meaningful and valued activity of daily living that contributes to one’s sense of self. In 2013, AOTA published a consumer fact sheet, “Sexuality and the Role of Occupational Therapy” (MacRae, 2013), which officially solidified the profession’s role in facilitating clients’ participation in the expression of human sexuality. *Sexuality* is a broader term than *sexual activity* and includes physical, emotional, and sociocultural dimensions; it encompasses intimacy, sex, reproduction, gender identity and roles, reproductive capacities, and sexual orientation (World Health Organization, 2002).

Although various health conditions can affect sexuality, the sexual consequences of suffering a spinal cord injury (SCI) can be substantial, especially because the majority of SCIs occur during the years when reproductive and sexual capacities are at their peak. Addressing a client’s sexual concerns is important because having positive sexual experiences after SCI is strongly linked to psychological well-being and quality of life after injury (Anderson, 2004; Cramp, Courtois, & Ditor, 2013; Esmail, Knox, & Scott, 2010). The interrelationship between disability and sexuality is particularly salient for women with SCI, who the literature suggests engage in partnered sexual activity after injury at higher frequencies than their male counterparts (McCabe & Taleporos, 2003) and identify regaining sexual function as a higher priority than do men with SCI (Anderson, 2004).

Despite the importance of sexuality to psychological well-being and quality of life, the topic of female sexuality after SCI remains understudied across the disability and rehabilitation literature (Cramp et al., 2013; Parker & Yau, 2012), in part because SCI occurs overwhelmingly in men, not women. Approximately 270,000 Americans currently live with SCI, and an estimated 12,000 new injuries occur each year; however, 80.7% of all injuries occur to

men (National Spinal Cord Injury Statistical Center, 2013). Although the epidemiology of SCI as a man's injury has certainly shaped the literature, some have argued that the lack of attention to the health of women with disabilities is a result of their status as a "minority of minorities," being women *and* disabled persons (Anderson, Borisoff, Johnson, Stiens, & Elliott, 2007; Deegan & Brooks, 1985). Moreover, women with disabilities are often seen as asexual and nonreproductive and, hence, are denied access to sex education; reproductive information; and gynecological services, including annual exams and birth control (Becker, Stuifbergen, & Tinkle, 1997; Dillaway & Lysack, in press).

These issues should be of concern to occupational therapy practitioners, yet research on the topic of sexuality and severe disabilities is scant. With a few exceptions (e.g., Miller, 1984; Sakellariou & Simo Algado, 2006; Taylor, 2011), the body of existing literature on this topic primarily consists of opinion papers about whether sexuality is under the purview of occupational therapy (Couldrick, 2005; Pollard & Sakellariou, 2007) or studies of practitioners' or students' views of addressing sexuality with their clients (Couldrick, 1999; Penna & Sheehy, 2000). Consequently, a paucity of research examining female sexuality after SCI remains. For example, little is known about how sexuality or sexual intimacy is defined (or redefined) after injury, how people draw satisfaction from their sexual experiences, the dynamics that affect their decisions to engage (or not) in sexual experiences after injury, and how they obtain information about sexual function after SCI.

A more complete understanding of women's sexuality after SCI may assist in developing evidence-based strategies for addressing barriers to sexuality for women with severe physical disabilities such as SCI. In light of the gaps in the literature, the purpose of this article is to explore women's perspectives on sexual intimacy after SCI by analyzing in-depth interview data from 20 women with SCI.

## Method

### *Design and Procedure*

With few exceptions, the understanding of women's sexual experiences after SCI is based on survey research, lab-based research, or write-ups of clinical practice (Whalley Hammell, 2007). Thus, we lack knowledge on how women with SCI actually define sexual intimacy or how they determine the possibilities for sexual intimacy and satisfaction after SCI. This study used a phenomenological approach,

which is appropriate for the exploration of topics about which we know little (Brown, Sorrell, McLaren, & Creswell, 2006; Creswell, 1998). Specifically, we used in-depth semistructured interviews with women living with SCI ( $n = 20$ ) in or around Detroit, MI. The study was approved by the Wayne State University institutional review board, and all research participants gave their informed consent before data collection. Each woman received \$35 at completion of the study interview.

### *Participants*

We recruited the participants for this study from an original interview study that included both men and women and focused on issues of access to health care and independent living ("Community Living After Spinal Cord Injury: Models and Outcomes"; National Institutes of Health Grant No. R01 1HD43378). Participants in this previous study agreed to be contacted for future research; therefore, the list of participants from the previous study became a sampling frame for the current study. Inclusion criteria for the women in this study were as follows: diagnosis of SCI, community dwelling, and willing and able to discuss reproductive concerns. We conceptualized *reproductive concerns* broadly to include diverse reproductive experiences (e.g., menopause, childbearing, menstruation, birth control, and pap smears) to better understand reproductive health across the lifespan.

### *Data Collection and Measures*

Each woman completed a single in-home interview, lasting 2–3 hr on average. These in-depth ethnographic interviews (Spradley, 1979) included questions about overall health and physical functioning, accessibility of doctor offices, interactions with health care providers, gynecological health-seeking behaviors, sexuality and sexual behavior, and complementary and alternative medicine use. Study interviewers (two research team members) were able-bodied and had more than 7 yr of experience conducting interviews in the context of women with disabilities, including SCI, and received additional training about gynecological and sexual health interviewing from the first author (Fritz). Training coupled with familiarity with this study population ensured that key topics discussed during interviews were recognized and pursued with additional probing questions but were also dealt with sensitively.

### *Data Analysis*

Study interviews were audiorecorded, and one of the four research team members transcribed them. Analysis began

with the authors closely reading all the interview transcripts to identify major patterns and thematic categories. Major ideas were noted and formed the basis for early discussions about the most important data revealed in response to the study questions.

Once agreement was reached on the set of major patterns and themes, each transcript was systematically reviewed and coded by multiple coders with the goal of identifying instances of each pattern and theme and assigning each a descriptive label, or code. This step involved the traditional method of cutting and pasting from interview transcripts in accordance with each topic and code (Creswell, 1998).

Overall, our work followed a *constant-comparison method* of analysis (Glaser, 1978), which involves comparing and contrasting data with each new section of data and coding and recoding data as patterns and tentative interpretations emerge. For the purposes of this article, we initially extracted data that involved the experience of sexuality and eventually recoded data by whether it dealt with educational access, self-definitions of sexuality, physical or social hindrances to sexual activity, or the connections between life stage and timing of injury and sexuality. Early findings were shared with 1 woman in the study, and discussions with her helped us finalize our analysis. This *member checking* is a common method of establishing validity in qualitative research (see Creswell, 1998).

The rigor of qualitative studies is determined by the criteria of credibility, dependability, confirmability, and transferability (Lincoln & Guba, 1985). *Credibility* and *dependability* are demonstrated by a thorough description of the data collection and analysis process. *Confirmability* is achieved by convincingly showing how the results were derived from the data (i.e., using participants' direct quotes). *Transferability* of the findings implies that the insights gained from the work can be beneficial in other contexts.

## Results

### *Participant Characteristics*

The average age of the sample was 46 yr (range: 27–66 yr), and the average time since SCI was 19.5 yr (range: 3–41 yr). Just more than half (55%) of the 20 women had paraplegia, and the remainder had tetraplegia. Automobile accident and pedestrian–auto accidents were the most common cause (60%) of SCI, followed by gunshot wounds (20%). Slightly more than half of the interviewees (55%) were European American/White, whereas

8 (40%) described themselves as African American/Black and 1 (5%) self-identified as multiracial. The majority of the sample (65%) had at least a high school education. The major source of income in this sample was Social Security disability, but 2 women (10%) worked in paid part-time employment. Nearly all (85%) had some form of health insurance. Table 1 presents an overview of study participant characteristics.

### *Perspectives on Sexual Intimacy*

Priscilla (age 57, 39 yr after SCI) made it clear that being paralyzed does not mean that sexual intimacy is taken away from her and that women with SCI are able to enjoy their womanhood:

Don't think paralysis takes away your womanhood because you don't feel sex anymore; it doesn't. First of all, you're a woman, you're pretty, and you're able. The point is to have the self-confidence to realize that you haven't changed so much, other than your paralysis.

Moreover, despite the physical limitations that SCI might bring, most women in our study still desired and engaged in intimate acts and relationships and saw sexual intimacy as an important part of their lives.

All the women in the sample considered themselves heterosexual; however, ideas widely diverged about what sexual intimacy meant. Participants emphasized different physical, emotional, and relational characteristics depending on their life stage, personal situations, and prior sexual experiences. For instance, Kendra (age 31, 14 yr postinjury) viewed sexual intimacy as an essential human need and desired behavior that was, in her mind, physiologically necessary for stress relief. She said, "A lot of stress will be relieved from my body. It's intimacy and penetration and that kind of stuff." Janet (age 55, 40 yr post-SCI) had never engaged in sexual activity after injury, aside from kissing, but still defined sexual intimacy in terms of behavior. When asked how she would define sexual intimacy, Janet replied, "I really don't know for sure; when your body parts are really involved with each other?" However, Terry (age 40, 13 yr postinjury) and Candace (age 57, 40 yr postinjury) understood the concept in more social and emotional terms, describing sexual intimacy as "just having a normal life, a married life, and being able to smile" and "it means making love, the closeness and all of the good things that go with it," respectively. Thus, sexual intimacy was more about a general state of well-being and the "normality" of stable sexual relationships for some, whereas it was understood as a much more narrowly defined set of physical behaviors for others.

**Table 1. Participant Characteristics**

Participant	Age, yr	Children	Marital Status	Yr Since SCI	Self-Reported Injury Classification
Cora	27	None	Never	10	Tetraplegia
Alicia	29	None	Never	13	Paraplegia
Kelsey	31	None and pregnant at time of SCI	Married	9	Tetraplegia
Rachel	36	Before SCI	Never	7	Paraplegia
Allison	37	Before and after SCI	Separated	9	Paraplegia
Kendra	31	Before SCI and pregnant at time of SCI	Divorced	14	Paraplegia
Simone	39	Before SCI	Never	7	Tetraplegia
Terry	40	Before SCI	Married	13	Paraplegia
Damita	44	After SCI	Never	25	Paraplegia
Stacie	48	After SCI	Never	17	Paraplegia
Justine	48	Before SCI	Divorced	5	Tetraplegia
Nina	55	Before SCI	Married	6–8 <sup>a</sup>	Paraplegia
Janet	55	None	Never	40	Tetraplegia
Mallory	56	Before SCI	Divorced	2	Tetraplegia
Priscilla	57	After SCI	Married	39	Paraplegia
Candace	57	After SCI	Married	40	Tetraplegia
Idell	58	Before SCI	Married	24	Paraplegia
Lana	58	None	Never	40	Tetraplegia
Mabel	58	Before SCI	Divorced	26	Tetraplegia
Lena	66	Before SCI	Married	17	Tetraplegia

Note. SCI = spinal cord injury.

<sup>a</sup>Progressive spinal cord disease.

### Satisfaction With Sexual Activity

**Relationships.** Regardless of participants' personal definitions of sexual intimacy, 15 (75%) reported wanting to be more sexually active than they currently were. Five women reported being satisfied with their current level of sexual intimacy, of which 2 were not sexually active at the time of the study and 2 women had never had sex. Dissatisfaction with level of sexual activity was noted in interviews with married as well as unmarried women; therefore, having an established partner did not always ease these feelings. Terry's comments suggested that being married does not ensure complete satisfaction of sexual desires. When asked the question, "Are you as sexually active as you'd like to be?" she answered, "No, but nobody is, OK? Especially us women, OK? I'd always like more, but you know my fiancé is getting old." She answered the follow-up question, "And so it's not your choice that you're not as active as you'd like to be?" by saying, "No, I think it's the age of him—age 51."

Not unlike able-bodied women, women in our study reported that partners' desires and abilities to engage in sexual behavior sometimes limited their own abilities to be sexually satisfied. In these cases, it was not women's SCI status that limited them but, rather, their relationship situation.

Some women were also dissatisfied with their sexual lives because of the lack of a partner. For example, Cora (age 27, 10 yr postinjury) expressed wanting to have

a husband and children but had not had a partner since injury (partially because of the nature of her high-level injury). Justine (age 48, 5 yr postinjury) also described being married before and at the time of injury but then going through a divorce after her SCI. Justine did not blame her divorce solely on her injury; she said that she was also the primary caretaker for her mother with Alzheimer's disease and that caregiving put a strain on her marriage. Ultimately, however, relationship dissolution led to a lack of sexual intimacy and sexual dissatisfaction at the time of interview.

**Physical Barriers Related to Spinal Cord Injury.** In addition to relationship issues, physical issues related to SCI also affected interviewees' satisfaction with their current sexual lives. SCI-related conditions, including pain, weakness, fatigue, pressure ulcers, sensory loss, and lack of bowel and bladder control, were discussed in our interviews as reasons for participants' dissatisfaction with sexual intimacy. The lack of bowel and bladder control was especially problematic for women who were developing new intimate relationships. We use lack of bowel and bladder control as an example here because participants explained that penetration, or simply orgasm, could result in embarrassing bowel and bladder accidents. The most poignant example of this struggle came from Damita (age 44, 25 yr after SCI), who explained the impact of her bowel and bladder issues on reengaging in sexual activity after injury:

It was 8 years later before [I had sex again], and I really wrestled with that. It wasn't because I didn't want to. It was because I didn't think a guy would be interested in having sex with me, and then I was dealing with complications like bladder management problems. When you're engaging in something like that and your bladder just lets out, or your bowels, you know, it's embarrassing! And that happened even during the course of my sexual activity, and that was very painful.

Women in our sample perceived that physical barriers to sexual activity were more consequential for women with SCI than for able-bodied women. For example, when Lena (age 66, 17 yr postinjury) was asked, "Do you think that your reproductive health experiences are different from other women's?" she responded, "Most definitely, yeah." When asked to clarify, Lena explained, "Well, when you're 'normal,' you can make decisions about loving each other and whatever. Does that make sense? . . . It's just the fact that you don't always feel well and that affects all of this [referring to sex]." Lena viewed able-bodied women as having more freedom to make decisions about sexual intimacy. For some women with SCI (particularly those with higher level injuries and more comorbidities), decisions about whether to "love each other" and engage in sexual activity could be dictated by physical issues, despite sexual desire.

*Faster Aging Process.* Aging bodies could also hinder sexual intimacy; thus, the impact of physical disability on sexual intimacy sometimes changed over time for women in our sample. Participants believed that women with SCI "age faster" than able-bodied women and that they experienced age-related barriers to sex at an earlier age than their able-bodied peers. Idell (age 58, 24 yr postinjury) explained, "I was always told that, and things that I've read, that spinal cord injury basically ages you 10 years." The middle-aged women in our sample reported that fatigue was a major age-related barrier to sexual activity. For example, Candace rated her overall level of functioning as excellent but, when asked specifically about her participation in sexual activity, replied, "No. I'd like to do more. It's just at our age you get tired!" Similarly, Lena expressed that "In the beginning [I was satisfied], but it became harder and harder with some of my injuries." Lena believed that because of her age, she had experienced more pressure ulcers and prolonged healing times, which had negatively affected her sexual activity. As discussed previously, Priscilla mentioned how her "womanhood" was important to her despite her paralysis and her age, but she went on to say that aging did make it harder to stay sexually active. Although aging has an impact on the sexuality of all women (disabled or not),

a "faster" aging process may uniquely affect women with SCI as they try to maintain sexual lives.

In the face of these challenges, some participants coped with reduced sexual intimacy by revising their expectations and redefining what intimacy meant to them. For example, Damita explained that physical penetration during sex became less important to her over time and that she and her partner focused instead on alternative ways to show their affection:

Well, at this point in my life, it isn't just the, you know, the [sex]; it's also an emotional thing. It's a common response for women with spinal cord injury. It's just wanting to be intimate, you know, holding hands, being held—it's that kind of thing. I think that's where I am at this point—it's not just the act itself.

### *Sexual Education After Injury*

*Lack of Education.* Lack of support and education about sexual activity also contributed to the challenges faced by participants in our study. The women discussed their difficulties learning what sexual positions would be feasible with their particular level of injury and how to adapt positions to accommodate functional declines across their lives. For example, Stacie (age 48, 17 yr postinjury) was afraid that she would not be able to maintain a sexual relationship because of her inability to manipulate her body. She stated, "I thought I'd never have sex again. You know, you're just not the same person in the way that you manage yourself physically [during sex]." Only Idell reported receiving any education during SCI rehabilitation regarding participation in sexual activity. Idell, fortunate that her physician was prepared to address her questions regarding sexual activity, stated,

Right off the bat, my O-B G-Y-N doctor . . . would bring up the sexual talk. He would say, "You know, there are other means of satisfaction . . . if you ever want to talk to kind of get a man's perspective. I know those things [about how] to satisfy your husband and all this other stuff." Yeah, well, women, I think, are always more "kissy" anyways . . . they always want to be more affectionate [and have] more "romance."

Idell's experience was an exception. For the majority of the women in the sample, "sexual education" after injury focused solely on informing women that they could still become pregnant and on recommending appropriate birth control options. Thus, women and their partners were left to engage in trial and error as they attempted to develop sexual intimacy after injury. Although this approach worked for some of the women, it resulted in negative experiences for others. Justine

provided a negative example when discussing her attempt at sexual activity with her ex-husband. Justine received no information regarding sexual intercourse; consequently, she and her spouse were uncertain whether it would be safe to have sex. She stated, "I have no sensation; he and I tried once, but it wasn't productive—he was afraid he was going to hurt me. I think that was the first and last time [having sex before the divorce]." For Justine, this negative sexual experience left her reticent about further intimacy. Her husband was also concerned, which jointly limited their incentive to engage in intimate behavior. They lacked basic information about how to maneuver a body with SCI, and sexual education would have helped this situation.

Women in the study also reported that education about how to deal with very particular SCI-related conditions during sexual activity is also needed. Damita said she had always had questions about how to broach the topic of possible bowel and bladder accidents with a new partner or how to modify the environment to accommodate these physical issues during sex. She suggested that these questions have been left unanswered by medical providers. These and other participants' statements draw attention to the complicated nature of sexual activity after SCI and the dearth of information and support available to assist people with SCI in their sexual lives.

*Timing of Sexual Education.* The life stage of participants and their level of adjustment to their injury affected how ready and interested they were in education about sexual intimacy and the types of concerns they reported about their sexual lives. Directly after their injuries, the majority of study participants were informed that they could still become pregnant. Nonetheless, they had many reasons why they were not ready to process such information. For example, Kelsey (age 31, 9 yr postinjury) described how she was unable to focus on sexual education at the time of injury (at age 22) because of other more pressing medical concerns: "I think they wanted me to be on birth control. I wasn't sexually active at that time. I was in a nursing home. Why would I [have sex]?" Priscilla was injured at a stage in her development (age 18) when sex had not yet become a concept of interest. She had not been sexually active before her injury and described her reaction to being offered advice on birth control options as follows: "I went to a Catholic high school, . . . so sex doesn't exist. And then you got someone who is just happy to be alive and going to school, and I'm not even thinking about boys or sex or anything like that."

Some participants were injured at even younger ages; thus, addressing sexual education in the initial rehabilitation phases did not make sense for them. However,

sexual education would have been useful later, after they became an adult with SCI and learned to live with their disability. Participants' comments illustrated that information about sexual activity should be considered within the context of clients' developmental stage, their prior experiences engaging in sexual activity, and their level of adjustment to the SCI. Some participants, such as Kelsey, had engaged in sexual activity before injury but had more immediate medical concerns directly after injury and did not want to hear information about a potential reproductive or sexual life at that time. Again, in her case, sexual education at a later date, after adjustment to the injury, would have helped.

*Connections to Reproduction.* For many of the women in our study, experiencing an SCI during peak reproductive years created challenges to childbearing. Therefore, developing intimate relationships and being engaged in sexual activity were associated with starting (or expanding) a family. Three women were pregnant at the time of their SCI, and 2 lost their unborn children as a result of the injury. Slightly more than half (11, or 55%) had not had children before injury, perhaps contributing to why issues surrounding motherhood and childbearing were of particular concern after injury. Damita explained,

I know one of my greatest concerns right after my injury wasn't so much about walking but whether I could be a mother or not. And I think that would be another interesting study. . . . I remember asking the doctor, "Can I still have children?" To me, that was far more important than being able to get back on my legs.

For Damita, becoming a mother was a valued and culturally normative role synonymous with "womanhood." She was 1 of only 5 women in the study who became pregnant and had a child after the injury. For women such as Damita, sexual intimacy was not separate from her desire for motherhood. Other women, such as Justine, Idell, and Terry, were finished having children at the time of injury; therefore, sexual intimacy after injury had nothing to do with reproduction. Because of the varied reproductive lives of the women in our sample, and because time of injury could come before, during, or after reproduction decisions, it appears that sexual education for women with SCI needs to take into account their reproductive life stage to be relevant.

### *Sexual Confidence*

Women in our study who were not sexually active or did not have a committed partner before their injury provided examples of how they faced additional challenges to developing a sexual identity and sexual confidence and

participating in meaningful sexual relationships. Ultimately, SCI can greatly alter a person's sexual identity and sexual self-esteem. Identity and self-esteem issues can further complicate a person's efforts to date potential partners or develop new intimate relationships. Becoming confident and learning to see oneself as a person worthy of love and intimacy were precursors to developing a healthy sexual self after injury. However, becoming accepting of oneself involved coming to terms with the physical changes caused by SCI and having the confidence to try to engage in intimate relationships and sexual behavior. For example, Stacie recounted how she had to "come to terms" with herself before dating and engaging in sexual activity after her SCI:

I thought I'd never have a relationship again. I thought I'd never have sex again. And finding somebody who is sensitive enough to be there for the need is a challenge. And you have to have enough confidence to allow yourself to go there, too, so I have to be all right with me in order for people to be all right with me. You know, 'cause the shock value when they see you, it's like, "Oooh . . . myyy . . . God, she's so pitiful," you know?

Although Stacie became more comfortable with her injury and learned how to develop the confidence to pursue intimate relationships and motherhood after her SCI, she explained how she remained somewhat guarded until she got to know a potential partner better:

You develop ways, I mean . . . it takes a while 'cause you gotta talk about it . . . and make sure they're OK with it. You know, because when people see, especially guys, guys are visual, so they see you, they are curious. They think you're pretty, you know, thank you. So I talk, you know? And I talk and I talk because I have to develop a level of confidence with what's happened to me. I can talk and we can be friends, but once it's time to get serious, then a wall goes up a little bit, 'cause it's like, What does he want, where is he coming from, what does he want?

Other people's initial reactions could have inadvertently affected Stacie's sexual self-esteem if she had not already come to terms with her changed body. Unfortunately, many women in the study faced societal perceptions of women with disabilities as asexual beings every day and struggled to resist internalizing such perceptions. Damita stated,

I think the hardest thing that I've had to come to grips with is that people look at me as an asexual being. . . . I just think it's a common response to women with disabilities. For example, you and I could be walking

down the street and my kid is with me, and they'll probably think that my kid is your kid, you know, 'cause they think, "How could she have sex?" It's implied.

In another part of her interview, Damita also discussed how unfeeling and uncomfortable American society is in thinking about physical intimacy and disability. Several women in the study discussed how physical interactions that are common in social interactions with able-bodied women (general touching, a hug, or a pat on the shoulder) are extremely uncommon for women with SCI. Damita suggested that the result of this pervasive aversion to physical contact with people with SCI is "emotional deprivation," which contributes to women's lack of confidence about sexual intimacy over time:

I think that's a huge problem in our culture . . . the lack of touch, the lack of hugging . . . even if it's not just with a partner but just in general [with family and children]. But that emotional deprivation is a problem because of the lack of touch, the lack of feel . . . not just among women but among men [with SCI] as well. . . . I think that's something that really needs to be dealt with. I know we've got surveys on dealing with sexual intimacy, but what about that touch? It doesn't have to be sexual . . . but it's physical intimacy. I think it's a great lack among people with spinal cord injury or even just those with disabilities.

Participants' narratives illustrate the diversity of sexual experiences after injury as developmental stage, timing of the injury, impact of the disability, and sociocultural and physical body challenges intertwine to complicate sexual activity. Yet, as cases such as Priscilla, Damita, and Stacie show, these challenges are not insurmountable. Women in the study were mostly desirous of sexual intimacy and thought of themselves as capable of leading sexual lives. However, to appropriately address the concerns women in this study raise, occupational therapy practitioners must take into account the diversity of sexual experiences and meanings associated with sexual intimacy.

## Discussion

Findings from this study demonstrate that sexuality remains important after SCI and draw attention to the widely divergent and evolving sexual education and support needs of women after injury. Despite this diversity across the sample, women in the study wanted more education about sexual intimacy after SCI. Occupational therapy practitioners are uniquely suited to support a client-centered approach to sexual education (MacRae, 2013). However, although studies have indicated that practitioners realize that their

clients are sexual beings, few actively pursue addressing sexual concerns (Anderson et al., 2007; Couldrick, 1999). Moreover, although women in this study received occupational therapy as part of their rehabilitation, they did not report receiving any education or assistance regarding sexuality from the occupational therapy staff.

One possible reason for not offering sexual education to clients with SCI is that some clinicians may be uncomfortable broaching the topic of sexuality with their clients (Couldrick, 1999, 2005). Moreover, sexuality after injury is a relatively new area of inquiry (Consortium for Spinal Cord Medicine, 2010), and the paucity of empirical research may limit clinicians' abilities to develop evidence-based sexual education programs for both training occupational therapy practitioners and assisting clients. However, our study findings provide some insight for addressing women's sexual concerns after SCI. Specifically, findings support the need for a lifespan perspective when addressing sexual participation, including the consideration of the developmental stage of the woman, her prior sexual experiences and relationship status, her desires for the future (e.g., marriage or family planning), and the changing nature of physical and social challenges across time.

Study findings also draw attention to the multiplicity of definitions of *sexual intimacy*, suggesting that sexual education should also encompass those different meanings. Existing research on women's sexuality has largely focused on how to facilitate "heteronormative" modes of sexual intercourse, including alternative means of achieving female orgasm through penetration and stimulation of (nonvaginal) erogenous zones and through the use of visual aids or fantasy to increase arousal (Courtois et al., 2011; Kreuter, Taft, Siösteen & Biering-Sørensen, 2011; Rembis, 2010). However, findings suggest that for many women, especially in the context of aging bodies, the act of sexual penetration may become less important. Expanding the conceptualization of what it means to be sexually intimate to include the "closeness," "kissy," and more romantic side of sexual lives and fostering the woman's sexual self-esteem appear to be equally important for developing and maintaining healthy sexual lives.

Another important finding is the connection between sexuality and family planning and motherhood. Although existing research has documented the challenges that mothers with disabilities face (Becker et al., 1997; Dillaway & Lysack, 2014), little research has examined the decisions that women with disabilities make about sex and birth control that are ultimately the precursors to motherhood. Therefore, it appears that sexual education for women

with SCI should also take into account women's reproductive life stage to be applicable. For women without a romantic partner at the time of the SCI, the timeline for having children and starting a family may be delayed. Although able-bodied women may face similar challenges, as Damita's case demonstrates, adjusting to the physical changes after SCI and developing the confidence to initiate new intimate relationships may take years.

Study findings also draw attention to the fear and uncertainty that existing romantic partners can experience when engaging in sexual activity after SCI. Considering Justine's case, it would be pertinent to include (when appropriate) the romantic partner in discussion of sexuality after injury so that both partners become more comfortable with exploring sexual possibilities. These findings are echoed in existing disability literature that suggests that through human encounters, people with SCI reconstruct their occupational identity and their need for participation in occupations (Isaksson, Josephsson, Lexell, & Skär, 2007). Similarly, through human encounters, women with SCI can restructure their sexual identities and desires for sexual intimacy after injury, and occupational therapy practitioners can play an integral role in the process.

## Limitations and Future Directions

We cannot generalize the findings of this small-scale pilot study; however, they suggest that additional areas need to be explored further. Future research could examine the intersection of aging, sexuality, and SCI and the ways sexual experiences before injury affect the development of sexuality after injury. In addition, it would be fruitful to examine what constellation of educational strategies best prepares women to address their sexual concerns. For example, is it sufficient to deliver didactic education alone, or might some women benefit from additional strategies such as scripts or role playing to address social challenges to sexual intimacy and initiating relationships? Finally, our sample included heterosexual women only. Further research should examine the sexual concerns of gay, lesbian, and transgendered people with disabilities, whose experiences remain understudied in the literature on disability and sexuality.

## Implications for Occupational Therapy Practice

As sexuality is acknowledged as an important part of health and well-being, it will be increasingly important for occupational therapy to actively address sexual concerns

across the lifespan. This study has the following implications for occupational therapy practice that support the role of occupational therapy in addressing sexual concerns:

- Occupational therapy practitioners can develop sexual education programs that are tailored to the client's life stage-specific sexual desires and goals.
- Occupational therapy scholars and practitioners can incorporate strategies into sexual education programs to increase sexual self-confidence and relationship-building skills.
- Occupational therapy practitioners (including faculty, staff, and students) can engage in reflective dialogue and advocacy for addressing the unique sexual concerns of underrepresented populations in the literature such as women and gay, lesbian, and transgendered people with severe physical disabilities. ▲

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