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Sexual Health Disparities in Women with Spinal Cord Injury: Implications for Life Care Planning

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Women with spinal cord injury may have questions regarding sexuality, fertility, and intimate relationships. As spinal cord injury more commonly affects men, many areas of female sexuality are often overlooked. This article highlights the ways life care plans, health care services, and health care providers for women with SCI may be impacted by social stigmas, disparities in research and practice, and the patient's sexual identity. Life care planners should consider addressing these factors before and during the development of a plan to provide an accurate and comprehensive plan for the individual. Sexuality and reproduction should be a large consideration during both life care planning and rehabilitation of women with SCI.

Spinal cord injury (SCI) occurs at a rate of 12,000 new cases per year (National Spinal Cord Injury Statistical Center (NSCISC), 2013). Of these cases, 19.3% of these injuries occur in women, which has increased from 18.2% in studies prior to 1980 (NSCISC, 2013). Cases of SCI are predominantly male and issues specific to women may be overlooked, especially topics that are perceived as sensitive such as sexuality (Jackson & Wadley, 1999).

Sexual pleasure and a desire for intimate relationships do not end following onset of a spinal cord injury. Unfortunately, the misconception exists that women with physical disabilities, including spinal cord injury, are asexual and lack the desire for intimacy (King, 2012). When physical disability is presented in a sexually positive way, health care providers can work to dispel the myth that women with a physical disability have little to no sexual interest. Unfortunately, this stigmatization has influenced the care provided by clinicians and the services they recommend to women with disabilities (Ballan & Frayer, 2012). Sexual desire, fertility, pregnancy, childbirth, and healthy intimate relationships remain a reality for women with spinal cord injury. There is room for growth in the field of life care planning to analyze and include these topics when preparing a life care plan. The life care plan provides an organized, concise map for current and future needs with associated costs for individuals who have experienced catastrophic injury or have chronic health care needs (Weed & Berens, 2010). Topics that are covered under a life care plan often include projected evaluations, projected therapeutic modalities, diagnostic testing/education assessment, wheelchair needs, wheelchair accessories/maintenance, aids for independent function, orthotics/prosthetics, home furnishings/accessories, drug/supply needs, home/personal/facility attendant care, future medical care-routine, transportation, health/strength maintenance, architectural renovations, potential complications, future medical care/surgical intervention, orthopedic equipment needs, and vocational/educational needs (Weed and Field, 2001).

Sexual intimacy is an important part of relationships, and therefore sexual counseling should be considered under the projected evaluations and projected therapeutic modalities as a key part of the life care planning process following the onset of an SCI. The process should include open discussions between clinicians, women with spinal cord injury, and their partners regarding sexual functioning. In fact, counseling is an important aspect as emotional, physical, and sexual abuse are more commonly reported in women with disabilities (Ferres, Megias, & Exposito, 2013; Winkler, Weed, & Berens, 2010). Although sexual expression and reproductive health are an integral part of the rehabilitation process, there are few clinicians who are comfortable discussing these issues with patients with disabilities (Consortium for Spinal Cord Medicine, 2010).

While coping with life changes such as adaptation to a disability or using a wheelchair, many areas of self-identity must be redefined and accepted. Sexuality must exist in a fluid state, which allows it to be defined in the context of their disability and left open to redefinition as life progresses. A systematic review discussing functional recovery in males and females with spinal cord injury found that sexual function is considered one of the top priorities (Simpson, Eng, Hsieh, and Wolfe, 2012). There is also a link between subjective quality of life and sexual health in people with physical spinal cord injury. Eighty-three percent of people with spinal cord injuries stated an improvement in sexual function would lead to an improvement in their quality of life scores (Anderson, Borisoff, Johnson, Stiens, & Elliott, 2007).

Social Stigmas

The idea that women with disabilities are defenseless also perpetuates the problem that sexual health concerns may be overlooked. People with disabilities face greater barriers than physical challenges, including society's beliefs regarding their sexual behaviors (King, 2012). By promoting an increased sense of self, self-esteem, and self-identification, women with disabilities can be empowered to break the cycle of being systemically devalued by the dominant powers in our society. When considering women with physical disabilities and sexual health, the power dynamics and relationships associated with women must not be overlooked. Within the patriarchal systems of male dominance, women are often seen as the weaker sex, reliant on others, and emotionally unstable (Weber, 2010). When coupled with a disability, women may feel self-negation, a form of internalized oppression. Weber (2010) defines self-negation as an acceptance and belief of the dominant group's negative ideology by members of the subordinate group, which leads to self-imposed limits on their lives. The idea that women, people with disabilities, or even people in a lower position in the economy are lesser than others has been justified, excused, and accepted as the norm due to the enforcement and continuation of the dominant group ideology (Weber, 2010).

Fortunately, there has been a strong resistance to disability-related oppression. The Americans with Disabilities Act (ADA) resulted from a robust movement working toward enforcing civil rights and prohibiting discrimination among those with disabilities. The ADA set the stage for the empowerment, social justice, and forward progress among people with disabilities, while actively challenging the dominant culture's social, political, and ideological oppression (Winter, 2003).

Disparities in Research and Practice

According to the literature on spinal cord injury, a gap exists between the amount of research available on sexual health for women when compared to men. The Center for Research on Women with Disabilities (CROWD) stated that a large variety of sexually-related treatments were created to help men with erectile dysfunction, but little has been done to help with sexual function in women with disabilities. Even with advancements set forth by the ADA, women with disabilities are greatly disadvantaged in regard to care when compared with women without disabilities. A study by Celik and colleagues (2014) interviewed women with spinal cord injury and found that all women in the study were open to receiving information about sexuality after their injury, but assumed the health care provider would begin the conversation rather than waiting for them to inquire.

Many women struggle to understand how SCI will affect their sexuality and have concerns regarding obtaining the proper contraception (Becker, Stuifbergen, & Tinkle, 1997). Oral contraceptives may have adverse effects, and health care providers should discuss these risks and all other options with patients who wish to avoid pregnancy (Greydanus, Pratt, & Patel, 2012). Deep vein thrombosis (DVT) is associated with SCI due to immobility; therefore contraceptives containing estrogen, including oral contraceptives, the patch, or the ring, may possibly be contraindicated, but an individualized treatment plan must be designed for each patient (Kaplan, 2006; McKinney, 2013). Over 70% of women report using contraception post-injury, with most common methods being condoms, sterilization, and oral contraceptive pills (Consortium for Spinal Cord Medicine, 2010). Anderson and colleagues (2007) found in a study of women with SCI that the most common method of contraception used was hormonal methods; however, it is also important to note that over 41% of the participants reported that they were using no birth control at all.

In addition to hormonal contraceptives, intrauterine devices (IUDs) and barrier methods should be considered. IUDs are long-term contraceptives and come in two forms, one with hormones and one without any hormones. Unfortunately, IUDs have been associated with a higher risk of pelvic inflammatory disease. This is especially problematic for women with SCI as decreased pelvic sensitivity can reduce perception of pain, which can be a sign of infection or expulsion of the IUD (Consortium for Spinal Cord Medicine, 2010; Becker, Stuifbergen, & Tinkle, 1997). These devices also require manual dexterity to evaluate string placement monthly. Barrier methods, such as condoms, provide contraception as well as protection from sexually transmitted diseases. These methods require physical dexterity and mobility in one partner, and fe-

male condoms require pelvic muscle tone to control placement and prevent movement (Kaplan, 2006).

While healthcare providers are essential in the discussion regarding contraception methods for women with SCI who wish to prevent pregnancy, they also play a key role in the conversation about fertility, conception, pregnancy, and childbirth. Pregnancy remains a reality for women with SCI, as most women have no changes to their fertility (Winkler, Weed, & Berens, 2010). Concerns may exist for the woman when determining conception methods, such as natural fertilization, intravaginal and intrauterine insemination, gamete transfer, sperm injections, and in vitro methods (Winkler, Weed, & Berens, 2010). Interprofessional team support involving the obstetrician, midwife, and physicians to provide patient-centered prenatal care is essential in preparation for a healthy pregnancy (Camune, 2013). In a qualitative study by Tebbet and Kennedy (2013), many women with spinal cord injury reported that the experience of childbirth was positive and straightforward, and support provided from professionals and partners was important during both pregnancy and childbirth. These women reported that the kindness and confidence received from healthcare providers helped calm them and made them feel confident in managing childbirth (Tebbet & Kennedy, 2013).

Sexual Identity

Research is also lacking in women of non-heterosexual orientation, those who are lesbian, gay, bisexual, or transgendered (LGBT). Women with disabilities may feel marginalized by the dominant culture's view of what is sexually normative; another misconception that needs to be dispelled is that all women with disabilities are heterosexual. Lesbian women with disabilities are a minority within a minority (Basson, 1998). In a study utilizing the Washington State Behavioral Risk Factor Surveillance System (BRFSS), it was noted that lesbian (36%) and bisexual (36%) women reported higher rates of disability than did heterosexual women (25%) (Fredriksen-Goldsen, Kim, & Barkan, 2012). Weber (2010) states that lesbians face sexual orientation and gender discrimination and oppression in the workforce by being paid less and having higher amounts of poverty. These rates of oppression would be exponentially increased if this woman also had a disability, in this case going from a minority to a double minority. Although not specific to women, one study on treatment of patients with physical disabilities states that 79% of clinicians have never considered that their patients may be lesbian, gay, bisexual, or transgendered (Burch, 2008). Burch (2008) found that only 44% of healthcare providers for those with spinal cord injury reported 'full respect' for the LGBT population. Sexual orientation is an important factor to consider when discussing sexual health of women with disabilities as clinicians making heterosexual assumptions of patients may reduce or deny care to them, either consciously or subconsciously (Burch, 2008). In a qualitative study of lesbian women's experiences with healthcare, many of the histories spoke of instances where the doctor became brutal, prejudiced, or uncomfortable after the patient disclosed their sexual preference (Bjorkman & Malterud, 2009).

Due to the advances and availability of childbearing options, non-traditional families are becoming more common, increasing the number of lesbian-led families (Wojnar & Katzenmeyer, 2014). Previous research indicates that lesbian women report struggling with heteronormativity in the healthcare field, including issues with insensitive treatment (Gartrell & Rothblum, 2014). In a longitudinal descriptive study in which lesbian birth mothers were asked about stigmatization and discrimination, all interviewed women and their partners reported concerns about raising a child in a lesbian-led family and the impact of homophobia (Gartrell et al, 1996; Gartrell et al, 1999; Gartrell et al, 2000). Fostering a culture of inclusion within the healthcare system will serve to reduce serious health risks and the disparate patterns should be investigated further (Fredriksen-Goldsen, Kim, & Barkan, 2012).

Sexuality and sexual orientation are integral elements of social structure and a source of personal expression and identity (Weber, 2010). The rights of people with disabilities to express sexuality and sexual orientation have been largely ignored by the cross-cutting political institution and suggest that a discussion is needed to push this topic to the forefront of the disability rights agenda (Fraley, Mona, & Theodore, 2007).

Exploitation is far more common in oppressed groups. When two inequalities, such as gender and disability, intersect with one another, the significance of the interaction may be magnified (Weber, 2010). Observations have been made that women with disabilities are ignored and underrepresented by both the women's movement and the disability movement, which has left them marginalized and exposed to increased experiences of violence (Chenoweth, 1996; Plummer & Findley, 2012). Women with physical disabilities have quadruple the rate of reported sexual abuse compared to other women and this population reports a higher incidence of physical violence in families, institutions, and across society (Ferres, Megias, & Exposito, 2013; Lubbers, Nuri, Brakel, & Cornelije, 2012). Ballan and Frayer (2012) found that the perpetrator of sexual abuse was most commonly reported as husband or intimate partner, who often acts as caretaker. Women with disabilities may experience multiple types of abuse, which may include: preventing access to mobility devices (such as wheelchairs),

withholding medications, personal care neglect, and prevention of doctor's office visits (Plummer & Findley, 2012).

Power relationships and dominant culture ideals may become more obvious in women with disabilities who have been sexually or physically abused. King (2012) mentions dominant-subordinate relationships in regard to sexual abuse by stating that it is common for societies to accept and even promote violence by men, especially within a society that is sexually repressive. Traditional gender roles support male sexual coercion as the norm and lead our society to accept sexual and physical abuse as a direct extension of the power struggles and dominant ideals in our society (King, 2012). In women with disabilities, the risks are higher for many types of abuse, including physical, emotional, and even sexual abuse, than that of women without disabilities (Young, Nosek, Howland, Chanpong, & Rintala, 1997). This violence is not strictly an extension of violence against women, but an intersection of the constructs of gender and disability (Ballan & Frayer, 2012). When oppressed groups suffer, with regard to less access to care and, in this case, higher rates of violence and abuse, it is obvious that something is wrong with the societal atmosphere. Utilizing and learning from the experiences in this group can lead to less exploitation for all (Weber, 2010).

Life Care Planning Considerations

Sexuality and reproduction should be a large consideration during life care planning and rehabilitation. Physicians and nurses should facilitate conversation before the patient has left the hospital. Victimization of women with SCI should be something of which providers are aware and partners of these women should be including in sexuality counseling. For younger women, family involvement may be important, as parents do not usually speak with their daughters about sexuality and sexual activity (Becker, Stuifbergen, & Tinkle, 1997). Some patients may be more open to discussing sexuality issues, while others may be more reserved.

Sexuality counseling and sexual issues should be considered before and during the development of a life care plan. Depending on the recommendation, sexual issues may be highlighted within different sections of the life care plan such as within the future medical care routine portion of a life care plan. The Veterans Administration recommends that individuals with SCI receive future functional evaluations, including evaluations on sexuality (Deutsch, 2008). These topics may also be discussed under the sexuality counseling section of the life care plan. For example, in a sample life care plan and case report for an 18-year-old woman with C6/C7 tetraplegia, sexuality education was provided in a group session with a counselor and video format, and sexual counseling was left up to the patient to initiate when she was ready (Deutsch, 2008).

The Consortium for Spinal Care Medicine published a list of clinical practice recommendations for healthcare providers to address sexuality and reproductive health in individuals with spinal cord injury. These recommendations include discussing sexuality openly through the treatment continuum, using a non-judgmental attitude when discussing sexual orientation and gender identity, and ensuring that sexual expression of individuals in rehabilitation settings are treated with respect (Consortium for Spinal Cord Medicine, 2010). These recommendations also included topics that are specific to women, including discussion of previous victimization, discussion and testing for sexually transmitted infections, importance of annual gynecological examinations and cancer screenings, and information about peri-menopause and menopause (Consortium for Spinal Cord Medicine, 2010).

Women with a history of victimization, abuse, or rape may have concerns in regard to how sexuality information is presented. For example, women who have experienced abuse may be more receptive to a female counselor or healthcare provider, or may shy away from group counseling (Consortium for Spinal Cord Medicine, 2010). The history of the patient should be taken into consideration when preparing the sexual counseling portion of the life care plan and recommendations for treatment.

Women with SCI should be adequately informed about their reproductive and gynecological health, receive pelvic exams, screening for STDs, cervical and breast cancer screening, and education about menopause as recommended by their physician (Consortium for Spinal Cord Medicine, 2010). Although sexually transmitted diseases occur at the same rate in women with disabilities as they do in able-bodied women, many disparities exist in other areas of women's health (CROWD, 2012; Andresen et al., 2012). A review of literature from 1995 to 2005 noted that most studies found women with a disability were less likely to have been screened for breast and cervical cancer when compared to women without a disability (Wisdom et al., 2010). A more recent study indicates that this has not yet changed, women with disabilities were still less likely to have received a mammogram within a two year period when compared to women without disabilities (Courtney-Long, Armour, Frammartino, & Miller, 2011). Purposeful planning of conversations about these topics and increased time spent in discussion of these issues with patients would be helpful for awareness (Beckor, Stuifbergen, & Tinkle, 1997). These conversations can easily translate into the life care planning process.

In a qualitative study of women with disabilities, the most common problem reported was lack of sensitivity from health care professionals (Becker, Stuifbergen, & Tinkle, 1997). Increasing knowledge in healthcare providers to assist and support people in addressing issues in sexuality openly, and without judgment should be the focus of further research. An appreciation for diversity and an increase in comfort level of physicians and staff to broach these topics would be helpful in facilitating discussion with patients.

Conclusion

Sexuality and reproductive health are essential for women's health and should be a concern of the rehabilitation professional. Sexuality and sexual expression is an important part of sense of self and empowerment. These freedoms should be extended to women with disabilities as well. Sexual counseling should be a key factor in functional rehabilitation for women with spinal cord injuries and clinicians should feel comfortable discussing sexuality frankly and openly. By removing the stigma surrounding sexuality within disability and breaking down the dominant perspective that women with disabilities are asexual, healthy sex lives and intimate relationships can be explored and oppression reduced. Life care planners should stay abreast of advancements in services and technology geared towards women with spinal cord injuries. Such knowledge would facilitate health care professionals' attitudes toward the acceptance of sexual expression and orientation to promote empowerment of women with spinal cord injuries.

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