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Sexual Satisfaction in Women with Physical Disabilities: Results of an Online Survey

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SEXUAL SATISFACTION IN WOMEN WITH PHYSICAL DISABILITIES:
RESULTS OF AN ONLINE SURVEY

PROFESSIONAL DISSERTATION
SUBMITTED TO THE FACULTY
OF
THE SCHOOL OF PROFESSIONAL PSYCHOLOGY
WRIGHT STATE UNIVERSITY

BY

JESSICA ROSE HESCHEL, PSY.M.

IN PARTIAL FULFILLMENT OF THE
REQUIREMENTS FOR THE DEGREE
OF
DOCTOR OF PSYCHOLOGY

Dayton, Ohio

September, 2012

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WRIGHT STATE UNIVERSITY
SCHOOL OF PROFESSIONAL PSYCHOLOGY

June 27, 2011

I HEREBY RECOMMEND THAT THE DISSERTATION PREPARED UNDER MY SUPERVISION BY **JESSICA ROSE HESCHEL** ENTITLED **ELEMENTS OF SEXUAL SATISFACTION IN WOMEN WITH PHYSICAL DISABILITIES: RESULTS OF AN ONLINE SURVEY** BE ACCEPTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PSYCHOLOGY.

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Abstract

The study of sexual satisfaction and pleasure in Women with Disabilities (WwD) represents a significant gap in the current literature. The present study, using a Participatory Action Research (PAR) approach, attempted to explore several areas of the sexual satisfaction of WwD. An internet-based survey was used to gather information in five specific areas: the messages WwD had received about sexuality and disability, their personal feelings about sexuality and disability, the specific elements that contribute to their sexual satisfaction, the amount of useful education and information they had received from mental and physical healthcare providers regarding their sexuality as WwD, and the degree to which professionals and institutions have negatively affected their sexual satisfaction. Results reflected the particular importance of several relational aspects of sexual satisfaction, as well as the importance of body image for WwD. Implications for the provision of services to WwD and for future research are discussed.

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Dedication

This work is dedicated to my parents, whose sacrifices and constant encouragement have cultivated my sense of social justice and inspired my successes. I am grateful for you every day.

Chapter I

Although estimates vary, about 7,617,000 women (approximately 7.7% of the population) in the United States, aged 16-64, reported having a physical disability in the American Community Survey in 2007 (Bjelland, Erickson, & Lee, 2008). Nosek and Hughes (2007) regard women with disabilities (WwD) as “one of the largest and most disadvantaged populations in the United States” (p. 156). These authors indicate that the study of disability and rehabilitation has historically focused on the health, function, and vocational needs of men during and after times of war and that it has therefore profoundly neglected the concerns of women. The synergistic impact of sexism and ableism in United States culture denotes the status of WwD as a double, and often multiple, oppressed minority and is evidenced in quality of life studies in which women with disabilities are reported to experience high rates of unemployment, poverty and poor access to healthcare (Carter & Markham, 2001; Turner & Turner, 2004).

Much of current literature, including that which concerns sexual health and satisfaction, continues to follow this trend of viewing WwD according to norms established by studying men, even though the minds and bodies of women do not always operate according to male norms. Despite the saturation of the media and culture of the United States with messages about sexuality, the topic is generally neglected as an area of overall health and wellbeing, particularly for individuals with disabilities (Gill & Hough,

2007; Teunis, & Herdt, 2007). In addition, research done in this area traditionally utilizes a medical model, (also known as the “normalcy” model among disability rights advocates) of sexual function and has given relatively little attention to the elements associated with having a subjectively satisfying sexual life (Ostrander, 2009).

Sexist and ableist attitudes saturate the sociopolitical discussion of sexual satisfaction for women with disabilities. WwD have long been viewed as non-sexual or asexual and have been actively discouraged from talking about sex, having sex, viewing themselves as sexual beings, and from seeking even basic information on sexual health and satisfaction (Kaufman, Silverberg, & Odette, 2003; Milligan & Neufeldt, 2001). In addition, societal attitudes and myths about disability create further discrimination, prejudice, and barriers for women with disabilities in having their physical, mental, sexual, and other needs met. The expression of sexuality and sexual health is only one area in which WwD are denied equal access to civil rights, citizenship, and full personhood by majority culture, though it is likely one of the most personal. The marginalization of WwD in the area of sexual satisfaction is reflected in the literature in that there currently appear to be no measures of overall, subjective sexual satisfaction for women with disabilities that have included the direct opinions of WwD in their creation. Therefore, existing measures are not likely to be sensitive to their needs or sufficiently relevant to their experiences.

A goal of the present study was to narrow the gaps in the current literature by understanding the ways in which WwD construct their own definitions of sexual satisfaction. It also sought to allow the voices of this double oppressed group to inform

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the practice of physical and mental healthcare as to their experiences, needs, and desires regarding their sexual access and satisfaction. It treated sexual satisfaction as a quality of life issue and human rights issue, and as an area of the WwD life that is intimately tied to overall well-being. It attempted to describe the cultural myths, assumptions, prescriptions, ideals, and taboos that marginalize women with disabilities and deny them access to sexual satisfaction. It asserted that these concepts and their consequences are perpetuated by the intersections of institutionalized sexism and ableism, which further intersect with institutionalized denial of access to sexual health information and education, sexual expression, and sexual satisfaction. The intended audience for the present study was WwD, their allies, and the healthcare professionals with whom they interact.

In addition, this work describes the importance and benefits of a healthy and satisfying sexual life. It attempted to provide professionals with insight into the elements of sexual satisfaction that are relevant for women with disabilities. It emphasized the importance of allowing the experience of women with disabilities, as described by women with disabilities, to inform the care they receive. It was hoped that professionals who use this information would be better equipped to provide knowledge and services regarding the subject of sexual satisfaction WwD. The present study had these goals because WwD are a population who has historically been, and currently is, denied access to sexual information and services, and because suffer the serious cultural and personal consequences of this denial. Finally, in addition to promoting the acceptance and celebration of the sexuality and sexual satisfaction of women with disabilities, a possible implication of this work is to provide the necessary and preliminary groundwork for the

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research and creation of a sexual satisfaction measure that is sensitive to the needs of this population. These goals were created with the intention to inform practice and to help professionals move toward social justice by providing culturally competent psychoeducation, empowerment, and celebration of the identities and desires of women with disabilities.

The qualitative data used in this work was gathered from surveys administered online to women with various physical disabilities. The participants were sought through a local college campus and a local independent living center for adults with disabilities. The survey measured the importance to the participants of various aspects of sexual satisfaction. It also measured the extent to which the participants feel that they have encountered barriers to sexual access and the effect of these barriers on the participants' self and sexual satisfaction. Consistent with studies conducted by Taleporos and McCabe (2002a, 2002b), the demographic variables measured were gender, age, partner status, sexual orientation, education level, and the nature, severity, and duration of disability.

Chapter II: Review of Literature

This review of the relevant literature had three specific purposes. First, it reviewed the models that have been used by professionals and by the larger culture and society to understand and define disability. Second, it reviewed the ways in which topics related to sexuality and disability, particularly with regard to women, have been excluded from scientific study and the implications of this exclusion. Third, it discussed the limited amount of literature that has examined the sexual satisfaction of women with disabilities and the consequences of these omissions.

Models of Disability

Smart and Smart (2006) provide a useful outline of the models of disability that have been developed and used throughout history. These models illustrate the ways in which disability has been conceptualized by society, and they have greatly informed the provision of disability related services, research, and programs across time. The oldest of the models of understanding disability is the religious or moral model, which views biological wholeness as a righteous virtue. Olkin (1999) notes that this model viewed disability as the result of a shameful problem of morality within the individual with the disability. It was the expression of inner sin and evil, which required corrective religious education and training. This model led to shame, isolation, blame, and denial of basic rights, including sexual and reproductive rights, for people with disabilities. It is no longer the prevailing point of view. However, it may still be present in our society through its influence on current models and the continued stigma of disability.

The next model to develop, the medical model, was more morally neutral but still upheld many of the assumptions of the moral model. This is the most well known and well researched of the models of disability (Smart & Smart, 2006). Within this model, disability is defined in the language of medicine and normalcy. Disability is located within the individual as something that is private and medical in nature. Given that disability is seen as an individual medical problem, the focus of care is narrowed to correcting, curing, and/or preventing the disability. Further, the cure or treatment is often determined by able-bodied (AB) “experts” whose goal is primarily to assist the individual in achieving an AB standard of normalcy as defined by AB people. Viewing disability as a completely personal pathology prevents individuals from having the opportunity to develop a positive disability identity and is dehumanizing in that it reduces the individual to a set of objective symptoms and treatments. Furthermore, it encourages the categorization of individuals with disabilities according to these symptoms and treatments, which can serve to divide the disability community and prevent the formation of an empowering and positive culture (Smart & Smart, 2006).

The medical model upholds some of the basic assumptions of the moral model in that it identifies disability as an inferiority (though biological rather than moral in nature) and as deviance from an ableist characterization of normalcy. Furthermore, it sees disability as located within the individual, which has the consequence of encouraging society to view the individual as somehow marred, thus to be scorned or pitied. On a systemic level, society is therefore able to absolve itself of the responsibility to eliminate barriers to access, expression, and civil rights. It is in these ways that the medical model excuses and even propagates the marginalization of people with disabilities. This is not

to say that we should ignore medical issues, but rather that we should use medicine to enhance quality of life and not to further objectify, dehumanize, and oppress people with disabilities.

In response to what has been deemed as an oppressive view of disability, leaders of the independent living movement within the disability rights community have constructed newer and more liberating models. These newer models target the interaction of the individual with their environment as well as the social construction of disability as the problem (Smart & Smart, 2006). For example, the functional and environmental models regard biology as important, but also take into account the interaction between the individual and his or her environment. Under these models, disability is defined in terms of biological and organic factors as well as the strengths, abilities, skills, and achievements of an individual (Smart & Smart, 2006). Therefore, the cause of the disability is not located entirely within the individual. This model recognizes that environmental and cultural factors can affect the very definition of disability and the degree to which it represents barriers and limitations. It reduces the categorization and dehumanization present within the framework of the medical model and increases the social responsibility for creating an accepting and accessible environment (Smart & Smart, 2006).

Functional and environmental models are still incomplete in that they do not recognize the power of discrimination and prejudice in creating the definition of disability. The most recent model for understanding disability, the sociopolitical model, is able to do this more effectively. This model, sometimes referred to as the minority

model, recognizes that prejudice and discrimination are often more difficult and limiting than the medical issues and functional differences involved with a disability. It views disability as a social construction located within an oppressive society rather than as a flaw located within the individual. This model encourages individuals with disabilities to define themselves as individuals and to celebrate disability as a viable identity and a beautiful part of human diversity. Slogans such as “disability is normal,” “kick the ‘d’ of disabled,” and “when you see disability, think competence” are examples of efforts made by disability communities to challenge the social narratives that oppress individuals with disabilities. This represents a culmination of the work of leaders in the independent living movement. It also signifies a move towards the use of civil rights language, which regards disability as a minority group status, versus special rights language, which marginalizes disability by identifying it as the opposite of that which is considered valuable and normal by the majority. This dissertation viewed disability from the sociopolitical model and attempted to illustrate how the social construction of disability and gender has impacted the sexuality of WwD.

Barriers to Research of Gender, Sex, and Disability

The conundrum of studying the sexual satisfaction of women with disabilities is that, culturally, the topics of sex and disability are both taboo and therefore are often avoided by professionals and researchers. Furthermore, these related fields of research have also largely ignored each other. That is, the literature regarding sexuality has rarely acknowledged issues related to disability and research on disability rarely acknowledges aspects of sexuality, particularly aspects of sexual enjoyment and satisfaction. When these topics have found crossroads, they have tended to focus on each other only

cursorily (Olkin, 1999). The silence around sexuality and disability propagates ignorance and reinforces the societal attitude that people with disabilities either are not, or should not be, engaged with their sexuality.

Further complicating the subject is that women's issues have also been neglected in research on sexuality and in research on disability. In the realm of sexuality, the majority of information about and directed toward women serves to perpetuate sexist and patriarchal dogma. Girls and women receive little information about their bodies, their sexuality, and their capacity for experiencing sexual pleasure from sexual education courses, medical professionals, the media, and other sources. In light of this lack of education, several negative messages are communicated regarding female sexuality and sexual pleasure, such as the idea that these concepts are somehow inherently dangerous (Fields, 2007). Female sexuality is often not acknowledged as important, or even as existing in any way that is not completely phallogentric. Thus, the message is sent that the sole function of female sexuality is to satisfy the needs of a husband, within a heterosexual marriage, without desire or enjoyment on the part of the woman (Miller & Marini, 2007). Sex is often culturally viewed as a resource that is begrudgingly rationed out by women to the men who seek and desire it according to their nature (Shuttleworth, 2007). Therefore, sexual access, which will be defined in this work as access not only to information, but to sexual expression, sexual pleasure, and recognition as sexual beings, has been continually and systematically denied to women throughout history, and this trend continues to influence research.

Nosek and Hughes (2007) provide the historical context of the disregard of women in the disability literature. These authors state that research on disability and rehabilitation has been done largely during and after periods of war and, therefore, in response to the health and vocational needs of men. The needs of men with spinal cord injury (SCI), amputation, or other acquired musculoskeletal disabilities were given particular attention. Services rendered to women have been provided in such a way as to regard gender as unimportant, approaching the needs of women using male norms and traditional social roles. However, demographic and health variables differ significantly between men and women (Nosek & Hughes, 2007) and this assumption that women may be treated as similar to men physically and as inferior to men socially has likely done harm in far more instances than not.

From the mid 1970's to the mid 1990's, the study of and delivery of services concerning sexuality in women with disabilities was largely limited to issues of fertility, pregnancy, labor, and delivery (Nosek & Hughes, 2007). Thus, women were given the message that their ability to conceive and bear children was the nexus of their sexuality, and encouraged to disregard all other aspects. It was only in the late 1980's and early 1990's that points of neglect in research on the sexuality of WwD were recognized. At this point, researchers began to ask women with disabilities about their sexual satisfaction and the sexual education they had been given by providers. The need for further literature and services became evident (Nosek & Hughes, 2007).

In light of these research and social trends of sexism and ableism, it is apparent that the study of the sexuality of women with disabilities must overcome many cultural

stereotypes. Research that promotes equality and social justice must cease to regard women's pleasure as inappropriate for scientific examination, disability as the polar opposite of health, and both gender and sexuality as unimportant in light of the characteristics of a disability (Nosek & Hughes, 2007). Overcoming these barriers are necessarily the building blocks of any research concerning the sexual satisfaction of WwD, which should allow the voices of the oppressed to inform our questions and conclusions on this subject.

Barriers to Research of Sexual Satisfaction

According to Olkin (1999) the concept of sexuality is composed of drive, desire, self-concept, body image, functioning, acts, behaviors, and relationships. This list illustrates the point that sexuality is a multifaceted capacity of human beings. However, it uses the language of medical models of sexual functioning, encapsulated within physiological stages, and thus does not include the multiple sources of satisfaction and pleasure. Despite the saturation of the media and culture of the United States with messages about sexuality, sexual pleasure and satisfaction have been ignored as legitimate areas of sexuality, sexual health, and wellbeing (Gill & Hough, 2007; Teunis, & Herdt, 2007). It was not until the 20th century that research in the areas of sex, sexuality, and sexual pleasure were tolerated and the topics normalized as part of the human experience. However, only the sexual experiences of AB's were used to create what has now become "normal" sexual behavior. Therefore, any experience falling outside of that which was considered normal became a labeled a dysfunction. Dysfunctions, then, became the focus of much of sex therapy. Furthermore, sexual pleasure and satisfaction has often been far more than ignored; it is often vilified and

resisted within institutions relied upon to provide services related to education, religion, law, and medicine. One of the only institutions which does not ignore pleasure as an element of sexuality is the media, which exploits it for financial gain and portrays it as a privilege of white, straight, young, attractive, single, AB individuals (Tepper, 2000).

These trends have made the seeking of sexual pleasure a political and transgressive act, particularly for marginalized groups (Teunis, & Herdt, 2007). This remains true, despite the number of sources documenting the benefits of sexual pleasure and satisfaction. For example, Tepper (2000) states that sexual pleasure can function to reduce pain, enhance relationships, and heal feelings of emotional isolation and of being undeserving of pleasure. Tepper further argues that to ignore the importance of pleasure is to perpetuate the asexual status and low self-esteem of individuals with disabilities. In addition, Walters and Williamson (1998) found that satisfaction in sexual relationships with a partner predicted overall quality of life in a sample of 77 amputees. Sexual satisfaction, therefore, contributes to overall well-being of many individuals and the denial of access to such satisfaction, through the internalization of negative messages or in any other way, serves to perpetuate the oppression and marginalization of WwD.

The Intersection of Gender, Disability, and Sexual Satisfaction

It has been difficult to conduct scholarly research on sexual satisfaction, and particularly that of WwD, due to social and political attitudes, lack of consensus on its definition, and lack of adequate measurements. When research on sexuality has been conducted, the lack of focus on satisfaction and pleasure correlates heavily with the focus on the medical model of sex. Within this model, subjective elements of sexuality are disregarded in favor of its objective elements, such as sexual function and reproduction

(Ostrander, 2009). This model serves to perpetuate the institutionalized denial of sexual access to women with disabilities. One would be remiss to assume that the objective and subjective aspects of sexuality are intimately tied, since common experiences of people with and without disabilities indicates that sexual function does not represent, by itself, the broad spectrum of sexuality and sexual life, nor does it necessarily correlate with sexual satisfaction.

The neglect of satisfaction in favor of functionality and reproduction is evident and relevant in the study of the sexuality of WwD. It is important to acknowledge the lack of information and education provided to this population on the subject of sexual function, reproduction, and other traditionally medically related topics. However, we must recognize that knowledge of sexual mechanics is necessary, but insufficient, to create a full understanding and appreciation of healthy sexuality (Olkin, 1999). Research on sexuality and disability is dominated by medical model thinking in which the meanings of the body are reduced to its impairments and functional limitations. When disability is viewed as a medical impairment, which often invokes the assumption of impaired sexual functioning, disability cannot be properly contextualized as a consequence of societal discrimination. Under this view of sexuality, individuals with disabilities are denied full participation in all aspects of life and consequently denied the fulfillment of their personhood (Teunis, & Herdt, 2007).

Disability and Sexuality: Myths and Internalized Oppression

Myths about WwD.

The consequence of the social construction of disability is the creation of myths about disability and sexuality, all of which stand in the way of sexual equality. These myths contribute to the marginalization and internalized oppression of WwD and thereby represent significant barriers to sexual access and satisfaction. The most pervasive of the ableist myths pertaining to the sexuality of individuals with disabilities is that they are asexual or non-sexual (Kaufman et al., 2003; Miller & Marini, 2007; Milligan & Newfeldt, 2001; Olkin, 1999; Sipski & Alexander, 1997). Kaufman et al. (2003) point out that media depictions of people with disabilities having sex lives is an extremely rare occurrence, which contributes significantly to the myth of asexuality. These authors discuss two possible reasons for this particular myth. First, non-disabled people tend to believe that they will not become disabled; perhaps due to the protective assumption that disability is something bad that only develops or occurs if an individual deserves to encounter this perceived tragedy. Such a belief, rooted in the moral-model of disability, causes people without disabilities to distance themselves from the feared concept of disability. As AB individuals consciously or unconsciously do so, the thought of people with disabilities being sexual becomes less and less conceivable to them. Second, non-disabled people view those living with a disability as essentially helpless, and childlike, which leads to the assumption that they are not sexual. In a culture which prizes the particular brand of self-sufficiency and independence of the AB population, those who utilize assistive devices and/or services are viewed as helpless and unfortunate beings that are without sexuality.

Milligan and Neufeldt (2001) provide another possible explanation for the myth that persons with physical disabilities are asexual: non-disabled people assume that those living with disabilities necessarily live with sexual dysfunction and that their opportunities for sexual gratification are so limited due to this dysfunction that their sexual needs are absent or subjugated. Olkin (1999) also notes the myth that people with disabilities cannot function sexually. This myth has dire consequences, one of which being the assumption that people with disabilities do not need sexual education or sexual health information, which leads to them being denied even the small amount of such services that non-disabled people receive (Kaufman et al., 2003). In addition, the myth leads to the neglect of sexuality issues in psychotherapy with people with disabilities (Miller & Marini, 2007). Perhaps the most personally devastating of the consequences of this myth is the internalization of ableist attitudes that invalidate sexual experiences and desires and can lead people with disabilities to view themselves as asexual (Milligan & Neufeldt, 2001). Similarly, as Olkin (1999) points out, stating the myth that persons with disabilities are asexual is not equivalent to the statement that they are raised to believe they are asexual, though this is often the case. The myth of asexuality contributes significantly to the institutional denial of sexual access to WwD.

A myth related to those that cast WwD as nonsexual and asexual is that sex is unimportant for people with disabilities, since they are perceived by AB culture to have have so much else (i.e. their functional differences) to worry about (Kaufman et al., 2003). Therefore, people with disabilities who do have sex or desire sex are cast as perverts, particularly if they enjoy anything more adventurous than passive, traditional sex (Kaufman et al., 2003). Olkin (1999) similarly notes the myth that women with

disabilities are always sexually passive, and that such myths are perpetuated by the lack of research regarding this population.

Not only are women with disabilities disallowed from desiring or having sex, but they are seen as undesirable and pathetic choices for partners. This leads to the view that only sick or desperate individuals would desire to become romantically or intimately involved with WwD (Kaufman et al., 2003; Olkin, 1999). This myth may help to create limitations in partner choices for WwD and limitations in modes of sexual expression that do not fit the traditional norm, thereby reducing opportunities for satisfaction.

The devastating psychological repercussions of these myths on WwD are far reaching and can lead them to engage in self-loathing and/or to become depressed. In addition, some argue that these myths lead to an increasing vulnerability to sexual abuse among WwD. Statistics show that WwD are sexually assaulted at high rates and often by multiple perpetrators (Martin, Ray, Sotres-Alvarez, Kupper, Moracco, Dickens, et al.; Nannini, 2006). It is important to recognize the effect of myths and assumptions about WwD and the internalized oppression they foster.

Myths about sex.

Kaufman et al. (2003) further point out the great number of myths and cultural assumptions about sex itself that perpetuate the marginalization of individuals with disabilities. An example of such a myth is that sex should be done only for the purpose of reproduction. This affects WwD in the context of another myth: that reproduction should be a privilege afforded only to specific (majority) groups. This myth casts individuals with disabilities as unable or unfit to reproduce and serves to prevent them

access to both sex and to the proverbial gene pool. These values not only deny the sexuality of people with disabilities, but also send the messages that they are inferior, unwanted, and that any children they produce will also be inferior and unwanted. In addition, the idea that sex is solely for reproduction discounts, or even paints as dangerous, the pleasurable or satisfying aspects of sex. Since people with disabilities are consistently viewed as childlike by society, it follows that they are viewed as being in need of protection from the inherent evils of sex (Tepper, 2000).

Another myth about sex is that it must be spontaneous and must happen without thinking, talking about it, or planning it. Perhaps, Kaufman et al. (2003) argue, this is because we are uncomfortable talking about our desires as they make us vulnerable to, and therefore potentially viewed as weak by, another person. The authors state that many women with disabilities find that sex is just as enjoyable when it involves planning and communication.

Another pervasive sociocultural belief that devastates sexual equality for a great many marginalized groups is that the only real or normal sex is heterosexual vaginally penetrative, phallocentric intercourse (Kaufman et al., 2003). Under this belief, all sexual activity (e.g. touching, oral sex, etc.) which does not fit the narrow definition of normality becomes pathologized. This can be a harmful view to many AB and WwD women, whose experiences and preferences are broader or entirely different than is accounted for by this definition. .

Masturbation is particularly taboo as a pleasurable form of sex, which becomes particularly relevant for those women with disabilities who may wish to experience

sexual pleasure and yet need physical assistance in the form of positioning and/or assistive devices to do so (Kaufman et al., 2003). The notion of needing assistance to experience any type of sex leads to the last myth that will be discussed here, which is that sex must be a wholly private experience that one may not talk about or let others know about, much less witness. Women with disabilities who live in an institution, where there are inherent limits to privacy, or who use attendant services, may be prevented from sexual expression because many institutions or personal attendants may view it as improper since it cannot be carried out privately. In summary, there are many common and damaging myths regarding the sexuality of WwD, only some of which are discussed in this review of the literature. In order to study the sexual satisfaction of WwD, it is important to understand that satisfying sex is desired and as much a part of well being, life satisfaction, and quality of life for WwD as it is for any other human being. However, satisfying sex for WwD may need to be talked about, planned, witnessed, and aided, and it may be different from the non-disabled idea of normal satisfying sex. The present study examined the importance of these and other elements of sexual satisfaction to WwD.

Truths.

In understanding of the sociopolitical myths concerning the sexuality of WwD, it is important to review some of the literature on the truths about sexuality and disability. Studies in this area provide further evidence of the toll of sexual marginalization and internalized oppression. For example, Tepper (2000) stated that many people with disabilities have feelings of not being the same and of not being normal sexually after the onset of an acquired disability. He points out that these feelings are rooted in the way

that people with disabilities learn about sexuality within the dominant culture. That is, we learn about what is normal for those whom we culturally view as normal, and usually only by having the privilege of experiencing this normality ourselves. Typically, what we are told to view as normal sex is that which is extremely genitally focused and performance-based. The lack of sexuality education in our culture leaves individuals with acquired disabilities without information on how to be a sexual being when they no longer fit into the category of normality that is so narrowly defined by AB culture.

In contrast, Ostrander (2009) indicates that women with SCI often experience more creative sex lives than they did prior to their injury and may pride themselves on paying greater attention to their partner's needs. This study also indicated that the age of a woman with SCI may be important, as younger women may have more frequent sex post-injury than older women. Ostrander points out the lack of sexual education given to women with SCI and indicates that what little education was provided was focused largely on the medical model. Furthermore, any discussion on other topics was geared towards men. Therefore, women in this study were likely given the message that their sexuality consisted only of its medical aspects, such as reproduction, and that other elements of sexuality (e.g. pleasure) were only important for men. Ostrander also indicated that a difficulty for those with SCI may be the struggle to reconcile the experience of sex pre and post injury, and to cope with loss of, or change in, orgasmic capacity.

Lack of a Sexual Satisfaction Measure

Due to unique sociopolitical forces, such as the myths described above, and to functional differences, it is clear that the experience of sexual satisfaction may be

different for WwD than the AB population. However, no sexual satisfaction measure exists which has been constructed based on the unique experiences and opinions of WwD. It is important to recognize that no adequate and sensitive measure for the sexual satisfaction of women with disabilities can be created without the direct and extensive participation of WwD in the research involved in its creation. Olkin (1999) states that this level of participation is paramount for research on disability to be useful in promoting better delivery of services. Specifically, persons with disabilities should be involved in determining what questions need to be asked within the research. The present study, therefore, sought the opinions and experiences of women with disabilities throughout its development and execution (see Participatory Action Research section). The study was created to involve WwD in determining what elements of sexual satisfaction healthcare providers should be asking about and providing information about. Once it is determined the elements of sexual satisfaction that are relevant for women with disabilities and their experiences are heard, it is possible that a sexual satisfaction measure could be developed in future research which utilizes this information.

Relevant Existing Measures

The majority of the assessments that focus on elements of sexuality that have been developed focus exclusively on the physiology of sexual functioning. Arrington, Cofrancesco, and Wu (2004) provide a review of 62 such questionnaires related to sexual function and sexual quality of life that were published in English between 1957 and 2001. They found that there were several measures published from the 1950's to the 1970's that were designed to measure satisfaction with specific sexual activities but these measures did not relate the results to overall sexual satisfaction. Of the 57 questionnaires that

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measured sexual function from the patient's perspective, six domains were represented consistently: interest and desire; satisfaction and quality (aspects of which consisted of satisfaction with quality of an erection, ejaculation or orgasm, and pain or discomfort with sex); excitement and arousal; performance; attitudes and behavior; and relationships. The measures that included a satisfaction component, therefore, only attempted to measure satisfaction with sexual functioning rather than satisfaction with the overall sexual experience.

Of the 45 measures that were designed to measure sexual functioning specifically, twenty-eight were designed for use with women, and only five were designed for use with women alone. Ten were designed for use with women with chronic medical illnesses. Twelve measures were designed for measuring quality of life in patients with chronic diseases, six of which had a component to measure satisfaction with or quality of sexual functioning (Arrington et al., 2004). This review provides evidence that a few measures have been developed that focus on women with illness or disease and on their satisfaction with sexual function. However, for most people, sexual satisfaction likely requires much more than satisfaction with sexual functioning. It is therefore necessary to measure many more aspects of sexuality to explore the overall subjective sexual satisfaction of WwD.

In reviewing available literature, one scale was found that measures the sexual satisfaction of men and women with various types of disabilities. The measure was developed for a study that involved 609 Mexican participants, including 464 women, who resided in 16 states of the Mexican Republic (Rodarte & Muñoz, 2004). The authors indicate that the scale was developed to measure areas of sexual response (including

desire, arousal, and orgasm), sexual satisfaction, and factors that interfere with sexuality in persons with disabilities. However, the authors indicate that, in the study for which the scale was created; only the area of sexual response is mentioned. The methods, results, and conclusions of the study do not discuss the sexual satisfaction content of the measure and the measure has apparently not been used in any other studies to date. It is therefore not possible to determine the generalizability of this measure to the sexual satisfaction of WwD in the United States.

Several measures have been developed which measure some of the aspects that may be important to the sexual satisfaction of WwD. For example, Taleporos and McCabe (2002a) have developed and validated a scale for measuring sexual and body esteem in men and women with disabilities. This scale, however, does not directly address sexual satisfaction. In addition, two measures were found that addressed the sexual functioning, including sexual pleasure and discomfort, in women with specific disabilities: breast cancer (Thirlaway, Fallowfield, & Cuzick, 1996) and multiple sclerosis (MS; Sanders, Foley, LaRocca, & Zemon, 2006). The study by Thirlaway et al. (1996) focused specifically on sexual activity or inactivity, possible reasons for inactivity, and sexual functioning, in order to determine the effects of a particular medication on sexual functioning. These authors asked several questions pertaining to sexual pleasure, sexual discomfort, and changes in frequency of sexual activity. Although it is important to note that these authors acknowledged the sexual satisfaction of women with breast cancer, their goal was to evaluate sexual functioning rather than satisfaction. In addition, the nature of the study necessitated the inclusion of those participants with a specific disability. It is important to create a measure that has its

focus on sexual satisfaction and one that includes the perspectives of women with various disabilities.

Sanders et al. (2006) constructed a self-report measurement to assess the influence of MS symptoms on sexual activity and satisfaction. They included 36 questions asking both male and female participants to rate the frequency with which various MS symptoms have interfered with sexual activity or satisfaction over a period of six months. Items included concerns about attractiveness, fear of being rejected sexually, concerns about ability to satisfy a partner, lack of confidence about sexuality, lack of desire, concerns about orgasm, and sexual function. The authors found their instrument to be a reliable and valid measure of the influence of MS symptoms on sexual activity and satisfaction. It could, therefore, be useful in determining specific hindrances to sexual satisfaction in women with MS. However, this study focuses on both genders, and on only one disability. It was also not designed to allow participants to communicate their own subjective definition of sexual satisfaction and their opinions about the components of their satisfaction.

The present study acknowledged the importance of allowing participants to create their own definitions and to decide what questions should be included in the measures which are designed to promote their well-being. For this reason, the present study did not attempt to provide a working definition of sexual satisfaction. In addition, the measure developed for this study will be altered based on the results obtained and will, therefore, be adapted for future studies. This is consistent with the tenants of Participatory Action Research (PAR), which is described in detail below.

In several studies of sexuality in WWD, sexual satisfaction has been measured using a single question asking participants to rate on a Likert-type scale their agreement with the statement that they have been sexually satisfied over a given period of time (McCabe & Taleporos, 2003; Taleporos & McCabe, 2002a, 2002b; Valtonen, Karlsson, Siösteen, Dahlöf, & Viikari-Juntura, 2006). For example, the one question measure used in two studies by Taleporos and McCabe (2002a; 2002b) read, “Looking back over the past six months, how sexually satisfied do you feel overall” (p. 169; 180). Such one-question measures, while acknowledging the importance of including subjective experience in assessing satisfaction, are inadequate to inform healthcare professionals about the unique experiences and the needs of women with disabilities, and were not intended to do so.

Another example of a study using a single-question measure of sexual satisfaction is that conducted by Valtonen et al. (2006). These authors measured the sexual satisfaction in 190 men and women with spinal cord injury (SCI) and 41 men and women with meningomyelocele (MMC), a type of Spina Bifida, on a 0-10 point scale with 10 being high satisfaction. They found that the median level of satisfaction for women with SCI was a four on their scale, and for men it was a five. For those with MMC, the median was eight for women and five for men. These results indicate that satisfaction with sexual life was rather low among persons with SCI. The authors suggest that adequate treatment of problems such as incontinence and pain might improve satisfaction. It is important to note, however, that this study only evaluated the elements related to sexual dissatisfaction, not sexual satisfaction. The authors advocate for sexual counseling for people with these disabilities.

It is evident that no research has been conducted which attempts to gather information capturing the variables and constructs that contribute to sexual satisfaction as identified by WwD in the United States. There exists a need to explore in depth such variables. In addition, the interactions between WwD and their healthcare professionals should be explored for the extent to which they increase sexual knowledge and sexual satisfaction. Knowledge of these experiences and interactions will serve to inform professionals about the needs of this minority group. It is also possible that such knowledge will lead to the future development of a sexual satisfaction measure to be used by such professionals, which directly addresses the needs of women with disabilities. It was the goal of the present study to provide the groundwork for such an advance in the provision of services to WwD.

The Importance of Sexual Satisfaction

There is limited, but important research that has attempted to acknowledge the importance of sexual satisfaction in women with disabilities and the variables that contribute to this important area of health and wellbeing. This body of literature provided a starting block for the questions that were asked of the participants in the present study. For example, Taleporos and McCabe (2002b) examined the sexual satisfaction, sexual esteem, and body esteem of men and women with various physical disabilities and that of non-disabled men and women. Of the 748 participants with a disability, 381 were women. The demographic variables included in this study other than gender included partner status, sexual orientation, education level, and the nature, severity, and duration of the disability. The authors measured sexual satisfaction with one, 7-point Likert scaled question. Although only a single-question measure of sexual

satisfaction was used; and although the results pertaining to each participant's level of sexual satisfaction were not provided, the study has several important implications. For example, the authors found that high sexual esteem, body esteem, and sexual satisfaction predicted high self-esteem in people with physical disabilities. In addition, body esteem and sexual satisfaction predicted lower likelihood of depression. Body esteem was particularly important for the self-esteem of the women in the study. An important finding of this study was that sexual well-being and body esteem were more closely related to overall psychological well-being in people with a physical disability than in non-disabled participants. Although these results do not indicate the direction of the relationship between the examined elements of sexuality and psychological well-being, they show the importance of sexual esteem, body esteem, and sexual satisfaction for an individual's well-being. This must be taken into consideration in research and provision of services where women with disabilities are concerned.

There also exist benefits to physical health through sexual satisfaction.

Komisaruk, Beyer-Flores, and Whipple (2006) review literature that indicates the medical benefits of orgasm and sexual activity, and sexual satisfaction. These authors indicate that sexual expression can reduce the risk of cancer (Murrell, 1995; Petridou, Giokas, Kuper, Mucci, & Trichopoulos, 2000). In addition, they reviewed studies reporting that orgasm can have a sedative and sleep-inducing effect (Odent, 1999; Ellison, 2000). The review also points out that sexual activity and orgasm during menstruation can potentially protect against endometriosis (Meaddough, Olive, Gallup, Perlin, & Kilman, 2002), preterm deliveries (Sayle, Savitz, Thorp, Hertz-Picciotto, & Wilcox, 2001), pain (Ellison,

2000; Evans & Couch 2001; Komisaruk & Whipple, 1984; Whipple & Komisaruk 1985, 1988), and stress (Charnetski & Brennan, 2001; Ellison, 2000; Weeks, 2002).

McCabe & Taleporos (2003) in another study utilizing a one-question measure to assess satisfaction. These authors also obtained important findings regarding the significance of sexual satisfaction for WwD, although it is important to use the lens of the minority model of disability to interpret these findings. For example, they found that more severe physical disabilities were correlated with lower levels of sexual satisfaction and higher levels of depression than were disabilities of milder severity or non-disabled status. Women with disabilities in this study, and both men and women who had lived with their disability for longer periods of time, had more positive feelings about sexuality and more frequent mutual sexual experiences than did the men with disabilities and those who had lived with a disability for shorter periods of time. For the women with disabilities, an important predictor of sexual satisfaction was the frequency with which they engaged in deep kissing with a partner, indicating that the type of sexual activity may be an important predictor of satisfaction for WwD. It is also possible to infer from these results that depression may be correlated with low levels of sexual satisfaction and with less frequent mutual sexual experiences. In addition, this study may indicate that severity and length of time living with a disability may be correlated with lower levels of satisfaction.

Studies examining sexual functioning and satisfaction after SCI have found similar results. For example, Sipski (1997) reviewed several studies, which seemed to show the trend that SCI in women results in a significant decrease in sexual satisfaction

and in frequency of sexual activity. Miller and Marini (2007) support this conclusion, and note that women with SCI may prefer types of stimulation other than traditional intercourse, and may prefer stimulation in areas of the body other than the genitals.

However, one cannot assume from the correlations found in these studies that the disability of the participants, or the degree of its severity, were a cause of decreases in sexual esteem, body esteem, self-esteem, or sexual satisfaction, or were responsible for increases in depression. These studies were not designed to investigate possible reasons for the correlations they found. This represents a serious gap within the literature. It is likely that, rather than being caused by the disability or the severity of the disability, these correlations were influenced by oppressive cultural standards of beauty, lack of sexuality information and education received by participants, and barriers to sexual access for individuals with disabilities. For example, individuals with severe disabilities may have lower levels of sexual satisfaction and high levels of depression if they are institutionalized due to lack of privacy or opportunity for sexual expression, lack of help for sexual activities, restrictions on other freedoms, or many other reasons. In other words, although studies may report low sexual satisfaction and frequency of sexual activity in WwD, their results may be due in large part to sexist and ableist attitudes in society, the internalization of these attitudes, and barriers to sexual access and expression. This viewpoint is consistent with the minority model of disability.

Olkin (1999) points out several elements that may be important when considering the sexual satisfaction of WwD. This author states that having a satisfying sexual relationship may be experienced differently based on the nature of the disability, whether an individual's disability is congenital, acquired during an ongoing relationship with a

partner, or acquired before such a relationship. Olkin (1999) also points out that the availability of a sexual partner or partners may be an important element of the sexual satisfaction of a woman with a disability. In addition, in the case of one partner having a disability that was acquired during an ongoing relationship, it may be important to consider that a couple may have found it necessary to make changes to their previous sexual habits in order to continue to have a satisfying sexual relationship.

Participatory Action Research

Participatory action research (PAR) is a broad term for research that seeks to reduce the power dynamics involved in more traditional research methods, which treat researchers as experts and participants as objects of study, in order to involve participants in a collaborative process that embraces their voices and seeks social change and justice (Kindon, Pain, & Kesby, 2007a, 2007b; Taylor et al., 2004). PAR engages participants in determining research questions and the ways in which the results are used. As it is a collaborative approach, an important goal is for both the researchers and participants to gain knowledge and discover ways to use that knowledge (Taylor et al., 2004).

Balcazar , Keys, Kaplan, and Suarez-Balcazar (1998) point out that participatory research with people with disabilities seeks to use their voices, experiences, and knowledge to increase the relevance of research to their needs. These authors review several general principles of PAR with people with disabilities. The first principle is that people with disabilities should articulate the problem that the research focuses on and participate in the process of defining, analyzing, and solving it. This requires gaining access to the disability community and cultivating relationships with the community. The authors point out that this requirement can represent a barrier to PAR research if

there is a lack of preexisting community ties and if there are relevant identity differences between the community and the researchers (e.g. disability, class, etc.). In the present study, both the principal researcher and her advisor (second author) identify as WwD. The second author of the study has long-standing ties to the disability community and organizations within the community. Therefore, these identities and community ties represented significant advantages to the present study, in that members of the target population were involved in all aspects of the research process, from initial development to data analysis and interpretation.

Several members of the WwD community participated in the development and execution of the present study via communications between the researchers and the local Access Center for Independent living (ACIL). The authors presented information regarding the development and progress of the study to members and clients of the ACIL on two occasions: once during conception and development of the study and once following data collection. During these presentations, the authors actively sought the input and guidance of those in attendance and incorporated their input into the development of the study and interpretation of data. Additionally, current research (e.g. Kaufman et al., 2003), much of which was done by individuals with disabilities, was used to define the methods and goals of the study. Finally, because the present study is a pilot, it is the intention of the authors to use the data provided by WwD participants to inform a more extensive similar study. The present study represented an attempt to seek the experience and knowledge of women with disabilities in order to inform further research and influence healthcare practices. This is also consistent with the second general principle discussed by Balcazar et al. (1998), that people with disabilities should have

direct involvement in the research process in order to provide a more accurate analysis of their social reality. The third and fourth principles outlined by Balcazar et al. (1998) are that PAR can increase the awareness of people with disabilities about their own resources and strengths; and that its goal should ultimately be to increase the quality of life of people with disabilities.

Balcazar et al. (1998) also outline several challenges to using PAR approaches. First, they state that obstacles may arise in gaining entry to the disability community and in developing relationships with people with disabilities. The current study recruited participants through organizations that provide services to women with disabilities such as independent living centers, and in this way, attempted to build constructive relationships with the disability community. Second, PAR often implies the relinquishing of experimental control. The present study is qualitative in nature. However, Balcazar et al. (1998) state that qualitative studies are very socially relevant and important to disability research and that qualitative methods are not less valid, less useful, or less productive than quantitative methods. The present study sought to provide groundwork for future research and development in an understudied area with a marginalized group of participants. Therefore, a qualitative study was warranted. Third, PAR approaches can be extremely complex and time consuming. The present study, therefore, sought to use the internet in collecting data in order to make the process more efficient. Finally, due to the fact that PAR approaches often allow everyone involved to develop a more critical world view, unintended consequences of a study may arise if it leads to the participants criticizing the research process, the researcher, services they receive, or any other related factor. However, this criticism can provide opportunities for

empowerment of the participants and the betterment of the study and should be handled with serious attention and appropriate action. Despite the concerns outlined by Balcazar et al. (1998), they conclude that PAR is both effective and a socially responsible form of inquiry.

Internet Research

There are several benefits and drawbacks of conducting research through an online modality. According to Kraut et al. (2004) the benefits of conducting internet research can include the lowered cost of data collection over traditional methods, the ability of online research to reach a large and diverse sample of participants, and the ease and efficiency of providing instructions and debriefing materials. However, drawbacks may include the difficulty of ensuring that participants understand instructions and informed consent materials, the inability to verify demographic information, and the inability to monitor the behavior of participants to ensure that they are involved in the study and taking it seriously. Using an online modality creates more opportunity for people to participate frivolously or with malicious intent due to the anonymity of the internet (Kraut et al., 2004). This modality also allows individuals to participate in the study without verification of disability status or severity.

Concerns about risk of harm, confidentiality, and sample bias may also be particular concerns in online research. For example, online research makes it more difficult to assess the effect of the research study on the participants and intervene effectively, and to guarantee confidentiality due to the reduced ability to secure information online (Kraut et al., 2004). However, Kraut et al., (2004) state that internet research poses no more inherent risk than comparable research conducted through other

modalities. In fact, participants are likely to feel less social pressure to continue with the study if they become uncomfortable during participation when doing so online. These authors indicate that individuals conducting online research should take care to assess the risk to participants and to structure online materials accordingly. In addition, debriefing material can be provided online. Researchers can also take steps to safeguard confidentiality, such as separating identifying information from study data.

Suarez-Balcazar, Balcazar, and Taylor-Ritzler (2009) indicate that internet research tends to reach a middle and upper income sample largely consisting of professionals. According to these authors, socioeconomic differences may cause minority populations, including people with disabilities, to be more difficult to reach in online research. The present study collected demographic information on race, ethnicity, and education and income level to evaluate the generalizability of the results to women with disabilities who may belong to other minority groups.

Gardos and Mona (1994) describe several benefits of conducting online research on the sexuality of individuals with disabilities. They state that using the internet to gather information on sexuality from this population allows researchers to reach people with disabilities who reside in settings other than institutions, which have commonly been used to provide a convenient source of participants. In addition, people with disabilities do not need to leave their homes, to participate in online research, eliminating concerns about transportation and accessibility of research facilities. The anonymity of the internet may provide another benefit to this type of research by allowing participants to feel more comfortable communicating about sexuality, particularly since this

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population is often discouraged from speaking honestly and openly about this taboo topic. People with disabilities may also communicate more candidly online since this modality is less likely to require the need for a third party to help participants communicate their responses to self-report measures due to the accessibility technology of many computers. Finally, individuals with disabilities are freer to work at their own pace without social pressure to finish materials quickly as may be the case when conducting research in person.

Chapter III: Methods

This study piloted an internet-based survey to gather information from women with physical disabilities on their subjective definitions of sexual satisfaction, the elements important to their sexual satisfaction, the internalization of negative messages about their sexuality as WwD, their personal feelings about their sexuality as WwD, institutional barriers to their sexual satisfaction, and their interactions with healthcare providers concerning topics of sexuality and sexual satisfaction. These areas were chosen based on the research reviewed and the experiences and opinions of the WwD who were involved in the execution of this study (see Participatory Action Research section of reviewed literature). Additionally, in keeping with the principles of Participatory Action Research, the survey was designed to gather information on the relevancy of the included items to the experiences of the participants. Open-ended comments and feedback on the utility of the items were also solicited in order to further develop this survey for wider dissemination.

Goals

The present study had several intended goals. First, it was a goal of this study to gather demographic information on participants in order to determine the level of possible generalizability of the pilot study's results (see questions 1-16 of the survey in Appendix A). Second, it was intended to explore the subjective definitions of sexual satisfaction given by WwD participants (see item 17 in Appendix A). Third, it was a goal to gather subjective information from WwD participants on the ways in which they

learned about their sexuality and any negative messages they may have received about WwD sexuality (see items under question 18 in Appendix A). Fourth, it was intended to gather information on the importance of sexuality in participants' lives, as well as on their perceptions of their capacity and desire for sexual enjoyment (see items under question 19 in Appendix A). Fifth, it was intended to explore the interactions that WwD participants have had with health care providers, and to ascertain whether they felt that healthcare providers have met their needs regarding their sexuality concerns and questions (see items under question 20 and question 29 in Appendix A). Sixth, it was intended to explore which elements contribute to their sexual satisfaction (see items under question 23 and question 26 in Appendix A), and to compare these to the elements that have been shown in literature to enhance or reduce the sexual satisfaction of AB women. Seventh, it was intended to explore what institutional barriers to sexual satisfaction that participants had experienced (see items under questions 27 and 28 in Appendix A). Eighth, it was the intention of the authors to solicit feedback from participants regarding the survey items that would enrich the present data and inform future versions of this study (see questions 21, 22, 24, 25, and 30 in Appendix A).

Materials

An online survey was developed and utilized in this study in order to gather quantitative and qualitative data concerning the experiences of women with physical disabilities. The survey included several demographic questions designed to solicit information about the age, gender, ethnicity, race, partner status, sexual orientation, level of education and income, and current living situation. In addition, demographic items were included regarding the specific disability of participants, whether the disability was

congenital or acquired, and the severity of the disability. If the disability was acquired, further information about the age of onset, the circumstances surrounding its onset, and partner status at the time of onset was requested.

The remaining survey questions were designed to solicit information regarding the subjective definition of sexual satisfaction for each participant, the internalization of negative messages about sex and disability, the elements relevant to the sexual satisfaction of participants, and the quality of information on sexuality and sexual satisfaction provided to the participants by healthcare providers. Survey questions were designed to reflect many of the themes and ideas represented in the literature reviewed in this dissertation. In addition, there were several questions designed to solicit feedback regarding the relevance of the survey items to the experiences of the participants. The survey is included in Appendix A.

Participants

Participants with disabilities were recruited from Wright State University Office of Disability (ODS), the Dayton ACIL, and the Wright State University School of Professional Psychology (SOPP) community. The selection criteria for the present study was restricted to women 18 years of age and older and having a physical disability. Participants were recruited via the email listserves of these organizations. A recruitment email, which included a persistent link to the online survey, was generated and distributed to all individuals on these three listserves. The recruitment email is included in Appendix B. In addition, a recruitment flyer was generated and distributed to the leaders of disability therapy groups at both the ACIL and the Wright State University Counseling and Wellness Services (ODS) office. These leaders agreed to distribute the

flyer to participants in the therapy groups they facilitated. The survey was launched online using www.surveymzmo.com on July 30th, 2010 and remained open until March 4, 2011.

Procedure

Human subjects' approval was obtained through the Wright State University department of Research and Sponsored Programs. The Wright State University Office of Disability Services (ODS) and Dayton, Ohio ACIL both submitted letters of permission for the authors to recruit participants via their list serves. A consent form was generated and was provided to participants online. Participants could not begin taking the survey without viewing the consent form and indicating agreement. The consent form is included in Appendix C.

Because the surveys were completed online, no in-person contact or identification is required. E-mail addresses and names were not collected. The website used to host the survey was www.surveymzmo.com. This site prohibits third parties from accessing participant information. Survey pages are dynamic and database-generated and thereby cannot be stored by the participant's computer. In addition, all surveys have redundant server-side codes to ensure that they always load directly from a server and not from a prior cached version.

All surveys created through the host are encrypted. This technology encrypts both the questions displayed to the participants and their responses. Thus, all responses are instantly encrypted and remain so until they are received at the database. Interception of data when it is being transmitted between the Internet browser (i.e., Internet Explorer or Netscape Navigator) and the database is highly unlikely. However, should

interception of encrypted data occur that data could not be decoded without the unique encryption key that is held only by the host.

Once research data are collected, they are stored on the host server. Data are held in an isolated database that can only be accessed by a researcher with the correct username and password. Surveygizmo employees do not examine customer data unless requested to do so by the account owner. Additionally, those employees are trained in the ethics of research involving human subjects. Any data collected such as frequency statistics and narrative responses will be stored in a locked cabinet in the Dissertation Chair's Office on WSU Campus.

Data Collection/Analysis

Data was analyzed using both quantitative and qualitative analyses. Descriptive statistics were generated from participants' responses to the structured/close-ended questions. Data was collected and analysis was carried out by tabulating verbatim responses from structured/close-ended items and comparing responses. Qualitative data gathered from open-ended questions on the survey will also be presented. Analysis of this qualitative data included the identification of themes via a comparison of the convergent and divergent views evident among the respondents and as related to literature review.

Open coding was used to generate categories of information contained in responses. For example, data regarding the elements of sexual satisfaction regarded as important to participants, the internalization of sex-negative messages, and the feelings of participants regarding the need for sexual counseling. Qualitative data will be

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represented in part through qualitative narratives and discussion. Finally, conclusions and discussion were based on a comparison of the results with findings from the literature review.

Chapter IV: Results

Demographics

Of the 52 participants that began the study, 14 completed it. Twenty-seven individuals abandoned the study, meaning that they opened the study but did not agree to participate by clicking the “next” button at the end of the consent form, and they therefore answered no survey questions. Ten surveys were categorized as “partial” by the surveymonkey site but did not provide any data. This indicates that these individuals clicked the “next” button at the end of the consent page and were directed to the first page of the survey, but they did not answer any questions. One other individual provided a partial survey that included answers only to the demographic questions. Therefore, only the 14 completed surveys were included in data analysis. Two participants indicated that they were using a personal aide to complete the study, while the other 12 denied doing so.

Of the 14 participants who completed the survey, all self-identified as female and 12 identified as White/European American. Two participants identified as Black/African American. The participants overwhelmingly identified as heterosexual, with only one participant providing a different response by indicating that she would prefer not to state her sexual orientation. The sample was relatively young, with five respondents falling in the 18-23 age group, three falling in the 24-30 age group, and four respondents in the 31-40. There was one respondent each in the 41-50 and 51-60 age groups.

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Six participants indicated that they were in romantic relationships at the time of the survey. Of these women, three indicated that they were living with their partners and three were not. The three respondents who indicated living with their partners were all in the 31-40 age range. Seven participants indicated that they were single and one was separated or divorced. Four participants were living with family member(s), three were living with roommate(s), and three indicated living alone. One participant did not provide her living situation.

The sample was well-educated. Only one participant indicated having a GED or high school level education and one reported having an Associate's degree or equivalent. These participants reported income levels of \$5,000-10,000 and \$15,000-30,000, respectively. Seven participants indicated that they had completed some college. Of these participants, four were in the 18-23 age range and reported an income level of \$4,999 or less. One 18-23 year old participant who had completed some college reported her income at \$5,000-10,000. Two other participants who had completed some college were in the 24-30 (income \$4,999 or less) and the 31-40 (no income reported) age ranges.

Of the three participants who indicated having Bachelor's degrees, two were within the 31-40 age group. One of these women reported her income at \$11,000-15,000 and the other did not report her income level. Another participant with a Bachelor's degree was in the 51-60 age group and reported an income of \$61,000-75,000. Two participants indicated having a graduate-level degree. One of these women was in the 24-30 age range and reported an income level of 5,000-10,000 while the other was in the 41-50 age range and reported an income of \$76,000 or above.

Disability-related demographics.

All participants provided the name of their disability/diagnosis and information pertaining to the severity of their disability. They also indicated whether their disability was congenital (present from birth) or acquired (onset later than birth), and provided additional information if their disability was acquired. This additional information included circumstances surrounding onset, age of onset, and partner status at the time of onset.

Participants also indicated whether or not they had additional non-physical disabilities. Twelve participants denied having a secondary or additional non-physical disability while two participants endorsed this item affirmatively. One of these participants indicated having a learning disability. The other participant did not specify the type or name of the secondary or additional non-physical disability.

Eight participants reported having congenital disabilities and six reported having acquired disabilities. The most commonly reported disabilities were congenital Spina Bifida and acquired paralysis, with four participants reporting disabilities in each of these categories. Of the four women who reported congenital disabilities other than Spina Bifida, one woman reported each of the following: Muscular Dystrophy – Spinal Muscular Atrophy Type II, Multiple Sclerosis, and Down’s Syndrome. One participant reported having two congenital physical disabilities: Dyskinesia Orofacial and Cerebral Palsy.

Of the six participants that reported acquired paralysis, one participant indicated having quadriplegia and three indicated having paraplegia (including one woman who

defined her disability as “paralysis of the lower extremities” rather than as paraplegia specifically). All four of these women reported that their paralysis was the result of various accidents. They each reported their ages of onset, which were five years-old, 19 years-old, 30 years-old, and between 13-22 years-old. The latter participant provided a specific date rather than an age of onset, and the age range for onset was determined by subtracting the date given from the upper and lower limits of her age range. The date of disability onset will not be reported here in order to protect confidentiality. Two women reported acquired disabilities other than paralysis. One of these women reported having bilateral hip replacements due to a medication side effect with onset at age 20. The other woman reported an onset at age 28 of Multiple Sclerosis.

All six women with acquired disabilities reported their partner status at the time of onset. Four participants reported being single at the time of onset and two reported being partnered (one living with her partner and one living apart from her partner). Of the participants that were single at the time of onset, two reported being partnered at the time of the survey and two reported being single at the time of the survey. Of the two who were partnered at onset, one reported being partnered at the time of the survey, and one reported being separated or divorced.

Two questions, which were adapted from Taleporos and McCabe (2002) measured self-reported and identified severity of disability (see items 14 and 15 in Appendix A). Four participants classified their disability as severe, five as moderate, and five as mild. Of the participants who self-classified their disabilities as severe, three indicated that they regularly used assistance for grooming and personal hygiene and one

indicated that she did not. Three participants who self-classified their disabilities as moderate denied using assistance for grooming and hygiene, while one stated that she did require assistance. Of the participants who self-classified their disabilities as mild, two indicated regular use of such assistance and three denied doing so. A Fisher's Exact Chi Square test was performed on these data, which indicated that there was no association between self-reported severity of disability and use of assistance for grooming and personal hygiene at the .05 level of significance ($p = .3340$).

Definitions of Sexual Satisfaction

Only one participant chose not to respond to the item pertaining to subjective definition of sexual satisfaction. Another respondent indicated that she had no answer due to not understanding the question even after explanation from another individual. Three participants responded to this item with qualitative descriptions of sexual satisfaction: "great," "fairly ok," and "good." Other participants defined the term by emphasizing the importance of the relational or physical aspects of sexual satisfaction. For example, responses that reflected relational aspects included "to feel "complete with and by someone and to feel confident that pleasure is received mutually" and to feel "like someone loves you and isn't afraid to show that in public and in private." Examples of physical themes included "being satisfied by being touched or orgasm." Additionally, some responses emphasized the importance of combining physical, relational, and/or mental aspects of sexual satisfaction. Responses reflecting this theme included the following: "a little physical combined [sic] with a lot of mental 'massaging' goes the longest way in my book" and "an intimate connection and physical pleasure."

Several women combined the above themes with an indication that their ability to be sexually active or sexually satisfied was important to their definition of sexual satisfaction. For example, one woman defined sexual satisfaction as “being personally content with my level of sexual activity and being content with myself and my partner’s performance.” Another woman defined the concept as “being able to be sexually active and achieve satisfaction mentally and physically.” One woman provided a statement regarding the ability to achieve sexual satisfaction rather than a broad definition, stating, “I am able to get aroused and satisfied by my husband.” Finally, one response was more ambiguous than others were, stating that sexual satisfaction was “feeling like a woman.”

Messages about Sexuality as WwD

Overall, participants’ responses generally reflected that their families of origin were not very open to discussing issues of sexuality with them. The Strongly Disagree (SD) or Somewhat Disagree (SWD) responses to this item totaled 50.0%. Additionally, participants indicated that their families were not open to discussing sexuality as related to their specific disabilities (SD+SWD=57.1%). However, participants more frequently provided Strongly Agree (SA) or Somewhat Agree (SWA) responses (42.8%) than SD or SWD responses (28.3%) to the statement that they had received positive messages from family and friends about their sexuality. Participants generally disagreed with the statement that they had received positive messages about their sexuality from the media and society (64.3% SD or SWD). They indicated that they were Neutral toward (35.7%) or generally disagreed (35.7%) with the statement that messages about sexuality as a WwD had made it difficult to feel positively about their sexuality. In addition, 35.7% of respondents also were Neutral toward the statement that negative messages about the

sexuality of WwD had negatively impacted their sexual satisfaction. However, more respondents Strongly Disagreed or Somewhat Disagreed with this notion (42.9%) than Strongly Agreed or Somewhat Agreed (21.4%).

A distribution of the scores for this section was calculated (based on the 5-point Likert scale). A SA response was coded as 1, SWA as 2, Neutral as 3, SWD as 4, and SD was coded as 5. Two items in this section were reverse scored (see Appendix D). The possible range of scores was 6-30, though all scores fell from 10-29. The mean response for this section was 19.14 with a standard deviation of 5.051. This indicates that the average response to items on this section was 3.19. Results of the survey questions pertaining to the messages participants have received about their sexuality as WwD can be found in Table 1 in Appendix D.

Personal Feelings about Sexuality as WwD

Participants overwhelmingly agreed (Strongly or Somewhat) that sexuality is an important area of their lives (78.8%), that they had a strong desire for sexual intimacy and satisfaction (92.9%), that they enjoyed sexual intimacy and activity by themselves or with partners (64.3%), and that they had strong capacities for sexual satisfaction (85.7%). Participants also generally agreed (Strongly or Somewhat) that they feel good about their bodies (57.1%), that they feel good about their sexuality (78.5%), and that sexual satisfaction was attainable for them personally (64.3%). However, 50.0% of participants indicated disagreement (Strongly or Somewhat) with the statement that they have a satisfying sexual life while only 35.7% agreed (Strongly or somewhat).

On the item stating that disability has had positive effects on sexual satisfaction, 28.6% Somewhat Agreed, 28.6% provided a Neutral response, and 28.6% Somewhat

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Disagreed. In addition, the Strongly Agree and Strongly Disagree categories contained only one response each for this question. Therefore, the data for this item show no clear preference.

A distribution of the scores for this section was calculated (based on the 5-point Likert scale). A SA response was coded as 1, SWA as 2, Neutral as 3, SWD as 4, and SD was coded as 5. The possible range of scores was 9-45, though all scores fell from 7-36. The mean response for this section was 20.93 with a standard deviation of 7.343. This indicates that the average response to items on this section was 2.33. Results of the survey questions pertaining to participants' personal feelings about their sexuality as WwD can be found in Table 2 in Appendix D.

Interactions with Mental and Physical Healthcare Providers

Participants disagreed (Strongly or Somewhat) that they had been able to discuss their sexuality with mental or physical healthcare providers (64.3%). Participants also disagreed (Strongly or Somewhat) that they had been able to discuss their sexual pleasure or satisfaction with their healthcare providers (71.4%). In addition, half (50.0%) of participants disagreed (Strongly or Somewhat) that they had received adequate sexual information and education from providers about their specific disability and sexual needs. Some participants felt that they had received adequate sexual information from providers (21.4% SA or SWA) and 28.6% gave a neutral response to this item. 64.3% of participants agreed (Strongly or Somewhat) that they wished providers would have spent more time or effort discussing these issues with them, and the same percentage indicated feeling that providers had been hesitant to, or uncomfortable with, such discussions.

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When asked whether counseling about sexuality or sexual satisfaction as a WwD now or earlier in life would positively influence their experience of sexual satisfaction, more than half of participants provided a Neutral response (57.1%) while the remaining 42.9% Somewhat Agreed with this item. There were no responses to this item in the Strongly Agree, Strongly Disagree, or Somewhat Disagree categories.

A distribution of the scores for this section was calculated (based on the 5-point Likert scale). A SA response was coded as 1, SWA as 2, Neutral as 3, SWD as 4, and SD was coded as 5. Two items in this section were reverse scored (see Appendix D). The possible range of scores was 6-30, though all scores fell from 12-29. The mean response for this section was 20.64 with a standard deviation of 3.934. This indicates that the average response to items on this section was 3.44. Results of the survey questions pertaining to participants interactions with their mental and physical healthcare providers can be found in Table 3 in Appendix D.

Relevancy of Survey Items

Participants were asked to rank the relevancy of the questions in the three sections that inquired about received messages about sexuality as a WwD, personal feelings about sexuality as a WwD, and interactions with mental and physical healthcare providers. The majority (71.4%) of participants indicated that these items were Somewhat relevant to their experiences as WwD and to their sexual satisfaction, and 7.1% indicated that they were Very Relevant. However, 14.3% identified them as Somewhat Irrelevant and 7.1% were Neutral. There were no participants who indicated that the questions were Very Irrelevant.

Participants were also asked to expound on their relevancy ranking by providing additional questions that would more completely represent their experiences with sexual satisfaction as a WwD, or to provide any additional information that would help healthcare professionals understand their experiences. One participant responded to this item by stating that, as a virgin, it was difficult to answer questions about sexual satisfaction. This participant also indicated that, as a Catholic, she felt uncomfortable with some of the questions. One other participant indicated that she was raised Catholic and that she would therefore never talk to her family about sexuality or expect a therapist to initiate discussions on the subject. Another participant indicated that her disability did not impact her sexuality in any way.

One participant indicated that questions about peer influence, religious influence, and cultural influence would have helped the survey more completely represent her experiences. This participant also suggested questions about the “hang-ups” of partners or their families. Two participants had specific suggestions for healthcare providers. One of these participants indicated that providers should help patients to discover different sexual positions in order to achieve satisfaction, and the other stated her feeling that providers tend to discuss the negative aspects of disability and “what if’s” more than they discuss ways to gain sexual satisfaction.

Elements Important to the Experience of Sexual Satisfaction

Quantitative Responses.

There were several of the listed elements that participants rated as important (Very Important or Somewhat Important) by over 90% of participants. The element most consistently rated as Very Important (VI) to the sexual satisfaction of participants was the

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quality of communication they have with partner(s). This element was rated as VI by 78.6% of participants, and as Somewhat Important (SI) by 14.3%. Therefore, a total of 92.9% of participants ranked this item as important. There were two elements with the next highest frequency of VI responses, emotional intimacy with partner(s) and engaging in sensual touching or caressing with partner(s). Both of these elements were rated as VI by 71.4% of participants, with another 21.4% ranking these elements as SI (VI+SI=92.8%).

There were three elements that were rated as VI and SI with the exact same frequency. These were romantic closeness with sexual partner(s), engaging in deep kissing with partner(s), and the participants' perceptions of the attractiveness of their own bodies. All of these elements were rated as VI by 64.3% of participants and as SI by 28.6% of participants (VI+SI=92.9). For body attractiveness and deep kissing, the other 7.1% of participants rated these items as Neutral. For romantic closeness, the other 7.1% rated the item as Very Unimportant (VU). The last element which was rated as important (VI or SI) by over 90% of participants was having privacy to engage in sexual activities alone or with partner(s). This element was rated as VI by 61.5% and as SI by 30.8% (VI+SI=92.3). Only 13 participants responded to the item concerning privacy.

There were also a number of elements that were rated as VI or SI by 70-80% of participants. Among these, the element most frequently rated as VI was engaging in sexual foreplay with partner(s). This element was ranked VI by 50.0% and as SI by 28.6% of participants (VI+SI=78.6%). The element rated as important with the next highest frequency was the availability of sexual partners, with VI=42.9% and SI=35.7%

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for a total of 78.6%. Participants indicated that their partners' experiencing an orgasm was also important with VI=50.0% and SI=21.4% for a total of 71.4%. The participants' perception of their own ability to perform sexually was rated as VI by 42.9% and as SI by 28.6% (VI+SI=71.5%), and the frequency with which participants had sexual contact with partner(s) was rated as VI and as SI by 35.7% each (VI+SI=71.4%).

Four elements were rated as VI or SI by 50-70% of participants. Of these, the element most frequently rated as important was lack of pain or discomfort during sexual activities alone or with partner(s). This element was rated as VI by 30.8% and as SI by 28.5% (VI+SI=69.3%). Only 13 participants responded to the element concerning lack of pain or discomfort. The ability to experience clitoral orgasm was rated as VI=35.7% and SI=21.4% for a total of 57.1%, and the ability to experience vaginal orgasm was rated as VI and SI both at 28.6% for a total of 57.2%. Engaging in oral sex with partner(s) was rated as VI=16.7% and SI=41.7% for a total of 58.4%. Only 12 participants responded to the item concerning oral sex.

Two items were rated as VU or as Somewhat Unimportant (SU) by the majority of participants, and two items were rated in this manner by slightly less than half of participants. Among these four elements, engaging in anal sex with partner(s) was most consistently rated as VU (71.4%) or SU (7.1%). Therefore, a total of 78.5% of participants rated this item as unimportant. There was one participant (7.1%) that ranked this item in each of the other categories (VI, SI, and Neutral). Use of personal aide services to engage in sexual activities alone or with partner(s) was rated as VU by 46.2% and as SU by 15.4% of participants (VU+SU=61.6%). This item was ranked as VI by

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15.4% and as SI by 7.7% (VI+SI=23.1%). One participant did not respond to the item concerning use of personal aide services.

Use of sexual toys alone or with partner(s) was rated as VU by 28.6% and as SU by 14.3% (VU+SU=42.9%). This item was ranked as VI and as SI by 7.1% of participants each (VI+SI=14.2%), and as Neutral by 42.9%. The final element included in the survey was masturbation, which was ranked as VU and SU by 21.4% of participants each (VU+SU=42.8%). This item was ranked as VI by 7.1% and as SI by 14.3% of participants, and as Neutral by 35.7%. These two elements were the only two for which the most frequent response was Neutral.

A distribution of the scores for this section was calculated (based on the 5-point Likert scale). A VI response was coded as 1, SI as 2, Neutral as 3, SU as 4, and VU was coded as 5. The possible range of scores was 20-100, though all scores fell from 40-100. The mean response for this section was 75.11 with a standard deviation of 12.738. This indicates that the average response to items on this section was 3.76. Results of the survey questions pertaining to the importance of these various elements of sexual experience to participants can be found in Table 4 in Appendix D.

Relevancy of items.

Participants were asked to rank the relevancy of all of the above elements of sexual satisfaction to their experiences as WwD. Half (50.0%) of participants ranked these items as Very Relevant and another 42.9% ranked them as Somewhat Relevant. Only one participant ranked them as Neutral (7.1%) and no participants ranked the items as Somewhat Irrelevant or as Very Irrelevant.

Participants were also asked to list any related elements that would have helped the survey more completely represent their experiences with sexual satisfaction as WwD. Three participants provided a “no” response and 10 participants did not answer this question. One participant provided the response “cannot [sic] achieve sexual satisfaction by myself.”

Effect of changes in disability status.

Participants were asked to explain, if applicable, the ways in which changes in disability status or physical abilities has affected the importance of the elements listed in this section to their experience of sexual satisfaction. Nine participants provided no answer to this question. One participant gave the response “not applicable” and another gave the response “sort of a confusing question.” Another participant gave the response “hands and fingers don’t work at all.” Two participants gave more descriptive responses, with one stating that she was “scared to have sex after [her] accident for a long time” and one stating, “as my disability progresses sex is more difficult and more painful. My partner has to do more and it becomes harder for him. Sex is very infrequent.”

Barriers to Sexual Satisfaction

Quantitative responses.

There was one participant who only responded to one item in this section. Her results were not used for statistical analysis but are included in descriptive results. In this section, the largest proportion of responses fell into the Neutral category for each item. However, some trends did emerge. Religious institutions or professionals and the media were the two items that participants most frequently rated as having limited or negatively affected their experience of sexual satisfaction. For both of these items, 46.2% of

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participants agreed (strongly or somewhat) and 23.1% disagreed (strongly or somewhat) that these institutions have had negative effects on their sexual satisfaction. In both cases, 30.8% of responses were in the Neutral category. Two other items, friends and the participants themselves, were ranked as having had negative effects on sexual satisfaction by 30.8% of participants, while 21.1% disagreed that these institutions have had negative effects. For both of these items, 46.2% of responses were Neutral. Family was rated as having had negative effects by 30.8% of participants as well, but 15.4% of participants disagreed that family had had negative impact. Neutral responses to the family item were 53.8%.

Laws/legal professionals, medical institutions/professionals, and mental health institutions/professionals were all rated similarly. For these items, 46.2% of responses were Neutral. The percentage of participants who disagreed with the statement that these institutions had negatively affected their experience of sexual satisfaction was 30.8. Another 23.1% agreed that these institutions have had negative effects.

Educational institutions or professionals was the only item in this section to which all 14 participants responded. For this item, 57.1% of responses were Neutral. The percentage of participants who agreed that they had been negatively impacted by educational institutions and professionals was 14.2%, while 28.6% disagreed that these institutions had negative impact.

Sexual partners and romantic partners were the two items for which participants most frequently disagreed with the notion that they had been negatively impactful. For

these items, 53.9% of participants disagreed with the notion of their negative impact and only 7.7% agreed. In both of these cases, 38.5% provided a Neutral response.

A distribution of the scores for this section was calculated (based on the 5-point Likert scale). A SA response was coded as 5, SWA as 4, Neutral as 3, SWD as 2, and SD was coded as 1 (note that all items were reverse scored, see Appendix D). The possible range of scores was 11-55, though all scores fell from 16-45. The mean response for this section was 34.00 with a standard deviation of 6.481. This indicates that the average response to items on this section was 3.09. Results of the survey questions pertaining to the degree to which various people and institutions negatively affected participants' experience of sexual satisfaction can be found in Table 5 in Appendix D.

Qualitative responses.

Participants were asked to briefly describe the ways in which the above people or institutions limited or negatively affected their experience of sexual satisfaction. Four participants provided no response. In addition, one participant indicated that she did not understand the question and did not have a response after having it explained to her. The table below lists the verbatim responses that were provided. They have been changed only to correct minor spelling errors.

“Family being overprotective”

“I was not educated in rehab and I went years with no understanding”

“I've been negatively affected with the lack of knowledge provided to me by outside sources, other than that, I consider myself my only hindrance.”

“The only people that can actually affect my sexual satisfaction experience is myself and the person I am engaging in the sexual act with. It isn't about anyone or anything else.”

“My family has never discussed sexual issues. I had a partner with a disability that was

wonderful and he passed away. It is difficult to have a relationship with a non disabled person.”

“I don’t want anyone to know about anything I am doing/reading/watching to bring me sexual pleasure.”

“I answered earlier in questions, I wish the healthcare professionals would have been more open to me and asked me questions. I was young at the time and afraid to initiate the topic myself at the time of my accident. “

“The media has made it look like since I have a disability I am less attractive to men because my body is not formed perfectly and that hurts. “

A lot of my friends did not have disabilities. I remember becoming very close with a friend of my personal assistant (in college). My personal assistant introduced me to him, but never thought that we would hit it off because he had NEVER been around PWDs. He and I got very close and he was working through his own issues of “disability.” He was as surprised as I was that we were at a point in our friendship that we were thinking about taking things to the next level. I was in love with him. My personal assistant “out of concern for him and his potential to get hurt” informed him that my disability was considered terminal and he should consider how that would affect him. One thing led to another and we went separate ways.

Factorial MANOVAs

Two factorial MANOVA tests were performed on the scores from each of the five question areas (Messages about sexuality as WwD, Personal feelings about sexuality as a WwD, Interactions with health providers, Elements important to sexual satisfaction, and Barriers to sexual satisfaction) to test for the effects of age, education, income level, and disability type (congenital or acquired). In order to do this, the small sample size made it necessary to separate participants into two groups for each of the four variables used. For age, participants 18-30 were the *younger* group and participants 31-60 were the *older* group. For income, participants making \$10,000 or less were in the *lower income* group and participants making \$11,000 or more were in the *higher income* group. For education, participants with less than a BA were in the *less education* group and participants with a BA or more were in the *more education* group. There was a perfect

correlation between age and income, meaning that all participants in the *younger* group also were in the *lower income* group and all participants in the *older* group were also in the *higher income* group.

The first factorial MANOVA used the grouping variables age and education. At the .05 level of significance, there were no significant effects for age, education, or the interaction between these two variables (Wilks' Lambda p values all > .05). The second MANOVA used the grouping variables education and disability type. The main effects for education and disability type were not significant, but the interaction effect was marginally significant (p= .061). The two scales for which there were significant interaction effects were Messages about Sexuality and Barriers to Sexual Satisfaction. In both of these cases, education made a difference in the scores of participants with congenital disabilities, but not in the scores of those with acquired disabilities. For Messages about sexuality, the mean score for participants with less education and congenital disabilities was 15.71 and the mean for participants with more education and congenital disabilities was 28.00 (p= .040). For Barriers to sexual satisfaction, the mean score for participants with less education and congenital disabilities was 35.17 and the mean for participants with more education and congenital disabilities was 27.00 (p= .017). These results indicate that a higher level of education appears to be correlated with having received more positive messages about sexuality as WwD and with less negative impact on sexual satisfaction from institutions and professionals.

Other Comments Provided by Participants

Participants were asked to provide any other information that they wished for their healthcare professionals to know about their sexual satisfaction and the ways in

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which it relates to their overall wellbeing as WwD. Five participants responded to this question. Their verbatim responses are included below.

“I have to do things a little differently, but I am very satisfied and so is my partner.”

“I think it’s important to know that we are all human beings and all have similar wants/needs.”

“How do I do this?”

“That we are just women wanting the same things as those able bodied women.”

“Sexuality is inherent in every human. It’s not learned behavior and should be recognized and embraced.”

Participants were also asked to indicate whether any other questions would have helped the survey more completely represent their experiences with sexual satisfaction as WwD. One participant gave the response “no” and 11 provided no response. One participant gave the response “don’t know how to achieve sexual pleasure without being able to touch myself.” Another participant stated, “for many individuals (with and without disabilities) adult entertainment and films are used as a release of built up desire.”

Chapter V: Discussion and Conclusions

Demographics

The sample was largely white and heterosexual. In addition, participants were relatively young and well educated. However, eight of the 14 of participants reported an income that was below \$11,000. Therefore, it is likely that most, if not all of these 14 women received an income that was at or below the federal poverty level for one person according to federal standards (\$10,890; Federal Register, 2011). Many of the participants who reported this extremely low income were within the age-range typical of traditional college students and reported having achieved some college. In addition, when participants were separated into two age and two income groups for statistical analyses, all younger women had lower incomes and all older women had higher incomes. Therefore, the prevalence of low-income levels in this study may be due to many factors, such as low sample size, young age of participants, and lower education levels of many participants. However, it cannot be ignored that WwD often face discrimination that increases levels of unemployment and poverty (Turner & Turner, 2004). Low income and poverty may be particularly prominent among WwD who have multiple disabilities and among those who are also members of other oppressed groups (see Banks and Marshall, 2005 for a relevant discussion of the intersection of social class, race, gender, and disability).

The two questions pertaining to self-reported and identified disability severity (see items 14 and 15 in Appendix A) were not statistically correlated with each other in this study. There may be several reasons for this. For example, the small sample size may have prevented a statistically significant finding. Another factor may be that self-identified severity is contextual. A woman who uses assistance to complete grooming and personal hygiene tasks may rate her disability as mild when she has access to a personal aide or other appropriate accommodations but may feel more severely impaired when these accommodations are not available. In addition, it should be noted that these two items might not be well correlated due to differences between the perceptions of women with disabilities and those of the medical community that has traditionally defined severity. In other words, the need for assistance with grooming and hygiene tasks may not necessarily increase a woman's perception of her disability severity.

Definitions of Sexual Satisfaction

Participants reported various definitions of sexual satisfaction and a wide range of elements that contribute to their sexual satisfaction. Their definitions primarily reflected the importance of the relational and physical aspects of sexuality. In addition, past research indicates the similarities between these definitions and the qualities important to the sexual satisfaction of AB women. For example, Byers, (2001) and Dundon and Rellini (2010) discuss the importance of relationship satisfaction and adjustment to sexual functioning and sexual satisfaction. Hurlbert, Apt, and Rabehl (1993) indicate that relationship closeness may be even more important to the sexual satisfaction of women than are more physical factors such as sexual functioning and frequency of sexual activity. Similarly, Philippsohn and Hartmann (2009) showed that, in a sample of

German women, feeling close to one's partner was an important factor in determining sexual satisfaction. These authors also indicated that orgasm frequency and sexual intercourse were important factors, which is consistent with the results of the present study.

Messages about Sexuality as WwD

Generally, participants indicated that their families of origin were not open to discussing sexuality in general or sexuality as related to disability. Despite this, many participants indicated that they had received positive messages from family and friends about their sexuality. Participants generally indicated, however, that they had not provided them with positive messages about sexuality as WwDs. Though participants may have received some negative messages from various sources, they were generally Neutral toward or disagreed with statements that such negative messages had affected their ability to feel positively about their sexuality or their sexual satisfaction. It is possible that many women felt that they had been able to disregard the negative messages they received, or that they had received enough other positive messages to ameliorate the effects of the negative messages. It is also possible that some of these responses reflect the possible internalized shame regarding the power of negative social messages. Some participants may have sought to protect themselves, or the WwD population as a whole, by indicating that negative messages were unable to exert enough power over them to reduce their satisfaction.

A high proportion of responses to the items pertaining to messages about sexuality as a WwD fell into the Neutral category, and the average response to this set of items was about Neutral (3.19). There are many possible reasons for this. For example,

participants may have found the questions to be confusing or irrelevant to their experiences. It is also possible that participants were unsure about the messages they had received from various sources, or that they genuinely did not agree or disagree with the items. In addition, participants may have received both positive and negative messages from the various sources listed, leading them to weigh both and to choose the Neutral response.

Statistical analyses revealed that more highly educated women with congenital disabilities had higher overall scores on these items. This indicates that, for women with congenital disabilities, education may mediate the effect of negative messages. Another possibility is that women with more education came from families of origin who were also highly educated and able to provide them with more information, resources, etc that contained positive messages about sexuality as WwD. Since there was no effect for women with acquired disabilities, it may be that the items about family of origin were not relevant to their experiences, if the disability was acquired in adulthood. They may have therefore been more likely to rate these items as Neutral, SWD, or SD. These results are consistent with those of McCabe and Taleporos (2003), who found that WwD who had lived with their disability for longer periods of time had more positive feelings about sexuality.

Personal Feelings about Sexuality as a WwD

The majority of participants reported believing that sexuality is an important area of their lives, that they have a strong desire and a strong capacity for sexual satisfaction, and that they enjoy sexual intimacy and activities. This is consistent with the work of Vansteenwegen, Jans, and Revell (2003) which found no differences in sexual desire

when comparing a sample of 82 WwD and 85 AB women on responses to a sexuality questionnaire.

Participants indicated generally feeling good about their sexuality. In addition, over half of participants indicated feeling good about their bodies, although several participants did not. Generally, participants felt that sexual satisfaction was attainable for them personally, though again there were exceptions. Responses were mixed to the item on the potential positive effects of disability on sexuality in the present study. Arno (2002) conducted interviews with women with Lupus and found that two of the 10 participants reported having greatly improved sex lives due to their illness, and another two stated that lupus had led to improvements in their relationships with sex partners. These women indicated that adapting to their illness increased their sexual self-acceptance and sexual pleasure, and well and their understanding of the characteristics they desired in romantic partners. Taken with the results of the current study, these results indicate that a subset of WwD may feel that they have experienced positive sexual consequences of disability, and counselors should take care not to assume that disability leads only to negative consequences in this area.

Half of the participants disagreed that they had a satisfying sexual life. This latter item particularly lowered the average response to this set of questions, which was 2.33. The set of questions pertaining to personal feelings about sexuality in WwD was the only one to which the average response based on statistical calculations was less than Neutral. Participants in this study were not asked to provide reasons for feeling positively or negatively about their bodies, their sexuality, the positive effects of disability on

sexuality, or their general sexual life. However, these may be considerations for future studies in the area of sexuality and disability.

Interactions with Mental and Physical Healthcare Providers

Participants generally indicated that they have not been able to discuss their sexuality or sexual satisfaction with mental or physical health providers and those mental and physical health professionals have been hesitant to, or uncomfortable with discussing sexuality and sexual satisfaction with them. While some participants felt that they had received adequate sexual information and education, the majority did not feel this need had been met or were Neutral toward this item.

Bridges, Lease, and Ellison (2004), who performed a nationwide study of sexual satisfaction in the general population of women, discuss the importance of adequate training for counselors in the area of sexuality. They state that counselors need to be trained in communicating with clients about this topic and in teaching clients to understand and communicate about their own sexuality. In addition, Juergens and Smedema (2009) discuss the ways in which myths about disability and sexuality, as well as the societal barriers to sexuality for people with disabilities. These authors emphasize the importance of including discussions of sexuality in the rehabilitation and treatment of individuals with disabilities.

Providers must take responsibility for initiating discussions of sexuality with WwD. As is reflected in many of the open-ended responses of the women in this study, WwD may be uncertain about how to talk about sex and sexual satisfaction with their providers, or may be embarrassed to introduce these topics. In addition, some

participants suggested that religious or cultural beliefs might be very important to consider in discussing issues of sexuality. Providers should always attempt to ensure that they provide counseling and information that is sensitive to the spirituality and culture of WwD (Curry and Simpson 2011).

It is interesting that most participants generally indicated that they wished providers would have spent more time discussing issues of sexuality with them, but were did not necessarily indicate a strong past or present desire for sexual counseling. Given that no participants disagreed with the item pertaining to a desire for counseling, the responses could possibly reflect uncertainty that counseling could help to increase their experience of sexual satisfaction. Another possibility is that participants are uncertain about or unfamiliar with the process of counseling. Mental health stigma may also have affected participants' reactions to the word counseling.

Yet another strong possibility for the tepid response to the desire for counseling in the current study is evident in the work of Li and Yau (2006). These authors indicate that the attitude of health professionals toward sexuality can be a very influential factor in the sexual lives of women with disabilities. These authors interviewed 10 Chinese women with disabilities secondary to polio or SCI. These women consistently stated that they had not been provided with sufficient information on sexuality during hospitalizations. Similar to the present study, the participants of Li and Yau stated that rehabilitation professionals and mental health professionals were often reluctant to discuss sexuality, or were not well educated on issues of sexuality and disability themselves. In addition, the educational materials they were provided focused on male sexuality. Some of the women

in this study indicated that receiving education for themselves and their partners about sexuality and disability was very helpful and reduced the negative impact of the disability on their relationships. However, not all women desired information and education on sexuality. A commonly stated reason for this was the perception and experience that health professionals were not sensitive or knowledgeable about their patients' needs during recovery. Therefore, when working with WwD, counselors and professionals should be aware that many of their clients have had negative, disappointing, or demoralizing experiences with other health professionals. These authors also suggest that inviting partners into sexual education or counseling can reduce clients' feelings of helplessness during recovery.

Elements Important to the Experience of Sexual Satisfaction

Participants indicated the importance of many sexual activities and elements of sexuality. Some of the items most frequently related as Very Important included those pertaining to relational aspects of sexuality including romantic closeness, emotional intimacy, and the quality of communication with a partner. These data are consistent with the many of the definitions of sexual satisfaction provided by participants. They are also consistent with several studies that emphasize the importance of intimacy, emotional closeness, and relationship satisfaction for sexual functioning and satisfaction (Byers, 2001; Dundon & Rellini, 2009; Hulbert, Apt, & Rabehl, 1993; Philippsohn and Hartmann, 2008).

Engaging in deep kissing and sensual touching were rated highly with similar frequency. This is consistent with the results of McCabe and Taleporos (2003) who found that the sexual satisfaction of WwD was predicted by the frequency with which

they engaged in keep kissing. However, Philippsohn and Hartmann (2008) found that only 41.1% of the 102 AB women they surveyed reported high levels of satisfaction from sexual petting, or mutual touching of the genital areas. Although the present study did not specifically define sensual touching as being restricted to the genital area, these concepts may be similar. It may be possible; therefore, that sensual touching is of greater importance to WwD than to AB women, although it would be necessary to compare these groups directly in future studies to determine the validity of this speculation.

Finally, perception of one's own body attractiveness and having privacy to engage in sexual activity were rated highly by almost all participants. Dundon and Rellini (2002) found that, in a sample of 93 AB women between the ages of 40 and 70, attitudes towards one's body did not predict sexual satisfaction. This is in contrast to the more recent work of Pujols, Meston, and Seal (2010), who found that many aspects of body image predicted sexual satisfaction in a sample of 125 women between the ages of 18 and 49. Moin, Duvdevany, and Mazor compared 70 women with disabilities to 64 women without disabilities and found that both body image and sexual satisfaction were significantly lower in WwD. Li and Yau (2006) and Taleporos and McCabe (2002b) also discuss the importance of body image in sexuality for WwD. Body image appears to be a very important factor in the sexual satisfaction of WwD, and may also be very important for AB women.

Those elements that were with rated highly with slightly less frequency, although still considered important by the majority of participants, were engaging in sexual foreplay with a partner, the frequency of sexual contact with a partner, the partner

experiencing orgasm, and the participants' ability to perform sexually. Three of these might also have a strong relational component, as they are activities performed with a partner. Slightly over half of participants considered the elements of oral sex, vaginal and clitoral orgasms, and lack of pain or discomfort during sex to be important to their sexual satisfaction. Results of the items pertaining to orgasm were consistent with the results of Philippsohn and Hartmann (2008), who found that orgasm was often important to the experience of sexual satisfaction in AB women, but that many women reported high satisfaction despite low orgasm frequency, or low satisfaction despite frequently experiencing orgasm. Therefore, while orgasm may be important for some women, it may be a much less essential part of sexual satisfaction for others.

Elements that generally received Neutral responses, or were considered generally unimportant, were masturbation and use of sexual toys. Regarding masturbation, Philippsohn and Hartmann (2008) found that their sample of AB women engaged in masturbation relatively infrequently (median less than once per month), and that masturbation was significantly less important for satisfaction than intercourse. In addition, Bridges, Lease, and Ellison (2004), who surveyed a nation-wide sample of 2,632 women in the United States (disability status was not reported for participants); found that frequency of masturbation was negatively correlated with sexual satisfaction from intercourse and other genital contact. Conversely, Hurlbert and Whittaker (1991) found that women who masturbated reported a higher degree of sexual satisfaction than women who did not. Therefore, it is possible that many women do not find masturbation important or have specific religious or cultural values that prohibit it, but that it is an essential part of sexual satisfaction for other women. Bridges, Lease, and Ellison (2004)

posit that frequent masturbation may be an indication of increased comfort with one's body or sexuality. This level of comfort, therefore, may make them more likely to obtain sexually satisfying experiences. It is also possible that the relatively low importance of masturbation for WwD in this sample may have been impacted by partner status or the inability to engage in unassisted masturbation. These may be considerations for future studies.

Two items were rated as Very or Somewhat Unimportant by more than half of participants. These items were those pertaining to engaging in anal sex with a partner and the use of a personal aide to engage in sexual activities alone or with a partner. It may be that these activities were rated as unimportant because their taboo nature reduces the frequency with which they are practiced. Regarding the latter of these two elements, it should be considered that 92.3% of participants rated having privacy to engage in sexual activity as Very or Somewhat Important. Therefore, it is possible that participants have internalized shame regarding the use of a personal aide to engage in sex. In addition, only two of the 14 participants stated they used a personal aide to complete the study, and six participants stated they regularly used assistance for grooming or hygiene. Given these factors, it may be reasonable to conclude that many participants did not need the services of a personal aide to engage in sexual activity by themselves or with partners. Another possibility is that partnered participants relied on their partners, rather than a personal aide, for any assistance they required to have sex.

Barriers to Sexual Satisfaction

Responses on questions pertaining to barriers to sexual satisfaction overwhelmingly fell in the Neutral category. However, participants generally indicated

that religious institutions or professionals had negatively affected their sexual satisfaction. They also indicated that their sexual satisfaction had been negatively impacted by both the media and by themselves. The fact that many respondents indicated that they had negatively affected their own experience of sexual satisfaction may represent self-blame for societal and institutional barriers to sexual satisfaction or internalization of negative messages about their sexuality. Participants generally indicated that their sexual and romantic partners had not negatively influenced their experience of sexual satisfaction. This may indicate that participants have generally had positive sexual experiences with their partners.

Statistical analyses revealed that more highly educated women with congenital disabilities had higher overall scores on these items (reverse scored). This indicates that education had a mediating effect of the barriers to sexual satisfaction for women with congenital disabilities. As with the similar effect of education on messages about sexuality (above), educated families of origin, better understanding of cultural biases, more educated or understanding peer groups, and longer time living with disability than WwD with acquired disabilities might have contributed to this result. It is important to understand these results in the context of the small sample size, however. The meaning of these results, as well as their generalizability, is limited.

Qualitative responses provided to expound upon ratings of barriers to sexual satisfaction revealed several themes. Some of the nine participants who provided open-ended responses in this area indicated that their family or other significant persons either were not open to discussing sexuality or was overprotective of them. Some others indicated that healthcare professionals did not provide sufficient education or information

about sexuality. One participant commented that the media representation of disability negatively affected her sexuality. Two participants indicated the viewpoint that their sexuality should be private. This may indicate that they feel their sexual satisfaction is not hindered by other people or institutions, or may be a reflection of a lack of desire to talk to professionals about sexuality.

Feedback on Survey Items

While conclusions in this area are limited due to the low response rate, there are several implications of the feedback provided by participants. For example, the majority of participants indicated that the items pertaining to messages about sexuality, personal feelings about sexuality as a WwD, and interactions with mental and physical health professionals were Somewhat Relevant to the experiences as a WwD. In addition, 13 participants indicated that the items pertaining to elements important to sexual satisfaction were Somewhat Relevant to Very Relevant to their experiences as a WwD and the one remaining participant indicated that she was “neutral” as to the relevance of the listed elements to her experience of sexual satisfaction. These results indicate that, in general, participants found the survey questions relevant to their experiences. However, there was some variability in responses.

Qualitative responses provided some insight into ways in which the relevancy of this survey might be improved, and also raise important points. For example, one participant indicated that her lack of sexual experience made it difficult to answer some questions, and they may not have been relevant to her for that reason. Future studies or surveys may benefit from items that assess participants’ sexual experience. Another

participant indicated that her disability did not affect her sexuality in any way, which also may have reduced the relevancy of some questions for this participant.

In addition, some responses indicated the importance of religious or cultural influence on the sexual expression and satisfaction. It may be particularly important for healthcare providers to consider the intersection of specific religions and their views on sex and disability. That is, the religion's views on the purpose of sex, its purported reasons that particular individuals have disabilities, its prescriptions for living with disability, and its level of encouragement and support for WwD who wish to be sexually active or to reproduce.

Other responses indicated the desire for specific information from healthcare providers that may also be relevant for future versions of this survey. Specifically, participants indicated that information on sexual positions, general functionality, and adaptations for sex with disability would be helpful. Some participants indicated a desire to be understood and perceived as having similar sexual interests as AB women. These responses could inform future survey items.

Limitations and Implications for Future Research

Survey.

There were several limitations of the present study that should be considered in future research pertaining to the sexuality of WwDs. First, the present survey did not sufficiently account for the impact of multiple physical disabilities, which may be either congenital or acquired. The present study asked WwDs to identify the name of their disability and classify it as either congenital or acquired. It also asked a question pertaining to non-physical disabilities. However, within the present study participants

with multiple physical disabilities may have been forced to choose the one they wished to represent for the survey.

Another limitation of the survey was that participants who were partnered at the time that they acquired their disability were not directly asked whether they were currently with the same partner. Participants were only asked to identify whether they were partnered at the time of disability onset and whether they were currently partnered. This information is not sufficient to make inferences about the frequency with which participants' intimate relationships remained intact or ended following disability onset. Li and Yau, (2006) discuss the possible impacts of disability on partners, and this may be an important element to consider in future studies. Future versions of the study may also benefit from inquiring about the disability status of the participants' partners. One participant in the present study commented that she has found it difficult to have relationships with AB men, and partner disability status may be relevant to the sexual relationships and satisfaction of many WwDs.

Some participants may have had partners or other friends or family members that aided them with daily tasks, and may have also aided them in completing the survey. Participants may be confused about how to answer the item inquiring about use of a personal aide to complete the study if someone other than a hired personal aide was providing assistance. The question may also have been confusing if participants interpreted mechanical or technological assistance as sufficient to answer the question in the affirmative. Therefore, it may be appropriate to expand and alter the item. Using an item that inquires about the use of help from any other person to complete the study may

also increase the relevance of a comparison between the survey responses of those using the help of another person to complete the study and those completing it by themselves.

The survey used in the present study included items pertaining to the quality of sexuality education and information received by participants. The addition of a question that measures specific knowledge about sex and disability may have been useful in this section. For example, participants could have been asked about the specific resources on the subject with which they were familiar, if any, such as particular books, magazines, or websites. This may have provided a more objective measure of knowledge about sexuality and disability.

It may be possible to enrich the data collected from the participants' subjective definitions of sexual satisfaction (with a larger sample) by conducting an analysis of the most frequently used words. This would be similar to the study conducted by Bridges, Lease, and Ellison (2004) in which women were asked to list feeling states that they experienced following satisfying sexual activity. The authors then ranked the words used according to their frequency, with the most frequently used word being "loved." It would also likely be helpful to assess the reasons that participants indicated that they were either sexually satisfied or not sexually satisfied.

There are an infinite number of elements that might contribute to the sexual satisfaction of WwD and the list used in the present study is certainly not exhaustive. Based on participants' qualitative responses, it may be useful for future studies to inquire about the importance of pornography and adult entertainment, the participants' perceived ability to perform sexually, and knowledge about specific sexual positions. The

comments of one participant alluded to the fact that lack of sexual experience might significantly affect the relevancy of the survey questions as well as the responses given. Future studies may benefit from including an item that assesses whether or not participants have been sexually active. In addition, the present study did not inquire about the importance of intercourse, specifically, and this may be an important addition in future studies. Other possible elements or areas to assess include specific effects of religious or cultural prescriptions on sexual behavior, the frequency of specific sexual behaviors, the importance of partner-initiated versus self-initiated sex, the importance placed on the spontaneity of sex, and the importance of the partner's sexual functioning. It may also be helpful to inquire as to the reasons that particular items are rated as important or unimportant. For example, the current study generally placed lower importance on the element of masturbation, though there may be many reasons for this (see above Discussion and Conclusions section).

Because the literature indicates that WwD experience high prevalence of sexual assault (Martin, Ray, Sotres-Alvarez, Kupper, Moracco, Dickens, et al.; Nannini, 2006), it was considered that future studies could inquire about assault victimization to explore how this factor might affect sexual satisfaction. However, the inclusion of such items would have to be carefully considered to avoid confounding responses to other survey questions. In addition, the possibility of inducing discomfort or distress due to participation in the study might be significantly increased with the inclusion of such items. It is the intention of the authors of the present study to continue to discuss such concerns with members of the disability community in making decisions about which items should be included in future versions of this research.

Future studies may also contribute significantly to the literature on sexuality and disability by delving into specific reasons that participants feel that some elements are more important than others. It may also be useful to explore the reasons that participants felt either positively or negatively about the other areas investigated in the study, such as their bodies, their sexuality, and the effects of disability on sexuality or their general sexual life. Finally, while the present study solicited comments from participants following the questions pertaining to the relevancy of survey items, richer data might have been received by asking which items specifically were less relevant and why participants viewed them as such.

Study.

The biggest limitation to the present study was the extremely low response rate. It is estimated that the request for participation reached several hundred people through the list-serves employed for recruitment. There may be several reasons for the low level of participation in this study. First, the taboo nature of the subjects of sex and disability, particularly in women, may have contributed. This seems particularly likely given the high number of people who opened the study but did not answer any questions. Participants also may have feared that the researchers, or others, would discern their identity based on their responses, even though confidentiality was explained in the consent form at the beginning of the survey.

The fact that 27 individuals opened the study but proceeded no further than the initial consent form is interesting. It is possible that, after reading the consent form these individuals were no longer interested in participating. It is also possible that, after noting the amount of time required to participate, they were unwilling or unable to continue.

Another possibility is that individuals were curious enough about the study to open it, but did not wish to provide responses. It may be useful for future studies to explore the reasons for attrition. If possible, an item could be included at the end of the consent page that asks individuals to indicate why they are not participating, should they make that choice. There are several possible ways to increase participation and/or reduce attrition in future studies. These include such strategies as offering an incentive to participate (e.g. a drawing for a gift certificate), reducing the amount of time needed to participate (e.g. by shortening the survey or creating multiple pathways to complete it to reduce the need to answer irrelevant items), recruiting from a national sample, and creating multiple formats of the study (e.g. internet and pencil/paper forms).

Due to the small sample size, as well as possible sampling bias, the generalizability of the current study is questionable. For example, the taboo nature of the study may have ensured that only those WwD who had a certain level of comfort with discussing sexuality completed the study, despite the fact that some participants did express discomfort with the subject. In addition, the racial and educational diversity of the sample was severely limited, as was diversity in sexual orientation. While the sample had some diversity in income level, the sample is consistent with the assertion of Suarez-Balcazar, Balcazar, and Taylor-Ritzler indicating that internet research tends to reach individuals with higher levels of education.

The disabilities most frequently reported among participants were Spina Bifida and acquired paralysis. While other types of disability were also reported, results may not generalize to all WwD. In addition, most of the participants were recruited through the disability services office of a university and through an organization that aids

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individuals with disabilities in living independently. Therefore, it is possible that the current results are not generalizable to WwDs who do not regularly require the types of assistance or accommodations that these organizations provide.

Chapter VI: Summary

There exist many cultural myths and assumptions about sex, disability, and women's issues that have the potential to negatively affect the sexuality and sexual satisfaction of WwD. Though there has recently been a paradigm shift to the social minority model of disability, both society and psychological literature have much room to improve the ways in which WwD are viewed, treated, counseled, and understood. The present study attempted to provide descriptive groundwork for a better understanding of the sexual satisfaction of WwD that could possibly lead to the future development of a sexual satisfaction measure for this population.

There are several clinical implications of the present study. For example, counselors and healthcare professionals should be aware that sexual satisfaction may be highly important to the general well-being of their WwD clients. . Moin, Duvdevany, and Mazor (2009) found that WwD had significantly lower general life satisfaction, and that 42% of the variance in life satisfaction among WwD was due to sexual satisfaction. The present results also reflect the importance of sexuality and sexual satisfaction in the lives of WwD. Davison, Bell, LaChina, Holden, and Davis (2009) demonstrate that this is also the case for AB women by showing a similar link between sexual satisfaction and general well-for that population.

In addition, results of the present study and other reviewed literature highlight the importance of relational aspects of sexuality as well as concerns about body image.

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Counselors and healthcare professionals should pay particular attention to these areas when working with WwD. In addition, it is important that counselors take responsibility for being sensitive and knowledgeable to the needs of WwD. The results of past or current research, while vitally important for increasing knowledge and sensitivity, are not sufficient for providing competent care. Professionals must understand the particular needs and experiences of their individual clients and must take into account their specific concerns and preferences. Professionals should consider that many WwD may be reluctant to discuss sexuality due to specific religious or cultural prescriptions, past negative experiences with providers, or the effect of internalized myths and oppressive sociocultural standards. Therefore, approaching topics related to sexuality should be done with respect, open-mindedness, and sensitivity to the multiple sociocultural and individual factors influencing clients.

It is also important that future research continue to explore the area of sexual satisfaction in WwD. Consistent with the tenants of PAR, this research should use the voices of WwD to inform it at all stages of development and execution. Continued knowledge in this area is essential to aiding healthcare professionals in improving the lives of WwD and to fighting the oppressive sociocultural elements of the dominant culture.

Appendix A

Elements of Sexual Satisfaction in Women with Physical Disabilities

Demographics

In the following section, select all that apply or fill in the blank. If you do not feel comfortable answering any of the following questions, skip to the next question.

1.) What is your gender?

- Male
- Female
- Prefer not to say

2.) What is your ethnicity?

- White/European American
- Black/African American
- Latino/Latina
- Asian American
- Other
- Prefer not to say

3.) What is your age range?

- Under 18 years
- 18-23 years
- 24-30 years
- 31-40 years
- 41-50 years
- 51-60 years
- 61 years or above
- Prefer not to say

4.) Which of the following best describes your partner status?

- Single
- Partnered and living apart
- Partnered and living together
- Separated or divorced
- Widowed
- Prefer not to say

5.) Which of the following best describes your living situation?

- Live alone

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- Live with partner
- Live with family member(s)
- Live with roommate(s)

6.) Which of the following best describes your sexual orientation?

- Heterosexual
- Bisexual
- Homosexual
- Prefer not to say
- Other

7.) What is the highest level of education you have achieved to this date?

- GED or high school diploma
- Some college
- Associate's or equivalent degree
- Bachelor's degree
- Graduate-level degree

8.) What is your current individual income range?

- \$4,999 or less
- \$5,000-10,000
- \$11,000-15,000
- \$15,000-30,000
- \$31,000-45,000
- 46,000-60,000
- 61,000-75,000
- 76,000 or above

9.) What is the name of your disability/diagnosis?

10.) Which of the following best describes the onset of your disability?

- Congenital (present from birth)
- Acquired (onset after birth) Please specify age of onset

11.) If your disability was acquired after birth, please briefly describe the circumstances surrounding onset (e.g. car accident, work-related injury, seizure, brain injury, etc)

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12.) If your disability was acquired after birth, please specify your partner status at the time the disability was acquired

- Single
- Partnered and living apart
- Partnered and living together
- Separated or divorced
- Widowed
- Prefer not to say

13.) Do you have a secondary or additional non-physical disability?

- Yes: please specify
- No

14.) How would you define the severity of your disability? Question adapted from Taleporos and McCabe (2002).

- Mild
- Moderate
- Severe

15.) Do you regularly use assistance to complete tasks related to grooming and personal hygiene (e.g. getting dressed, brushing teeth, bathing)? Question adapted from Taleporos and McCabe (2002).

- Yes
- No

16.) Are you using a personal aid to help you to complete this study?

- Yes
- No

Influences on Sexual Satisfaction

17.) As a woman with a physical disability, how would you personally define sexual satisfaction?

18.) Please indicate your level of agreement with each of the statements below. Please note: WwD = Woman with a disability

Messages about sexuality as a WwD

	1	2	3	4	5
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	Strongly Agree	Somewhat Agree	Neutral	Somewhat Disagree	Strongly Disagree
My family of origin was open to discussing issues of sexuality with me growing up	()	()	()	()	()
My family of origin was open to discussing sexuality as related to my disability with me	()	()	()	()	()
I have received mostly positive messages about my sexuality as a WwD from family and friends	()	()	()	()	()
I have received mostly positive messages about my sexuality as a WwD from media and society	()	()	()	()	()
It is difficult for me to feel positive about my sexuality as a WwD due to the messages I have received from others and from the media about the sexuality of people with disabilities	()	()	()	()	()
Negative messages about the sexuality of WwD have negatively impacted my personal experience of sexual satisfaction	()	()	()	()	()

19.) Please indicate your level of agreement with each of the statements below. Please note: WwD = Woman with a disability

Personal feelings about sexuality as a WwD

	1 Strongly Agree	2 Somewhat Agree	3 Neutral	4 Somewhat Disagree	5 Strongly Disagree
I believe that sexuality is an important area of my life	()	()	()	()	()
I have a strong desire for sexual intimacy and sexual satisfaction	()	()	()	()	()
I enjoy sexual intimacy and sexual activities by myself and/or with partner(s)	()	()	()	()	()

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As a WwD, I believe I have a strong capacity for sexual satisfaction	()	()	()	()	()
My disability has had positive effects on my sexual satisfaction	()	()	()	()	()
I feel good about my body	()	()	()	()	()
I feel good about my sexuality	()	()	()	()	()
I feel that sexual satisfaction is attainable for me	()	()	()	()	()
I feel that I have a satisfying sexual life	()	()	()	()	()

20.) Please indicate your level of agreement with each of the statements below.

Interactions with Mental and Physical Healthcare Providers

	1 Strongly Agree	2 Somewhat Agree	3 Neutral	4 Somewhat Disagree	5 Strongly Disagree
I received adequate sexual information and education from mental or physical healthcare providers related to my specific disability and sexual needs	()	()	()	()	()
I have been able to discuss my sexuality with mental or physical healthcare providers	()	()	()	()	()
I have been able to discuss my sexual pleasure or satisfaction with physical or mental health providers	()	()	()	()	()
I wish that physical or mental health professionals with whom I have interacted would have spent more time and or effort discussing issues of sexuality and sexual satisfaction with me	()	()	()	()	()
I feel that physical or mental health professionals have been hesitant to, or uncomfortable with, discussing sexuality and	()	()	()	()	()

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sexual satisfaction with me					
I feel that receiving counseling about my sexuality and sexual satisfaction as a WwD now or earlier in my life would positively influence my experience of sexual satisfaction	()	()	()	()	()

21.) Please rate the relevancy of the questions on this page to your experiences as a WwD and the factors that influence your experience of sexual satisfaction?

- () Very relevant
- () Somewhat relevant
- () Neutral
- () Somewhat irrelevant
- () Very irrelevant

22.) Based on your answer to question #21, are there related questions that would have helped this survey more completely represent your experiences with sexual satisfaction as a woman with a disability? Please add and answer any such questions or provide any additional information that would be helpful for your physical and mental health professionals to know about your experiences.

Elements Important to the Experience of Sexual Satisfaction

23.) Please rate the importance of each of the following to your personal experience of sexual satisfaction

	Very Important	Somewhat Important	Neutral	Somewhat Unimportant	Very Unimportant
My perception of the attractiveness of my body	()	()	()	()	()
My ability to perform sexually	()	()	()	()	()
My ability to experience a clitoral orgasm	()	()	()	()	()
My ability to	()	()	()	()	()

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experience a vaginal orgasm					
My partner(s) experiencing orgasm	()	()	()	()	()
The frequency with which I have sexual contact with a partner(s)	()	()	()	()	()
The availability of a sexual partner(s)	()	()	()	()	()
Romantic closeness with a sexual partner(s)	()	()	()	()	()
Emotional Intimacy with a partner(s)	()	()	()	()	()
The quality of the communication I have with a partner(s)	()	()	()	()	()
Engaging in sexual foreplay with a partner(s)	()	()	()	()	()
Engaging in deep kissing with a partner(s)	()	()	()	()	()
Sensual touching/caressing with a partner(s)	()	()	()	()	()
Masturbating	()	()	()	()	()
Engaging in oral sex with a partner(s)	()	()	()	()	()
Engaging in anal sex with a partner(s)	()	()	()	()	()
Use of sexual toys by myself or with a partner(s)	()	()	()	()	()
Having privacy to engage in sexual activities by myself or with a partner(s)	()	()	()	()	()
Use of a personal aid to engage in sexual activities by myself or with a partner(s)	()	()	()	()	()
Lack of pain or discomfort during sexual activities by	()	()	()	()	()

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myself or with a partner(s)					
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24.) Please rate the relevancy of the elements of sexual satisfaction listed in question #23 to your experiences as a WwD and the factors that influence your experience of sexual satisfaction?

- Very relevant
- Somewhat relevant
- Neutral
- Somewhat irrelevant
- Very irrelevant

25.) Based on your answer to question #24, are there related elements that would have helped this survey more completely represent your experiences with sexual satisfaction as a woman with a disability? Please add and answer any such questions or provide any additional information that would be helpful for your physical and mental health professionals to know about your experiences.

26.) If applicable, how have changes in your disability status or physical abilities affected the importance of the above elements to your experience of sexual satisfaction?

Barriers to Sexual Satisfaction

27.) Please rate your level of agreement that the following have limited or negatively affected your experience of sexual satisfaction

	Strongly Agree	Somewhat Agree	Neutral	Somewhat Disagree	Strongly Disagree
educational institutions or professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
religious institutions or professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
laws/legal professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
medical institutions/professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
mental health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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institutions/professionals					
Family	()	()	()	()	()
Friends	()	()	()	()	()
sexual partners	()	()	()	()	()
romantic partners	()	()	()	()	()
the media	()	()	()	()	()
Myself	()	()	()	()	()

28.) Please briefly describe the ways in which the above people or elements have limited or negatively affected your experience of sexual satisfaction

29.) What else would you like for the healthcare professionals with whom you have worked to know about your sexual satisfaction and the ways in which it relates to your overall well-being as a woman with a disability?

30.) Are there any other questions that would have helped this survey more completely represent your experiences with sexual satisfaction as a woman with a disability? Please add and answer any such questions or provide any additional information that would be helpful for your physical and mental health professionals to know about your experiences.

V. Thank You!

Thank you for your time! You may contact Jessica Heschel at heschel.2@wright.edu if you have questions regarding this study or its results.

Appendix B

Recruitment Emails for Elements of Sexual Satisfaction in Women with Physical

Disabilities: Results of an Online Survey

TO: Clients of the Office of Disability Services (ODS) at Wright State University;
TO: Clients of the Dayton, OH Access Center for Independent Living (ACIL)
TO: School of Professional Psychology Community

FROM: Jeffrey A. Vernooy, Director, ODS;
FROM: Alan R. Cochrun, Executive Director, ACIL
FROM: Jessica Heschel, Psy.M.
 Doctoral Candidate
 Wright State University
 School of Professional Psychology

Julie Williams, Psy.D., C.R.C.
Dissertation Supervisor

Are you a woman 18 years or older with a physical disability?

If so, please consider participating in the following research study:

Jessica Heschel, a doctoral student in the School of Professional Psychology at Wright State University, is conducting an online survey that will investigate the ways in which women with physical disabilities define and think about their sexual satisfaction. This research is being conducted under the supervision and advisement of Dr. Julie Williams.

If you decide to participate, you will be asked to fill out a secure online survey about your opinions and experiences which, depending on your specific physical needs, should take approximately 20-30 minutes to complete.

If you are willing to participate, please click on the following link which will take you to the study:

www.surveymzmo.com/s3/340177/Elements-of-Sexual-Satisfaction-in-Women-with-Physical-Disabilities

For further information about this research study, you may contact Jessica Heschel at heschel.2@wright.edu or Dr. Julie Williams at julie.williams@wright.edu.

Recruitment Flyer for Elements of Sexual Satisfaction in Women with Physical Disabilities: Results of an Online Survey

Are you A Woman 18 or older with A Physical Disability??

If so, please consider participating in the following research study:

Jessica Heschel, a doctoral student in the School of Professional Psychology at Wright State University, is conducting an **online survey that will investigate the ways in which women with physical disabilities define and think about their sexual satisfaction.** This research is being conducted under the supervision and advisement of Dr. Julie Williams.

If you decide to participate, you will be asked to fill out a **secure online survey about your opinions and experiences** which, depending on your specific physical needs, should take approximately 20-30 minutes to complete.

If you are willing to participate, please take the survey at the following web address:

www.surveymzmo.com/s3/340177/Elements-of-Sexual-Satisfaction-in-Women-with-Physical-Disabilities

For further information about this research study, you may contact Jessica Heschel at heschel.2@wright.edu or Dr. Julie Williams at julie.williams@wright.edu.



Appendix C

Consent Form to Participate in Elements of Sexual Satisfaction in Women with

Physical Disabilities: Results of an Online Survey

You are invited to participate in a research study conducted by Jessica Heschel from the Wright State University School of Professional Psychology. The goal of the study is to understand the ways in which women with physical disabilities construct their own definitions of sexual satisfaction and the elements that are important to the sexual satisfaction of women with physical disabilities. You were selected as a possible participant in this study because you are a woman 18 years or older with a physical disability. If you decide to participate, you will complete the following online survey. Depending on your specific physical needs, the survey will take approximately 15-20 minutes to complete.

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Your identity will be kept confidential by keeping all study materials in locked cabinets at Wright State University Counseling and Wellness Services.

Your participation is voluntary. Your decision whether or not to participate will not affect your relationship with Wright State University or Counseling and Wellness Services. If you decide to participate, you are free to withdraw your consent and discontinue participation in the survey at any time without penalty. In addition, if you decide to participate, there will probably be no direct benefit to you for your participation.

The following survey asks questions related to sex and sexual satisfaction. It is possible that participation in this study may elicit mild psychological distress related to the disclosure of information of a personal and potentially difficult nature. Should you experience psychological distress that is intolerable or beyond what you expect following your participation in this study, please contact one of the following organizations or another mental health agency of your choosing:

Wright State University
Counseling and Wellness Services
022 Student Union
3640 Colonel Glenn Hwy.
Dayton, OH 45435
937-775-3407

Wright State University School of Psychiatry
627 S. Edwin C. Moses Blvd.
Dayton, Ohio, 45417
937-775-8840

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Duke E. Ellis Human Development Institute
9 N. Edwin C. Moses Blvd.
Dayton, OH 45402
937-775-4300

If you have any questions about the study, please feel free to contact me Jessica Heschel at heschel.2@wright.edu or my faculty advisor, Julie L. Williams Psy.D., C.R.C. at 937-775-4875. If you have questions regarding your rights as a research subject, please contact the Wright State University Office of Research and Sponsored Programs at 937-775-4462. You may print a copy of this form for your records.

After you have read the above information, if you are willing to participate in this study, please click on the "next" button below. This will indicate that you have consented to participate in the study.

Appendix D

Tables of Results

Table D1

Messages about sexuality as a WwD

	1 Strongly Agree	2 Somewhat Agree	3 Neutral	4 Somewhat Disagree	5 Strongly Disagree	Total
My family of origin was open to discussing issues of sexuality with me growing up	7.1% 1	14.3% 2	28.6% 4	14.3% 2	35.7% 5	100% 14
My family of origin was open to discussing sexuality as related to my disability with me	0.0% 0	21.4% 3	21.4% 3	21.4% 3	35.7% 5	100% 14
I have received mostly positive messages about my sexuality as a WwD from family and friends	21.4% 3	21.4% 3	28.6% 4	14.3% 2	14.3% 2	100% 14
I have received mostly positive messages about my sexuality as a WwD from media and society	7.1% 1	14.3% 2	14.3% 2	42.9% 6	21.4% 3	100% 14
It is difficult for me to feel positive about my sexuality as a WwD due to the messages I have received from others and from the media about the sexuality of people with disabilities*	14.3% 2	14.3% 2	35.7% 5	21.4% 3	14.3% 2	100% 14
Negative messages about the sexuality	7.1% 1	14.3% 2	35.7% 5	14.3% 2	28.6% 4	100% 14

of WwD have
negatively impacted
my personal
experience of sexual
satisfaction*

***Indicates items that were reverse scored for analyses**

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Table D2*Personal feelings about sexuality as a WwD*

	1 Strongly Agree	2 Somewhat Agree	3 Neutral	4 Somewhat Disagree	5 Strongly Disagree	Total
I believe that sexuality is an important area of my life	35.7% 5	42.9% 6	0.0% 0	14.3% 2	7.1% 1	100% 14
I have a strong desire for sexual intimacy and sexual satisfaction	50.0% 7	42.9% 6	7.1% 1	0.0% 0	0.0% 0	100% 14
I enjoy sexual intimacy and sexual activities by myself and/or with partner(s)	35.7% 5	28.6% 4	14.3% 2	7.1% 1	14.3% 2	100% 14
As a WwD, I believe I have a strong capacity for sexual satisfaction	35.7% 5	50.0% 7	7.1% 1	7.1% 1	0.0% 0	100% 14
My disability has had positive effects on my sexual satisfaction	7.1% 1	28.6% 4	28.6% 4	28.6% 4	7.1% 1	100% 14
I feel good about my body	21.4% 3	35.7% 5	14.3% 2	21.4% 3	7.1% 1	100% 14
I feel good about my sexuality	21.4% 3	57.1% 8	7.1% 1	7.1% 1	7.1% 1	100% 14
I feel that sexual satisfaction is attainable for me	50.0% 7	14.3% 2	14.3% 2	21.4% 3	0.0% 0	100% 14
I feel that I have a satisfying sexual life	28.6% 4	7.1% 1	14.3% 2	21.4% 3	28.6% 4	100% 14

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Table D3*Interactions with Mental and Physical Healthcare Providers*

	1 Strongly Agree	2 Somewhat Agree	3 Neutral	4 Somewhat Disagree	5 Strongly Disagree
I received adequate sexual information and education from mental or physical healthcare providers related to my specific disability and sexual needs	14.3% 2	7.1% 1	28.6% 4	21.4% 3	28.6% 4
I have been able to discuss my sexuality with mental or physical healthcare providers	14.3% 2	0.0% 0	21.4% 3	50.0% 7	14.3% 2
I have been able to discuss my sexual pleasure or satisfaction with physical or mental health providers	7.1% 1	7.1% 1	14.3% 2	35.7% 5	35.7% 5
I wish that physical or mental health professionals with whom I have interacted would have spent more time and or effort discussing issues of sexuality and sexual satisfaction with me*	21.4% 3	42.9% 6	21.4% 3	7.1% 1	7.1% 1
I feel that physical or mental health professionals have been hesitant to, or uncomfortable with, discussing sexuality and sexual satisfaction with me*	14.3% 2	50.0% 7	28.6% 4	0.0% 0	7.1% 1
I feel that receiving counseling about my sexuality and sexual satisfaction as a WwD now or earlier in my life would positively influence my experience of sexual satisfaction	0.0% 0	42.9% 6	57.1% 8	0.0% 0	0.0% 0

***Indicates items that were reverse scored for analyses**

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Table D4*Elements Important to the Experience of Sexual Satisfaction*

	Very Important	Somewhat Important	Neutral	Somewhat Unimportant	Very Unimportant
My perception of the attractiveness of my body	64.3% 9	28.6% 4	7.1% 1	0.0% 0	0.0% 0
My ability to perform sexually	42.9% 6	28.6% 4	21.4% 3	0.0% 0	7.1% 1
My ability to experience a clitoral orgasm	35.7% 5	21.4% 3	14.3% 2	14.3% 2	14.3% 2
My ability to experience a vaginal orgasm	28.6% 4	28.6% 4	14.3% 2	28.6% 4	0.0% 0
My partner(s) experiencing orgasm	50.0% 7	21.4% 3	7.1% 1	14.3% 2	7.1% 1
The frequency with which I have sexual contact with a partner(s)	35.7% 5	35.7% 5	14.3% 2	7.1% 1	7.1% 1
The availability of a sexual partner(s)	42.9% 6	35.7% 5	14.3% 2	0.0% 0	7.1% 1
Romantic closeness with a sexual partner(s)	64.3% 9	28.6% 4	0.0% 0	0.0% 0	7.1% 1
Emotional Intimacy with a partner(s)	71.4% 10	21.4% 3	0.0% 0	0.0% 0	7.1% 1
The quality of the communication I have with a partner(s)	78.6% 11	14.3% 2	0.0% 0	0.0% 0	7.1% 1
Engaging in sexual foreplay with a partner(s)	50.0% 7	28.6% 4	14.3% 2	0.0% 0	7.1% 1
Engaging in deep kissing with a partner(s)	64.3% 9	28.6% 4	7.1% 1	0.0% 0	0.0% 0
Sensual touching/caressing with a partner(s)	71.4% 10	21.4% 3	0.0% 0	7.1% 1	0.0% 0
Masturbating	7.1% 1	14.3% 2	35.7% 5	21.4% 3	21.4% 3
Engaging in oral sex with a partner(s)	16.7% 2	41.7% 5	16.7% 2	8.3% 1	16.7% 2

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Engaging in anal sex with a partner(s)	7.1% 1	7.1% 1	7.1% 1	7.1% 1	71.4% 10
Use of sexual toys by myself or with a partner(s)	7.1% 1	7.1% 1	42.9% 6	14.3% 2	28.6% 4
Having privacy to engage in sexual activities by myself or with a partner(s)	61.5% 8	30.8% 4	0.0% 0	0.0% 0	7.7% 1
Use of a personal aid to engage in sexual activities by myself or with a partner(s)	15.4% 2	7.7% 1	15.4% 2	15.4% 2	46.2% 6
Lack of pain or discomfort during sexual activities by myself or with a partner(s)	30.8% 4	38.5% 5	23.1% 3	7.7% 1	0.0% 0

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Table D5*Barriers to Sexual Satisfaction*

	Strongly Agree	Somewhat Agree	Neutral	Somewhat Disagree	Strongly Disagree
educational institutions or professionals*	7.1% 1	7.1% 1	57.1% 8	14.3% 2	14.3% 2
religious institutions or professionals*	23.1% 3	23.1% 3	30.8% 4	7.7% 1	15.4% 2
laws/legal professionals*	7.7% 1	15.4% 2	46.2% 6	15.4% 2	15.4% 2
medical institutions/professionals*	15.4% 2	7.7% 1	46.2% 6	23.1% 3	7.7% 1
mental health institutions/professionals*	7.7% 1	15.4% 2	46.2% 6	15.4% 2	15.4% 2
family*	15.4% 2	15.4% 2	53.8% 7	7.7% 1	7.7% 1
friends*	7.7% 1	23.1% 3	46.2% 6	7.7% 1	15.4% 2
sexual partners*	0.0% 0	7.7% 1	38.5% 5	15.4% 2	38.5% 5
romantic partners*	7.7% 1	0.0% 0	38.5% 5	15.4% 2	38.5% 5
the media*	23.1% 3	23.1% 3	30.8% 4	15.4% 2	7.7% 1
myself*	15.4% 2	15.4% 2	46.2% 6	23.1% 3	0.0% 0

***Indicates items that were reverse scored for analyses**

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