# Sexuality and Physical Disability: A Disability-Affirmative Approach to Assessment and Intervention Within Health Care

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Abstract The role of sexual health has been historically underaddressed in the assessment and treatment of people with disabilities. This is due to several factors, including provider discomfort and lack of competence in discussing sexual health, and few assessment tools or treatment strategies designed specifically for people with disabilities. However, the literature suggests that people with disabilities desire opportunities for sexual expression and are engaging in sexual activity. The research shows that sexual health is an important component of overall quality of life. We aim to update readers to ongoing and new discourse about the complex factors associated with sexual health for people with disabilities. review available assessments and interventions and make suggestions for how to integrate these into a disabilityaffirmative framework that is relevant for a range of healthcare providers in varied settings, and make recommendations for future inquiry and practice. We emphasize that providers working with people with disabilities need to be educated in the social model of disability and aware of the biopsychosocial factors affecting sexual health, as well as encouraged to develop insight into their own disability biases. People with disabilities represent the largest minority population in the USA, and the health-care system is now challenged to grow and adapt to the needs of this traditionally underserved population. Through the lens of a health-care system, we recommend incorporating discussions about sexual health into an integrative primary care model that promotes accessibility and patient-centered care for people with disabilities.

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#### Introduction

A frank discussion about sexuality or sexual health has been historically missing from the whole health conceptualization, assessment, and treatment of people with disabilities (PWD). This has been due in large part to long-standing myths, such as a belief that PWD are asexual, disinterested in or incapable of sexual behavior, or that there are no effective interventions for improving sexual health for this population [1]. In rehabilitation environments, sexual health has often been underappreciated or ignored due to provider's discomfort [2, 3]. In contrast, we know that people with disabilities desire the same opportunities for satisfying sexual expression as non-disabled individuals [4] and that sexual health is an important component of overall quality of life and specifically psychological well-being [4, 5, 6•, 7]. People with disabilities as a healthcare population cannot be ignored, as they represent approximately 15 % of the world's population [8] and are the largest minority group in the USA.

According to the World Health Organization (WHO), sexuality encompasses "...sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction... experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviors, practices, roles and relationships" and is understood to be influenced by biological, psychological, and social factors [9]. Relatedly, sexual health is defined as "a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity" [9]. Sexual health may be understood as comprising two independent but related



concepts: sexual functioning and sexual well-being. Sexual functioning here refers to the physiological sexual response cycle and frequency and quality of sexual behavior that can be impacted by injury and/or disability. Sexual well-being is a subjective concept that reflects an individual's evaluation of their sexuality, such as one's satisfaction with sexual function or quality of relationships [10]. However, discussions about sexual health and PWD have traditionally been limited to assessment of sexual functional impairment and pharmacological or mechanical interventions without acknowledgement of the multifaceted nature of sexual health.

A definition of disability is likewise multifactorial. For the purpose of this review, we adapt the WHO definition of disability to focus on permanent physical impairments whether congenital, developmental, or acquired—that result in activity limitations and participation restrictions [8]. Disability is not the same as impairment and does not occur in isolation; disability is understood as resulting from "the interaction between characteristics of the individual and those of the natural, built, communications, cultural, and social environments" [8, 11, 12]. Using this definition, it is the interaction, not the impairment itself, that is enabling or disabling, and disability can be diminished through accommodation and/ or adaptation. Thus, our conceptualization of sexual health for PWD is a mind-body phenomenon occurring within a sociocultural, developmental, and environmental context. Just like other diversity identities, disability shapes a person's physical, emotional, mental, and social experience and expression of their own sexual nature. Therefore, an open discussion about disability-relevant variations in sexual relationships and activity remains needed in health care.

The purpose of this review is threefold. First, we introduce readers to ongoing and new discourse about the complex factors associated with sexual health for PWD. Second, we review available assessments and interventions that holistically approach sexual health needs for PWD and make specific suggestions for health-care providers. Third, we identify gaps in research and practice and make recommendations for future inquiry. Given the recent legislative changes affecting the provision, delivery, and reimbursement of health-care services in the USA, we will discuss the aforementioned findings through the lens of a changing health-care system.

## **Factors Affecting Sexual Health for PWD**

Understanding the factors that influence sexual health for PWD is the first step in developing effective assessments and interventions. Factors impacting sexual health in PWD are diverse and may be biological (e.g., type of disability, side effects of medications), psychological (e.g., body image, internalized stereotypes), educational (e.g., provider

competence), or sociocultural (e.g., access to relationships) [4, 13–18].

Factors affecting sexual health can be understood as direct or indirect. Direct factors are those disruptions to the physiological sexual response cycle that are a physiologically direct consequence of the injury or disease, e.g., erectile dysfunction after spinal cord injury. Indirect factors, on the other hand, refer to issues associated with the condition that interfere with sexual experience (e.g., mobility, bowel and bladder function, concentration) as well as psychosocial variables associated with living with a disability (e.g., changes in body image).

For PWD, sexual health is associated with quality of life measures, especially psychological quality of life [4, 5, 6•, 7]. For example, recent studies have found that for individuals with multiple sclerosis (MS), sexual dysfunction is associated with the mental health component of health-related quality of life, and it appears to be a stronger predictor in this group than overall degree of physical disability [6•, 7]. Sexual functioning, however, should not be confused with sexual satisfaction, as they may not be related or have differential effects. For example, Abdel-Nasser and Ali [19] found that the degree of overall physical disability predicted sexual activity, while age, pain, and depression predicted sexual dissatisfaction for women with rheumatoid arthritis [19]. Even when physiological functioning may be unaffected by disability, indirect factors may affect sexual well-being [20].

Research into sexuality and disability has often reflected ableism, a prejudice against disabled people through the preferential promotion of a non-disabled norm [21]. This ableist bias prioritizes the development of interventions to restore "normal" sexual functioning by predominantly targeting direct biological factors; however, psychological factors, such as body image, sexual self-esteem, and internalized negative stereotypes about disability, and cognitive issues appear to be particularly salient predictors of the overall psychological well-being of PWD [6•, 14, 16, 22]. Even within the diverse group of PWD, research and intervention appear to have prioritized those conditions of the central nervous system that result in direct effects on sexual functioning, e.g., spinal cord injury, as opposed to conditions where indirect factors, such as mobility or body image, are the main concern, e.g., limb amputation [20].

Gender appears to also play a role in the types of factors affecting sexual health and the impact on relationships. Whereas men may be more likely to cite arousal issues, women may be more likely to cite indirect factors as negatively affecting sexual health, such as decreased desire, pain, bowel and bladder issues, poor concentration, and intimate partner abuse [22, 23, 24•, 25, 27]. There also may be differential effects of gender in terms of how sexual issues affect the partner relationship [25, 26]. McCabe and McKern [28] found that for women with MS, reported sexual dysfunction was negatively associated with relationship functioning, but that



this was not so for men with MS. For men with MS and their partners, common themes of good communication, readjusting sexual expectations and roles, and the acceptance of the MS were all noted as important for maintaining good relationships. These and other studies highlight the importance of including partners in the discussion of sexual health for PWD [28, 29].

Recent qualitative studies have explored themes linked to sexual health for PWD in order to better understand the sexual experiences of PWD. For individuals with a recent lower limb amputation, Verschuren, Geertzen, Enzlin, Dijkstra, and Dekker [30•] exposed several factors linked to sexual well-being, including how one defines sexuality, self-image, support, and mobility [30•]. Parker and Yau [31] interviewed women with spinal cord injuries and similarly found that perceived positive support and effective communication between intimate partners emerged as a sexual health-promoting theme, as was openness to sexual experimentation, peer support, and lesser degree of injury. On the other hand, negative changes in body image, limited opportunities for intimate relationships, negative disability stereotypes, and the hassles of preparation for sexual activity emerged as perceived barriers to optimal sexual adjustment [31].

When partnered, the quality of the relationship appears to be very important for sexual health, and it has also been suggested that attention be paid to the partner role in sexual well-being during the rehabilitation process [15, 25, 26, 30•]. The presence of a physical disability could put a strain on partners who live together [18], but fostering supportive and safe intimate relationships could be a potential buffer [15, 30•]. For PWD, however, there may be barriers to intimate relationships, including fewer opportunities for partnership [18], psychological barriers to engaging in relationships, and navigating dual partner-caregiver roles [32]. People with disabilities, and women with disabilities in particular, are less likely to be partnered than individuals without disabilities [33]. Though the risk of intimate partner violence for women with disabilities is similar to those without disabilities, the meaning and consequences of such abuse may be different for those with disabilities as intimate partners are often in dual roles as caregivers [33, 34]. In addition, co-occurring cognitive impairments could affect communication, judgment, and personality. This, combined with challenges associated with dual intimate partner/caregiver roles, means that it is also important to assess sexual consent and note the fluid nature of decisional capacity [35•, 36].

It is important to note that not all PWD view their disability negatively in terms of sexuality [30•, 37]. For some, their disability is a reminder of survival or has led to more partner-focused, creative sexual interactions. A sex-positive, adaptation-focused approach to assessment and treatment as described below draws on strengths as opposed to focusing on the limitations of PWD.

#### Sexual Health Assessment for PWD

Given the data supporting the link between sexual health and well-being for PWD, health-care providers need to support self-exploration of one's sexuality and be available to provide PWD with competent assessment and interventions necessary to optimize sexual health.

Sexual assessment is the first step in communicating to a PWD that the health-care provider understands the value of sexual health as part of whole health and is open to discussing sexual issues. Assessing the needs of PWD seeking medical and/or mental health care for issues related to sexuality requires an integrated biological, psychological, and social approach. Effective assessment will identify not only the barriers to desired sexual experience but also the values and preferences of the individual. Factors contributing to a full sexual experience may be biological (e.g., erectile dysfunction, orgasmic dysfunction), psychological (e.g., body image, sexual self-esteem, anxiety), and social (e.g., internalized ableism).

There are several potential barriers to effective assessment and intervention that health-care providers must overcome, including provider attitudes, education, and time. Many providers are uncomfortable discussing sexual health and/or they feel they lack the competence [2, 38–43]. Providers may focus on physiological changes in the sexual response cycle or heterocentric penetration/orgasm-focused sexual activities but miss the psychosexual or relationship-oriented issues that represent true barriers to sexual satisfaction [35•, 44]. While diagnosis can be an important tool to define the problem and choose effective treatments, providers should be cautious when it comes to over-pathologizing sexual health for PWD [35•].

The ALLOW framework [45] can be used by providers at various levels of expertise to facilitate discussion about sexual health through five graded steps. First, the provider asks patients about their sexual concerns. Suggestions for openended initial inquiry include, "To what extent are you currently satisfied with your sex life?" and "What questions might you have about the ways in which your health, condition, disability or functional impairment has affected your sex life?" [46]. Second, the provider *legitimizes* those concerns through normalization. Third, the provider assesses his or her own level of competence, or *limitations*, in the area; if needed, the provider makes a referral. However, if the provider feels that they are competent to treat these specific concerns, they proceed to step 4 and convey their openness for further discussion. Finally, the patient and provider work together to develop a treatment plan.

There are few clinical assessment guidelines or validated sexual health questionnaires available for assessing sexuality for persons with disabilities. Mona and colleagues [35•] offer an adapted version of a clinical interview to facilitate a



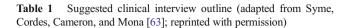
comprehensive conceptualization of sexuality, clarify referral questions, and direct intervention for PWD [47, 48]. The interview is a thorough biopsychosocial assessment that is sensitive to the ways in which sexuality intersects with a social model of disability. It includes assessment of the nature of the sexual issue and the patient's goals for treatment; a detailed assessment of current sexual functioning, including symptoms associated with desire, arousal, orgasm, and pain; factors influencing sexual well-being, e.g., sensations of pleasure, anxiety, partner status, and values; a thorough sexual health history, and current sexuality, including typical behaviors, relationships, attitudes, and beliefs; and medical and mental health history. See Table 1 for a suggested clinical interview outline.

Though existing measures of sexual health for the general population exist that may provide useful information, providers should use them with caution or qualitatively for PWD, as norms may inadvertently over-pathologize sexual dysfunction for PWD [35•]. Recent work by Foley and colleagues [49•] has resulted in validated 19- and 15-item questionnaires to assess indirect and direct effects of MS on sexual health, including the psychological and sociocultural factors affecting the full expression and experience of one's sexuality [49•]. This assessment may serve as a guide to developing assessments for other specific disability categories or a transdiagnostic approach, and can be used not only to identify the appropriate course of treatment but also to monitor progress as an outcome measure.

Research indicates that it is not only the providers who avoid sexual health assessment and interventions [23, 24•]. In a recent study of PWD by Kedde, van de Wiel, Schultz, Vanwesenbeeck, and Bender, 67 % of respondents with physical disability or chronic disease reported that they had considered or desired help for sexual health needs. However, only about 30 % of those desiring help had actually sought it and only 30 % of that group considered the contact positive. Reasons most often reported for not contacting a professional were "feelings of shame, shyness and anxiety." Among the factors predicting participation in sex therapy was a previous experience discussing sexual health issues with a provider, suggesting that early and frequent discussions about sexual health normalize the discussion and may increase comfort with providing and accepting these services as part of a holistic, patient-centered approach to health [24•]. Several studies confirm that PWD want more information about sexuality [30•, 31].

## **Sexual Health Interventions for PWD**

Adjustment to disability is a dynamic, ongoing adaptive process and a key focus of integrated health care for PWD. Sexual adjustment is part of this and has been defined as "the social,



- I. Presenting problems and goals for treatment
  - a. Nature of the sexual issue and client's beliefs about the cause(s)
  - b. Client's hopes/goals for treatment
- II. Sexual functioning and current symptoms (for each symptom, assess for frequency and context, i.e., type of sexual activity, presence of partner)
  - a. Desire
  - b. Excitement/arousal
  - c. Orgasm
  - d. Pain
- III. Sexual well-being (for client and partner, if applicable)
  - a. Biological (e.g., experience of pleasurable physical sensations)
  - b. Psychological (e.g., sexual self-esteem)
  - c. Social/relational (e.g., emotional intimacy)
  - d. Cultural (e.g., sexual values)
- IV. Sexual history
  - a. Past sexual functioning and course onset of current sexual issues
  - b. Coping strategies (including effectiveness)
- V. Current sexuality
  - a. Current sexual behavior, including a detailed description of the typical sexual encounter (i.e., where, when, how, and with whom)
  - b. Factors that may contribute to sexual problems (e.g. mobility, privacy)
  - c. Quality of partner relationships (if applicable)
  - d. Client's and partner's (if applicable) beliefs about the current sexual issue
  - e. Sexual orientation and gender identity
  - f. Beliefs, attitudes, and values about sexuality, disability, and relationships
  - g. Safer sex practices
- VI. Medical, psychological, and social status and history
  - a. Medical/physical
  - b. Health behaviors (e.g., diet, tobacco use)
  - c. Mental health
  - d. Cognitive health

psychological, and physical adaptation to sexual limitations or changes in sexual functioning, overall quality of life and attitudes toward sexuality" [31]. Whether a medical or psychological intervention, effective treatment requires an integrative, patient-centered, sex-positive, and disability-affirming approach [31, 35•]. Interventions based on a social model of disability described above will work to adapt the sexual script to emphasize the strengths of PWD (e.g., adaptation, flexibility, humor), rather than limitations [35•].

Regardless of the approach or provider, treatment of sexual health issues begins with establishing a trusting relationship. The PLISSIT model [51] describes a hierarchical approach to delivering sexual health interventions based on the provider's level of comfort and expertise: permission, limited



information, specific suggestions, and intensive treatment. Intervention is possible at each level. For example, the level of permission does not require specialized training but rather only an openness to discussing sexuality; the impact of this should not be underestimated, as it is an opportunity to normalize, validate, and encourage further exploration of sexual issues. At the level of intensive treatment, there are several evidence-based and emerging medical and psychological approaches for addressing sexual health concerns for PWD. A metatheoretical framework, disability-affirmative therapy (DAT), is recommended as a foundation for all interventions when working with PWD, regardless of whether the approach is psychological or medical [35•]. When concerns are medical and psychosocial, an integrative approach with appropriate referrals to medical and mental health providers should be made for further integrated assessment and treatment. Interventions can be delivered individually, with partners, or as a group. For a case study example of individual therapy and a proposed group approach, see Table 2 and Fig. 1.

#### Education

Education about sexual health is the first step in any intervention. A tailored educational program means that content is based on careful assessment of the client's needs and readiness for information, and the delivery method should be attuned to the client's preferences, e.g., individual vs. group presentation [17, 29]. Interviews with women following a spinal cord injury indicate that education continues to be male- and genitally focused [29].

The optimal time to provide education may vary greatly depending on several factors, including the type and duration of impairment, e.g., congenital vs. traumatic. Immediately following a traumatic physical injury, clients may not be ready to discuss sexual health as they are focused on medical concerns and optimizing physical functioning [17, 29]. Fisher, Laud, Byfield, Brown, Hayat, and Fiedler [50] found that the first 6 months post-acute inpatient rehabilitation was a time when clients with new spinal cord injuries first identified barriers to sexual satisfaction and therefore this period presents as an opportunity for assessment and intervention [50]. This, along with other research [29, 30•], supports the importance of timing interventions appropriately and considering partners in the assessment and intervention phases. This highlights the importance of meeting the client where they are. Regardless of timing, clients appear open to and appreciative of statements about the availability of resources and interventions, as this conveys that the provider is open to discussing the client's concerns and the value of sexual health for PWD [17].

Table 2 Unpublished group intervention. Citation: Andreski, S. (2015, January 1). Sexuality after spinal cord injury/disorder (SCI/D)—a psychoeducational and support group for veterans. Conducted from VA Long Beach Healthcare System, Long Beach, CA

Sessions	Brief description of topics
1. Intro and basics	Introduction of group members and individual goals
	• Introduction to structure, purpose, and content of the group
	• Completion of sexual health and general mental health questionnaires
2. Mourning the l oss/looking ahead	Biopsychosocial changes after SCI and the impact on sexual health
	• Rewriting the sexual script—defining sex and sexuality; adjusting to changes in sexual function, expression, and/or satisfaction; and validating sense of loss
	Debunking myths about sexuality and SCI/D
	Safer sex practices
3. Barriers to intimacy/ bowel and bladder	• Identifying barriers to sexual function and/or satisfaction
	Bowel and bladder issues as they relate to sexuality
4. Dating and mating (part I)	Relationships and sexual behavior with SCI/D
	• Influences of cultural norms, self-image, and communication
	• Barriers to dating and sexual behavior, and practical problem-solving
5. Dating and mating (part II)/neuroanatomy	• Introduction to neuroanatomy of the sexual response cycle
	• Continued discussion about sexual behavior with SCI/D
6. Assistive devices	Medical interventions
	• Sex toys
	Positioning equipment
	Caregiver role in sexual health
7. Peer guest speaker	• Invited peer to share personal experience of sexuality after SCI/D
8. Conclusions and next steps	Course review
	Personal reflection
	• Feedback
	Complete sexual health and mental health assessments



Fig. 1 Case study

Case Study

John is a 34-year-old, self-identified heterosexual male, who was recently admitted to an SCI sub-acute care facility. Four months ago, he sustained a spinal cord injury (T2 Asia C) as a result of a fall from three stories while employed at a construction site. His wife, Lisa, and their 4-year-old son visit him several times per week; however, visits are often interrupted by nursing staff and presence of John's roommate. It is anticipated that John will st ay in the facility for the next four months while participating in rehabilitation therapies.

John reports that he and Lisa have been together for 10 years and have a strong, supportive relationship. As a result of his injuries and decreased income, Lisa has returned to working part-time while her mother cares for their son. John reports feeling, "like a failure," endorsing shame and guilt, because of his inability to work and his perception that he is no longer able to support his family. He is less physically affectionate to Lisa and their son and he often cuts their visits short complaining of fatigue. However, he appears agitated after they depart and depressed on days when they are not able to visit at all. His roommate has noticed these changes and has commented on them; however, John is reticent to discuss these issues as he views them as private.

Lisa has also expressed concern over the lack of physical and emotional intimacy in their relationship. She has told staff that she believes that John is no longer attracted to her and no longer loves her. She appears to have lost weight, she is visibly fatigued, and is tearful during visits. At the encouragement of staff, Lisa shared her concerns with John and together they agreed to meet with the staff psychologist, Dr. Cole.

Dr. Cole met with John and Lisa together. Recognizing the unique considerations of couples' work, she indicated that she would also meet with them separately if needed, but would encourage them to disclose information shared in individual sessions during the couples' session to facilitate trust and an open therapeutic relationship.

As part of the intake, Dr. Cole took a holistic approach to assessment. She asked John and Lisa about their goals for treatment, assessed biological, psychological, and social factors contributing to current concerns, and got a detailed report of their past and current sexual functioning, as well as general medical and psychological histories. John and Lisa both indicated dissatisfaction with current sexual practices and indicated that they would like to increase the frequency and level of sexual activity. John indicated that prior to his injuries they, "were very happy with our sex life", and engaged in sexual activity several times per week. Since his fall, they have not been intimate or engaged in sexual activity. Lisa shared that she, too, was content with their level of intimacy prior to John's injury, but now she is, "grieving the loss of that intimacy."

Dr. Cole began by normalizing their experiences and reassured them that there were many options to choose from. She legitimized their concerns and the sense of loss they felt over, "life as it used to be." Through this process, Dr. Cole was able to foster a safe environment for the couple to feel comfortable sharing their concerns with Dr. Cole and one another. Dr. Cole shared her background in intimacy-related therapy, and they agreed on a treatment plan together.

John and Lisa were first given the rationale for cognitive-behavioral therapy (CBT) within a disability-affirmative structure. During the first few sessions, Dr. Cole provided foundational CBT psychoeducation about the relationship between thoughts, feelings, and behaviors. The initial phases of treatment emphasized developing awareness of and examining thoughts related to intimacy, in particular, John's feeling like a failure and Lisa's belief that John no longer found her attractive. Through Socratic questioning and reflective listening, Dr. Cole helped John and Lisa become aware of and challenge their thoughts in regards to intimacy following spinal cord injury, and understand the factors influencing their behaviors. Additionally, John and Dr. Cole did a role-play having a discussion with his roommate and other staff about finding time for he and Lisa to have uninterrupted, private visits each week.

Between sessions, the psychologist encouraged John and Lisa to think creatively about ways to re-engage in emotional and physical intimacy. They each created a list of ways to show affection, including items such as holding hands, kissing on the cheek and lips, and sending a card to one another through the mail. The list also contained items such as helping one another undress, kissing for ten minutes, and manual stimulation, and they were encouraged to engage in at least one of the aforementioned activities between each visit and to non-judgmentally explore their emotional responses. Doing so would help them to rewrite their sexual script—a sequence of sexual activities—adapting to John's injuries.

Over time, John and Lisa were able to better understand and respond to the connections between their thoughts, emotions, and behaviors. They were able to apply these insights and skills in order to adapt to new definitions and expressions of their sexuality. Sexual activity was clearly "not the same" as it had been previously but the difference in techniques, positioning, and communicating promoted their intimate connection in a new intriguing way.



#### **Psychological Interventions**

Disability-Affirmative Therapy Disability-affirmative therapy [1, 17, 36, 53] is a metatheoretical approach that provides a disability-positive context and a culturally centered framework through which to deliver tailored, evidence-based interventions. There are several defining characteristics of DAT: 1) empowerment and acknowledgement of social marginalization and environmental barriers, 2) appreciation of the dynamic nature of disability, 3) consideration of the medical realities of persons with disabilities and recognition of personal coping strategies, and 4) provision of a therapeutic environment that provides affirmative goal setting an integrated view of the self and encapsulates the values of flexibility and creativity that are prized in the disability community [1, 35•, 52, 53]. With DAT as a framework, providers can offer evidence-based interventions tailored to the unique psychological, social, political, and cultural experiences of a PWD [16, 35•, 54].

Cognitive Behavioral Therapy Cognitive behavioral approaches focus on the ways in which an individual's thoughts, emotional responses, and behaviors interact and either promote or interfere with sexual health goals. CBT has been found effective for addressing a variety of psychological issues for PWD, including depression, anxiety, and adjustment disorders [55]. By challenging potentially distorted cognitive patterns (e.g., negative thoughts related to body performance or appearance) and maladaptive behaviors (e.g., avoidance), PWD can rewrite their sexual scripts through more balanced and affirming self-talk and adaptive behaviors [35•]. Additional strategies common to CBT include psychoeducation, relaxation and mindfulness-based approaches to improve concentration and decrease anxiety, and socratic questioning to promote flexible thinking and behavior.

A natural adjunct to CBT is experiential/behavioral approaches, such as incorporating sexual enhancement products, "sex toys," and positioning devices, or incorporating sexual assistants [56, 57]. Providers will likely need to take a practical, problem-solving approach to work with PWD to adapt sexual behavior to take into account differences in mobility, dealing with pain, bowel and bladder issues, or privacy. Furthermore, developing and practicing effective communication skills is key.

Third-Wave Cognitive Behavioral Therapies—Acceptance and Commitment Therapy The emphasis of third-wave cognitive behavioral therapies is to improve the quantity and quality of activities that the individual finds meaningful and in line with their values. As opposed to trying to control and change internal experiences, such as cognitions, emotions, or physical symptoms, third-wave cognitive behavioral therapies like acceptance and commitment therapy (ACT) aim to decrease avoidance and encourage acceptance allowing for

purposeful refocusing on engaging in healthy, meaningful behaviors [58, 59]. ACT is "using a unique set of experiential and mindfulness exercises that promote acceptance of self and others, while working to define personal values and also to support efforts at making and keeping commitments related to those values" [60]. Philosophically, ACT promotes a present-focused, non-judgmental stance by emphasizing psychological flexibility, value-driven behavior, and increased awareness and acceptance. This can be especially useful for quieting negative self-talk, decreasing avoidance behaviors, and increasing pleasure during intimacy. Furthermore, ACT asks patients to reflect on their values and how these are connected to their sexuality. This process can help patients and therapists choose experiential tasks that are aligned with personal mores [35•].

For suggestions on how to integrate CBT and ACT into a DAT framework for issues related to sexuality, see the chapter by Mona and colleagues [35•].

#### Medical Interventions

Medical interventions for sexual dysfunction fall into two general categories—pharmacological and surgical—and generally target male erectile or ejaculatory problems. The standard of care is to prioritize least-invasive, evidence-based interventions [64]. Non-surgical interventions include oral phosphodiesterase 5 inhibitors (PDE5), which include sildenafil, tadalafil, and vardenafil; testosterone replacement; alprostadil or papaverine intracavernosal injection or intraurethral administration; and vacuum constriction devices. A combination of interventions may be used [65]. For males with ED and spinal cord injury, PDE5 has been found effective [66–68]. A 2012 review of studies examining the use of PDE5 for ED in patients with central nervous system disorders confirmed the utility of PDE5 as the first choice for ED for males with spinal cord injury (SCI), with preliminary support for its use in Parkinson's disease and MS [68]. Phosphodiesterase 5 inhibitors are also cost-effective [79]. However, the site and completion of a spinal cord injury [68]; comorbidity of vascular, endocrine, or psychological factors; or side effects of medication on arousal may limit PDE5 efficacy. A synthetic variant of prostaglandin E1, aloprostadil is a vasodilator that can be administered through intracavernosal injection or intraurethral administration for the treatment of ED. Though several studies have supported its efficacy with PWD and the general population, this method receives more mixed reviews from patients and rate of voluntary cessation appears higher compared with other methods [69–71]. Surgical options continue to evolve for treatment of ED and lack of penile sensation, including penile prosthetic devices and neurological bypass, though these are considered as a last resort in most patients [72, 73].

Brackett and colleagues [74] reviewed results from an 18year retrospective study of three methods of sperm retrieval for males with SCI and ejaculatory dysfunction. Based on the



success rates of each method and identification of contributing factors, they present an algorithm to guide sperm retrieval [74].

Medical guidelines for females with disabilities and sexual dysfunction are limited. While reproductive functioning may remain intact for women with physical disabilities, we know that other sexual response factors (e.g., genital sensation, lubrication, orgasm) and indirect factors (e.g., bowel and bladder issues, mobility, pain, relationship) are equally important. Pharmacological interventions may target symptoms that interfere with sexual behavior, such as urinary symptoms, spasticity, pain, and vaginal dryness [75, 76], while some success has been found with external stimulation devices [77]. Cordeau and Courtois [76] review factors associated with female sexual dysfunction in MS and include a review of biomedical treatments in MS, including the use of PDE5, alpha blockers, and estrogen therapy [76].

An integrative, interdisciplinary approach to treatment that assesses the role of psychosocial factors and incorporates partners is highly recommended, even when the presenting issue appears strictly medical in nature. For a review of integrative treatments for erectile dysfunction, see Berry and Berry [78].

## Addressing Sexuality for PWD in the Health-Care System

Based on the growing and multifaceted health-care needs of PWD, addressing sexual health for PWD requires an interdisciplinary team. Structural changes to the health-care environment as a result of the Patient Protection and Affordable Care Act (colloquially known as "Obamacare"), may promote greater attention to and effective treatment for sexual health needs of PWD by emphasizing increased access to a prevention-focused, patient-centered model of health care [16]. People with disabilities often require care through multiple medical and psychosocial services, potentially resulting in a fragmented vs. whole health approach. The integrated primary care model—an interprofessional approach aimed at culturally competent, whole-person health care—is a promising setting for delivering integrative sexual health interventions for PWD, and aligned with the American Psychological Association's guidelines for the assessment and treatment of PWD [53]. Sexual health counseling or sex therapy has traditionally been a specialty outside referral. However, the more providers a PWD has to juggle, the less likely they may be to follow through [16, 61]. Furthermore, mobility limitations often present as a barrier to accessing health care for PWD. Integrating sexual health into primary care is an ideal setting; health-care providers in the primary care setting are in a unique position to provide continuous, comprehensive, and coordinated care for most PWD and to build patient-provider relationships. Telehealth programs through primary care, too, are another

potentially effective avenue to deliver sexual health care for PWD [62•].

#### **Conclusions**

It is clear from the literature to date that sexual health is an important part of whole health for PWD but widely underaddressed in our current health-care system. The focus now can shift to developing disability-specific and transdiagnostic assessments that can be easily and effectively integrated into a patient's medical and/or mental health appointments; transdiagnostic assessment refers to measures that could be used to validly and reliably assess individuals with varying disabilities by focusing on common sexuality issues from a biopsychosocial model of disability, e.g., self-image, access to care, or side effects of medication. As assessment strategies become more universal and standardized, providers and patients alike will likely feel more comfortable discussing sexual health; asking about sexual functioning and satisfaction can become as routine as discussing diet.

To be able to address the sexual health needs of the growing PWD population, all health-care providers caring for PWD must be educated in the social model of disability, the multifactorial influences on sexual health, and strategies for starting the conversation with their patients. Above all, health-care providers must become aware of their own negative disability biases and how this may affect their interactions with PWD [16, 35•]. Our current cultural milieu often stigmatizes and dismisses PWD, and health is conceptualized as restoring function. Through building one's awareness, health-care providers can mindfully maintain a disability-affirming, sex-positive stance that empowers patients with disabilities and fosters therapeutic relationships.

## Compliance with Ethics Guidelines

Conflict of Interest Nina W. Eisenberg, Sarah-Rae Andreski, and Linda R. Mona declare no conflicts of interest.

**Human and Animal Rights and Informed Consent** This article does not contain any studies with human or animal subjects performed by any of the authors.

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