

Unspoken Challenges: Sexual Health in Sexual and Gender Minority People With Multiple Sclerosis

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CE INFORMATION

ACTIVITY AVAILABLE ONLINE: To access the article and evaluation online, go to <https://www.highmarksce.com/mscare>.

TARGET AUDIENCE: The target audience for this activity is physicians, advanced practice clinicians, nursing professionals, social workers, and other health care providers involved in the management of patients with multiple sclerosis (MS).

LEARNING OBJECTIVES:

1. Identify sexual health disparities in sexual and gender minority individuals with MS and recognize how these affect clinical care.
2. Apply inclusive sexual history-taking techniques and incorporate affirming, individualized strategies to manage sexual dysfunction and reproductive health concerns in this population.

ACCREDITATION:



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ABSTRACT

Sexual health is an integral part of overall well-being, encompassing emotional, psychological, and physical aspects that profoundly influence quality of life. Despite the prevalence of sexual dysfunction (SD) among people with multiple sclerosis (MS), it is too frequently underreported and undertreated. Sexual and gender minority (SGM) people with MS, in particular, may face stigma, discrimination, and clinician hesitancy that can bar access to necessary sexual health care. Recognizing SGM identity can help clinicians deliver more inclusive general and sexual health care, including but not limited to family planning and gender-affirming care. The 8 Ps model can aid in taking a nonjudgmental sexual history that allows for recognition of sexual dysfunction regardless of identity.

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Addressing sexual health is fundamental to holistic care. The World Health Organization defines sexual health as a “state of physical, emotional, mental, and social well-being in relation to sexuality and not merely the absence of disease, dysfunction, or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.”¹ As a vital part of emotional, psychological, and physical well-being, positive sexual health is associated with lower levels of depression and anxiety, higher quality of life, and greater life satisfaction in the general population.²

Sexual dysfunction (SD) is defined as persistent or recurrent problems with sexual response, desire, orgasm, or pain that cause significant distress or interpersonal difficulty. The major categories of sexual dysfunction include disorders of sexual desire/interest, arousal, orgasm, and sexual pain.³ Multiple sclerosis (MS) can lead to SD, with reduced libido and difficulties with sexual arousal, function, and satisfaction, all negatively impacting sexual health. While the majority of people with MS experience sexual dysfunction,^{4,5} there is notably little literature surrounding the intersection of neurological conditions, sexual wellness, and sexual and gender minority (SGM) identity. In this review, we summarize existing research on these topics, identify unmet needs for SGM people with MS, and suggest future research and clinical practice.

MS AND SEXUAL HEALTH

SD is a prevalent concern in people with MS; meta-analyses estimate that around 64% experience it.⁴⁻⁷ Despite its high

prevalence, SD is too often underreported, inadequately assessed, and undertreated in people with MS.⁵⁻⁹ Neglecting sexual dysfunction ignores a substantial concern for this population, as recent studies have revealed that SD contributes more to mental health and quality of life than neurological disability in people with MS.¹⁰

While SD's exact etiology in MS remains unclear, Foley et al proposed that it may manifest from primary, secondary, and tertiary causes.^{11,12} Primary SD refers to problems that result from direct damage to the nervous system as a result of cortex and spinal cord demyelination; this may include symptoms such as genital numbness, decreased lubrication, and erectile dysfunction. Secondary causes are neurological symptoms and physical disabilities that affect sexual function, such as fatigue, spasticity, pain, and bladder and bowel dysfunction. Finally, tertiary causes result from psychosocial stressors associated with living with MS. The majority of people with MS report that primary, secondary, and tertiary factors all contribute to their SD.

Treating SD in people with MS involves multidisciplinary interventions that aim to address both physical and psychological components. Pharmacologic treatments such as phosphodiesterase inhibitors for erectile dysfunction and topical estrogen for vaginal dryness in postmenopausal women can help manage physical symptoms.^{13,14} Psychotherapy has been shown to be effective in addressing emotional and relational challenges associated with SD, helping people with MS and their partners communicate effectively and rebuild intimacy.¹⁵⁻¹⁷ Additionally, physical therapy, including pelvic floor exercises,^{18,19} can improve muscle strength and control, thereby improving sexual function. Aquatic exercise²⁰ has also been proven to improve self-reported sexual desire, arousal, lubrication, orgasm, satisfaction, and pain, while yoga²¹ was associated with improved sexual satisfaction; both can be offered if people with MS seek nonpharmacologic or nontherapy strategies to address SD. This holistic approach to SD addresses the sexual health of people with MS by treating its primary, secondary, and tertiary causes.

SGM POPULATIONS

Discussing sexual health necessitates an overview of SGM people, which is a group that is underrepresented when discussing approaches to SD in people with MS.

The SGM population includes individuals whose sexual identity, gender identity, or reproductive development differ from conventional societal, cultural, or physiological norms.²² SGM individuals represent approximately 7% of the global population,²³ which is likely an underestimate due to past and present criminalization of and discrimination against this population in many parts of the world. Likewise, health care barriers in SGM populations are well-documented and include disparities in access to care, discrimination, and inadequate cultural

competence among health care professionals, with transgender individuals facing the greatest inequities.²⁴⁻²⁶ These SGM health care disparities can create a climate of reluctance to disclose sexual histories and problems in health care settings. A systematic review of many SGM individuals revealed that fear of unequal care, potential negative personal reactions from health care professionals, breaches in patient-clinician confidentiality, and documentation of SGM identity in medical records were all reasons for not disclosing their SGM identity in a health care setting.²⁷

Recent research indicates that those in the sexual minority may be more susceptible to SD compared to their heterosexual counterparts.²⁸ This disparity is attributed to multiple factors, including higher rates of mental health issues within SGM populations²⁹ and difficulties arising from societal perceptions of their relationships,³⁰ both of which can negatively impact

sexual satisfaction and functioning. Additionally, limited access to LGBTQ+ inclusive clinicians further restricts access to essential sexual health services.

INTERSECTIONALITY OF MS, SEXUAL HEALTH, AND SGM IDENTITY

In the context of MS care, comfort with SGM identity disclosure and perceived discrimination remain a concern. A survey of Italian people with MS demonstrated that sexual minority individuals were more likely to switch MS centers compared to their heterosexual counterparts, with 85.7% reporting at least 1 experience of homophobic behavior from clinical staff.³¹ More recently, a survey of 285 people with MS who self-identified as SGM documented less comfort discussing sexual health with their clinician and less satisfaction with their clinician overall compared to heterosexuals.³² Similarly,

Table 1. The 8 Ps Model for Taking a Comprehensive Sexual History (Adapted From Fenway Health³⁹)

1. Preferences	<ul style="list-style-type: none"> • Do you have preferred language that you use to refer to your genitals, such as medical terminology or affirming terms? • Are you currently sexually active? • Have you ever been sexually active? • What kinds of sex do you have?
2. Partners	<ul style="list-style-type: none"> • Are you sexually active with 1 partner or more than 1? • Are you dating anyone or sexually active? • Do you have any outside partners? • How would your partners identify themselves in terms of gender?
3. Practices	<ul style="list-style-type: none"> • Do you use toys inside your [insert preferred language for genitals] or anus, or do you use them on your partners? • Do you have any other types of sex that haven't been asked about?
4. Protection from STIs	<ul style="list-style-type: none"> • Are there some kinds of sex where you do not use barriers? Why?
5. Past history of STIs	<ul style="list-style-type: none"> • If yes: Do you remember the site?
6. Pregnancy	<ul style="list-style-type: none"> • Have you considered fertility preservation/banking gametes? • Have you thought about having biological children or carrying a pregnancy? • When you are having sex, is there any exposure to sperm or chance of pregnancy? • Have you considered contraceptive options?
7. Pleasure	<ul style="list-style-type: none"> • Do you feel you are able to become physically aroused during sex? • How satisfied are you with your ability to achieve orgasm? • Do you have any pain or discomfort during or after orgasm? • Is sex fun? • Are you having sex for pleasure, or are there other reasons (survival sex/transactional sex)?
8. Partner abuse	<ul style="list-style-type: none"> • Has anyone ever forced or compelled you to do anything sexually that you did not want to do? • Is there any violence in any of your relationships? Do you feel safe at home?

STIs, sexually transmitted infections.

Note: This framework serves as a guide for clinicians to take a comprehensive, inclusive, and affirming sexual history with all patients. It emphasizes open-ended, nonjudgmental questions that allow patients to share relevant information about their sexual health, relationships, and reproductive goals. Using this approach helps clinicians create a safe and supportive environment, identify potential concerns such as sexual dysfunction or intimate partner violence, and tailor care to meet diverse needs.

Anderson et al found that 30% of SGM individuals with MS felt uncomfortable discussing their SGM identities with their clinician. Additionally, this group reported lower mean satisfaction scores in the domain of sexual health relative to other health domains.³³

Clinicians' understanding of the SGM identities of people with MS is essential for bettering sexual and reproductive health. For example, all people with MS with gestational capacity must be made aware of disease-modifying therapy indications and timing surrounding pregnancy to ensure safe and informed family planning decisions. Considering that SGM individuals are often less likely to receive reproductive counseling,³⁴ clinicians should proactively and nonjudgmentally inquire about reproductive goals to ensure safe pregnancy outcomes. However, a recent survey of American Academy of Neurology members' preparedness to treat SGM individuals reported that one-third of those polled would not tailor neurologic care based on SGM identity, and 43% believed that sexual or gender identity has no bearing on the management of neurologic illness.³⁵ Further, a scoping review of all SGM research in the field of neurology revealed that a mere 1.7% of SGM papers focus on MS.³⁶ The paucity of literature concerning SGM people with MS could be contributing to neurologists'

decreased attention to the unique health care needs of this population, further exacerbating health care disparities for the SGM population.

INTERVENTIONS

Effective interventions are essential to overcoming barriers in SGM health. Two common reasons clinicians hesitate to take a sexual history are concern about making patients feel uncomfortable or feeling uncomfortable themselves. In an emergency department study, nearly 80% of clinicians believed patients would refuse to disclose their sexual and gender identity. However, only 10% of patients studied (including heterosexual individuals) stated they would withhold this information.³⁷ Thus, if a clinician feels that inquiring about SGM identity is appropriate, they should feel confident in doing so, especially if done in a respectful and affirming manner.

The process of taking a sexual history is often thought of as a means of assessing risk for sexually transmitted infections and/or pregnancy. However, the conversation presents a meaningful opportunity to discuss multiple aspects of care for people with MS. In addition to considerations like contraception or pregnancy planning for individuals with reproductive capacity, MS itself can lead to sexual problems, and many of

Table 2. Actionable Ways to Improve Sexual Health Care for Sexual and Gender Minority People With Multiple Sclerosis

Inclusive clinical practices	Implement the 8 Ps model for inclusive sexual history-taking.
	Normalize discussions on sexual health as part of routine MS care.
	Use affirming language and preferred terminology for gender and sexual identity.
Interdisciplinary care	Involve psychologists, social workers, and physical therapists in sexual health care.
	Provide referrals for sexual health counseling and therapy.
Training and awareness	Enhance neurologists' training in SGM- affirming care.
	Develop educational resources on SGM-specific sexual health concerns.
Research and policy	Include SGM individuals in SD treatment trials for people with MS.
	Conduct qualitative studies on barriers to sexual health care for SGM people with MS.
Screening and support	Screen for intimate partner violence routinely.
	Provide access to gender-affirming reproductive and family planning services.
	Offer mental health support for MS-related and identity-related stressors.

MS, multiple sclerosis; SD, sexual dysfunction; SGM, sexual and gender minority.

the medications used to manage MS symptoms may further contribute to these issues (eg, baclofen and selective serotonin reuptake inhibitors are associated with SD), impacting quality of life.³⁸ Proactively addressing the potential sexual adverse effects of medications can prevent frustration and help individuals make informed decisions about treatment options. For example, sexual issues are often treatable with changes in drug dosing time, amount, or duration, or additional therapies to increase function. Even if someone is not experiencing difficulties, having transparent, open-ended conversations can help put them at ease and will help them raise questions with their health care providers if the need arises.

Fenway Health, a Boston-based clinic focusing on SMG health care, created the 8 Ps model for taking a comprehensive sexual history based on best-practice guidelines from the Centers for Disease Control, but modified to be more inclusive (TABLE 1).³⁹ For SGM people with MS, we pay particular attention to *pregnancy, pleasure, and partner abuse*. As discussed previously, family planning should be discussed with all people with reproductive capacity. Here, it is also important to clarify *preferences* and vocabulary so that counseling can be both informative and affirming. People with chronic diseases⁴⁰ and SGM individuals⁴¹ are less likely than their healthy, cisgender, heterosexual peers to receive contraceptive counseling, highlighting the need for health care professionals to initiate these conversations to ensure inclusive, person-centered care and address potential disparities in reproductive health.

A survey of people with MS at a large, academic hospital found that over one-third of women with MS had experienced abuse in their lives, consistent with the general population, and 15% experienced abuse in the past year. Higher levels of neurologic disability were associated with increased experience of abuse.⁴² Poor mental health, cognitive challenges, and difficulty managing disease all contribute to increased vulnerability.⁴³ SGM individuals are also at higher risk for experiencing abuse.⁴⁴ Bisexual women are 1.8 times more likely to report experiences of intimate partner violence (IPV)—physical, sexual, emotional, or psychological harm caused by a current or former partner—and 2.6 times more likely to report sexual violence than heterosexual women. The lifetime prevalence of IPV among transgender people has been reported to range from 31% to 50%.⁴⁴ Given these statistics, it is crucial for clinicians to routinely ask about abuse in SGM people with MS and to involve social work services to provide appropriate support and interventions if indicated.

DISCUSSION

Sexual health significantly contributes to overall well-being, as sexual wellness is associated with decreased depression and anxiety and greater life satisfaction.² Despite affecting the majority of people with MS,⁴⁵ SD remains too frequently underreported and thus undertreated.⁴⁻⁸ SGM people with MS face disproportionate sexual health disparities; they are less comfortable discussing their sexual health with their clinicians and also report decreased satisfaction when doing so compared to heterosexual people with MS. Unfortunately, many experience homophobic behavior, prompting them to switch

PRACTICE POINTS



Sexual health is a vital aspect of well-being, profoundly influencing emotional, psychological, and physical quality of life for people with multiple sclerosis (MS), yet sexual dysfunction remains prevalent and often undertreated in this population.

Sexual and gender minority (SGM) individuals with MS face additional challenges, including stigma, discrimination, and health care disparities, which can limit access to sexual health services, including family planning and gender-affirming care.

Tools like the 8 Ps model for inclusive sexual history-taking can help enhance care for SGM people with MS, ensuring conversations are comprehensive, respectful, and person-centered. ■

MS centers as a result.³¹⁻³³ Many neurologists may still overlook the significance of SGM identity when managing MS.³⁵ Taken together, these barriers bar open patient-clinician communication, ultimately leaving SGM people with MS without the necessary support and interventions to treat SD effectively.

Neurologists can turn to adolescent oncology care for an example of where SGM health is prioritized. The National Comprehensive Cancer Network has published guidelines that emphasize the importance of creating an inclusive, safe, and comfortable space for SGM patients, writing that “integral to the comprehensive care of individuals with cancer...is an assessment for gender expression, gender identity, pronouns, and sexual identity.” These guidelines recommend involving SGM support persons identified by SGM patients, initiating referrals for psychosocial support, and considering referrals to specialized gender clinics for transgender youth.⁴⁶

Integrating SGM-affirming approaches into neurological care can enhance patient-clinician communication and trust, ultimately improving both sexual health and overall well-being for this population. Implementing inclusive sexual history-taking methods, such as the 8 Ps, can open the door to discussing SD and family planning regardless of sexual and gender identity.³⁹ Given the heightened vulnerability of both SGM individuals and people with MS to IPV, routine screening for this is critical and is part of the 8 Ps.^{39,41,43} Beyond the neurologic visit, interdisciplinary care can help address sexual health concerns, facilitate inclusive discussions, and ensure comprehensive care for SGM people with MS. Given the increasing demands on

physicians and limited visit times, referrals to psychologists, social workers, and physical therapists can enhance sexual health care for SGM people with MS. These interventions are summarized in **TABLE 2**.

CONCLUSIONS

Beyond making the clinical space more inclusive, adequately treating SD and improving sexual health in SGM people with MS requires more research, as our review of the literature identified several gaps in evidence surrounding this population. We did not identify any SD treatment trials that made note of sexual orientation, let alone any with a focus on SGM people with MS. Future SD treatment trials in people with MS should aim to include SGM individuals, and further qualitative studies surrounding their barriers to sexual health care and specific sexual health needs are essential. Research surrounding gender affirming hormone therapy, especially as it relates to sexual health, in people with MS is also lacking and would greatly enhance care for this population. ■

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