Let’s Talk About Sex

Creating the Conversation with Patients and Providing Useful Take-Home Tools

Objectives

- Discuss basic facts about MS and sex
- Define sexuality, types of sexual dysfunction
- Identify gaps in management of sexual dysfunction as a symptom of MS
- Learn tools to communicate effectively with patients about sexual dysfunction
- Describe communication techniques for patients and loved ones to use at home
MS Facts:
What You May Not Know

- Of people with MS:
  - Approximately 80-96% experience bladder symptoms
  - Approximately 35-45% experience bowel symptoms, most commonly constipation
  - Approximately 48-75% experience sexual difficulties

Why is this Important?

- Negative impact on quality of life
- UTIs can cause pseudo-exacerbation
- Skin breakdown from incontinence
- Decreased self-esteem
- Discomfort
- Anxiety
- Can cause increased spasticity
- Impact on intimate relationships
- Difficult to discuss with health care provider
Myths about Sex and MS

- It’s the least of my problems
- My doctor doesn’t want to hear this
- Sex should end in orgasm
- Sex must involve intercourse
- Physical contact = Sex
- People shouldn’t masturbate or use fantasy
What is Sexuality?

- It encompasses the whole person
- Touch
- Sex
- Intimacy
- Body image
- Caring
- Sexual identity

What is Sexuality?

- A person’s ideas about sexuality incorporate
  - Family
  - Society
  - Religion
- And are altered by
  - Aging
  - Health status
  - Personal experiences
Sexuality...

“is more than sexual function. It is an ever changing lived experience & is always affected by the manner in which we view ourselves and our bodies associated with constantly changing social and cultural influences.”

(Schmidt, E., et al., 2005)

Healthy Sexuality Requires...

- Positive self-concept
- Information about sexuality
- Positive relationships
- Managing barriers
- Maintaining optimal health and physical sexual function

(Christopherson, J., 2005)
What Impacts Sexual Function and How We Talk about it?

- Values and beliefs
- Cultural norms
- Religious beliefs and experiences
- Early sexual experiences
- Self-esteem
- Social issues
- Medical conditions

Other conditions that may affect sexual function include...

- Diabetes
- Vascular disease
- Heart disease
- Lung disease
- Arthritis
- Urinary incontinence
- Cigarette smoking
- Menopause
- Alcohol or drug abuse
- Medication side effects
  - Antidepressants
  - Blood pressure meds
  - Anticholinergics
  - Hormones
  - Narcotics
  - Amphetamines
Sexual Dysfunction
is a disorder of…

- Desire
  - Lack of interest
- Arousal
  - Don't feel body's response to sexual stimulation, or can't keep up with it
- Orgasm
  - Can't reach orgasm
- Sexual pain
  - Associated with many conditions

Symptoms must be distressful to you to be considered dysfunctional...

Sexual Dysfunction

- 3 Types:
  - Primary
  - Secondary
  - Tertiary

Primary

- From nervous system impairment
  - Impaired arousal
  - Sensory changes
  - Vaginal lubrication decrease
  - Erectile dysfunction
  - Anorgasmia

Secondary

- From MS symptoms
  - Spasticity
  - Bowel/bladder problems
  - Medication side effects
Tertiary

- From feelings related to disability
  - Feeling unattractive
  - Believing that sexuality can’t be a part of life with MS
  - Not wanting to communicate with your partner

Gaps in Provider-Patient Communication

- Don’t Ask, Don’t Tell
- Depressed patients are more likely to have sexual dysfunction
- Negative feelings about partner¹,² relationship affects sexual function¹

Who is More Uncomfortable…

- The provider or the person living with MS?
  - “How are things at home?”
    - “How is your relationship with your partner?”
  - “How are things working in the bedroom?”
    - “How is your libido?”
    - “Are you having any problems with sexual function?”

Are you speaking the same language?

- “Dr. or Nurse…I have no libido anymore…”
  - Libido
  - Erectile dysfunction
  - Anorgasmia
Talking to Patients about Sex

• Includes not just questions about sexual function, but also questioning symptoms that affect sexual function
  • Fatigue
  • Spasticity
  • Bowel/bladder dysfunction
  • Depression/anxiety
  • Pain


It Fits Right In…

• Review of Systems:
  • Bowel
  • Bladder
  • Sexual Function
Patients Do Not Bring Up Sexual Concerns

Poll of 500 US adults aged >25 years; percentages do not add up due to rounding

Has your doctor asked whether you have sexual difficulties (within the last 3 years)?

Note: Scale Ends at 50 percent
Physician Questioning Increases Patient Reporting of Sexual Dysfunction


Spontaneous Reporting

Reporting After Direct Questioning

Percentage of Patients* 14% 55%

*Patients receiving SSRI treatment (N=308)


Rehabilitation of Sexual Dysfunction in Multiple Sclerosis

Frederick W. Foley, Ph.D., Nicholas LaRocca, Ph.D., Audrey Sorgen, Ph.D., Vance Zemon, Ph.D.


Objectives:

Test Efficacy of Structured Cognitive Behavior Therapy Intervention (Focusing on Improving Communication) To Rehabilitate Sexual Dysfunction, Marital Satisfaction & Marital Communication in PWMS & Their Sexual Partners
Intervention

- Comprehensive Assessment (Sex hx., complete medical review, relationship hx.)
- Identification of interfering medical sxs. & or meds: management w/ health care team
- Structured communication skills training that included body mapping assessments, training in how to talk about sex & intimacy
- Cognitive-behavior therapy that addressed interfering ideas, beliefs (eg. body image, performance anxiety, relational problems)
- No PDE-5 inhibitors used
- Total of 12 counseling sessions

Results, Marital Satisfaction

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Note: MAT=Marital Adjustment Test, Pt=Person w/ MS, S=Spouse/Partner
# Results, Affective Communication

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Note: AC=Affective Communication Subtest of the Marital Satisfaction Inventory, Pt=Person w/ MS, S=Spouse/Partner

# Results, Problem-Solving Communication

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Note: PSC=Problem-Solving Communication Subtest of the Marital Satisfaction Inventory, Pt=Person w/ MS, S=Spouse/Partner
## Results, Sexual Satisfaction

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Note: SS=Mean Sexual Satisfaction Subtest Scores of the Marital Satisfaction Inventory, Pt=Person w/ MS, S=Spouse/Partner. SS Scores were reversed to indicate satisfaction. higher scores=higher satisfaction.

### Christopherson, J.M., Moore, K., Foley, F.W., Warren, K.G

**A comparison of written materials vs. materials and counseling for women with sexual dysfunction and multiple sclerosis**

(written materials focused on education & communication (Foley, 2005).

*Journal of Clinical Nursing, 15, 742-750, 2006.*

- 62 women w/ FSD randomized into 2 groups
- Group 1 - educational materials + referrals
- Group 2 - above + 3 counseling sessions
Results

- Baseline EDSS + MSISQ scores similar
- Repeated measures ANOVA found both groups had significant improvements in Primary Sexual Dysfunction \([F(1) = 14.79, p < .001]\).
- No improvement in Secondary or Tertiary
- Trend towards interaction effect (in favor of group 2) for Tertiary \([F(1) = 2.88, p = .096]\)

What Happens to the Caregiver?

- Male caregivers have more chronic health conditions such as hypertension, hyperlipidemia, and diabetes
- Female caregivers report feeling more burdened and having more stress; they take more medications for anxiety and mood disorders
- Therefore…they may also have their own issues with sexual function
- Most troublesome symptoms as reported by caregivers include: bladder dysfunction, personality changes, restricted mobility, and spasticity
- They symptoms affect sexual function of the person living with MS

Partner Support

• What is the viewpoint of the partner?
  • “I don’t want to hurt him/her”
  • “Our relationship has changed”

• Strategies aimed at improving partner support
  • Strengthening relationship satisfaction and communication

Barriers to Sexuality: MS Symptoms Affect Sexual Response

- **Common symptoms: Men**
  - Erectile dysfunction
  - Decreased genital sensation
  - Ejaculation difficulty
  - Fatigue and decreased interest in sexual intimacy
  - Mobility, spasticity, elimination dysfunction

- **Common symptoms: Women**
  - Fatigue, decreased desire, loss of orgasm
  - Reduced, altered, or painful sensations; spasticity
  - Vaginal dryness, anxiety about incontinence, UTI
  - Mobility, spasticity, elimination dysfunction

The Neurology of Sexual Dysfunction in MS

- Touch >> nerves send message to spinal cord; cord sends message to brain to “feel”
- Brain sends message down cord >> body responds
- Disconnect can occur on the way up or the way down!
Sexuality is an Important Part of Life

- Affects self-esteem, feelings of being masculine/feminine
- Communication with partner is important
  - Both halves of a relationship should search for ways to make sex comfortable and enjoyable

Sexual changes are emotional!

- They can cause
  - Anger
  - Resentment
  - Rejection
  - Guilt
  - Mutual blaming
  - Avoidance
  - Loss of trust
  - Isolation
  - Coercion
  - Intimidation

And all in the name of love?!
Sexuality: Overcoming Barriers

- Society has defined “normal” sexuality; create your own normal with your partner.

- Sexual expression includes:
  - Cuddling, caressing, massage.
Sexual Satisfaction

- Is associated with
  - Acceptance
  - Warmth
  - Confidence
  - Open communication
  - Personal security with partner
  - Erotic attraction and passion

Improving Sexual Function in MS

- Enhance stimulation and eliminate routine
  - Set a “date” with your partner
  - Read a sexy book or rent a video
Improving Sexual Function in MS

- Distraction techniques
  - Erotic or non-erotic fantasy
  - Background music or videos/TV
  - Eliminate unwanted distractions
    - Kids, pets, bills, etc.

- Encourage noncoital behavior
  - Sensual massage
  - Body mapping or massage of nonsexual areas with feedback about what feels good
  - Communication!
Sex Doesn’t Have to Mean Intercourse

- Erogenous Zones: Mouth, Ears, Breasts, Thighs, Feet
- Body Mapping
- Masturbation is okay!
- Oral Sex

Improving Sexual Function in MS

- Agree on time/place to discuss
- “I would like...” vs. “You don’t...”
- Discuss likes and dislikes with partner
- TIME for expression
- Rejection of a suggestion does not mean rejection of you!
How to Talk About Sex (cont.)

- Be aware that sexual feelings and preferences change, especially as MS symptoms fluctuate
- Use non-verbal communication assertively [take his/her hand and show how you like to be touched]
- Do not expect your partner to do anything unless you explicitly ask them or show them [no mind reading]
- Do not expect perfection

Recommended books:

- “Resurrecting Sex: Solving Sexual Problems and Revolutionizing Your Relationship”, David Schnarf, PhD
- “Hot Monogamy: Essential Steps to More Passionate, Intimate Lovemaking”, Patricia Love, MD & Jo Robinson

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