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The Impact of MS on Sexual Functioning and Relationships

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**OCCUPATIONAL
THERAPY**

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OBJECTIVES

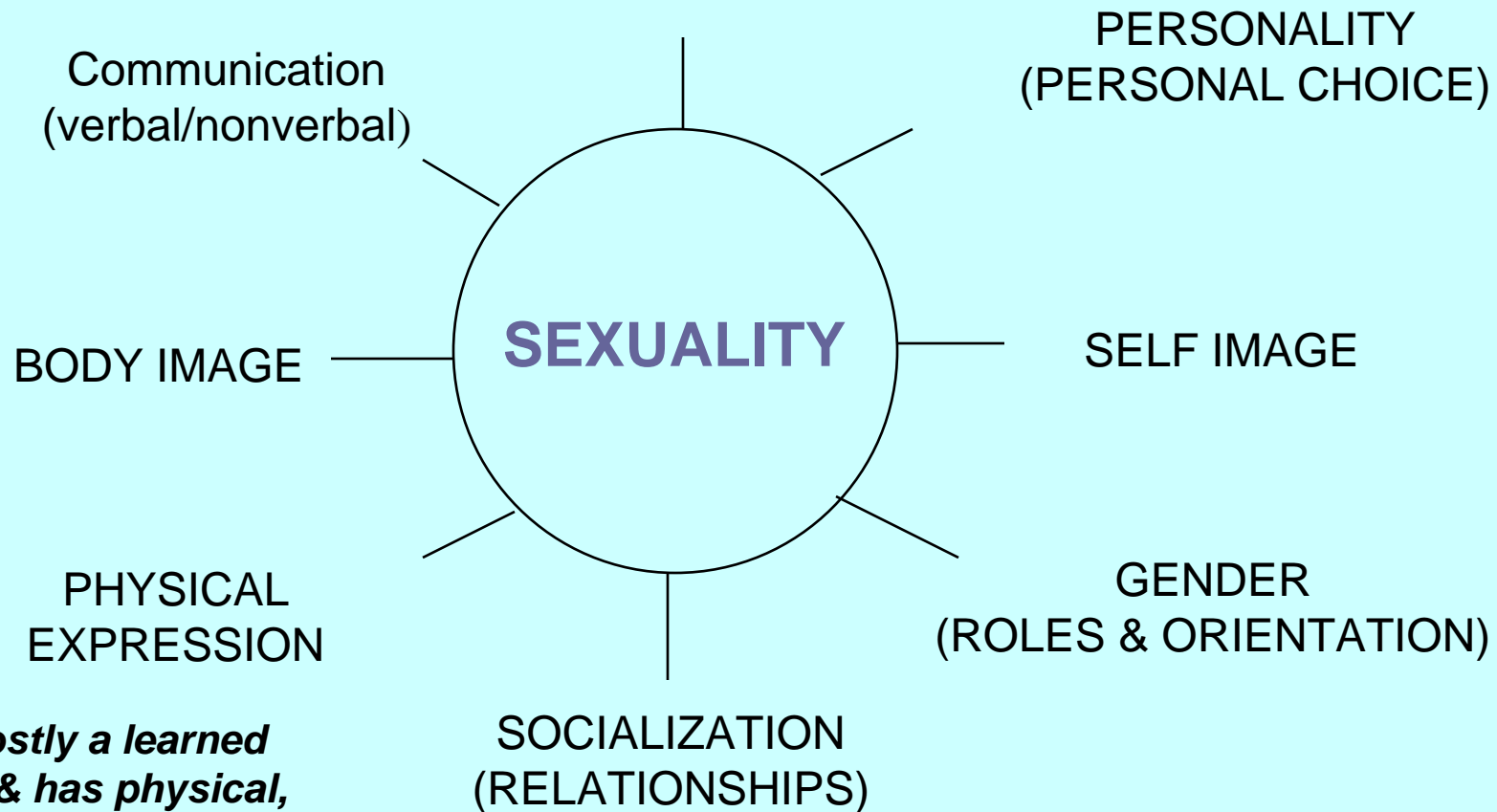


- Sexuality definition & overview
- Impact of MS on sexual functioning
- Strategies for dealing with Sexual dysfunction
- Comment and Questions

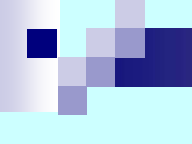


Sexuality: The whole person including sexual thoughts, experiences, learnings, ideas, values and imaginings

Beliefs and Values



Sexuality-mostly a learned phenomena & has physical, emotional and spiritual aspects



MS and Sexuality

Incidence of Sexual Dysfunction

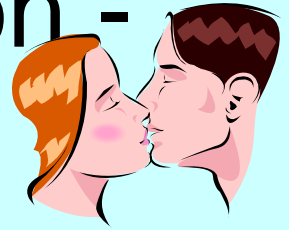
- healthy – 12.7%
- chronic disease – 39.2%
- individuals with MS – 73.1%
- women with MS: 39 - 72%
- men with MS: 64 - 91%
- up to 90% of individuals with MS report changes in their sex lives after the beginning of the symptoms (e.g. decrease frequency).

(Szasz et al, 1984, Zorzon et al, 1999)

Sexual Dysfunction

- Primary - A result of MS - changes in the central nervous system that **directly** impair sexual feelings and/or response
- Secondary - A result of MS-related physical changes that **indirectly** affect sexual feelings and/or response
- Tertiary - Refers to psychological, social and cultural issues that interfere with sexual feelings and/or response

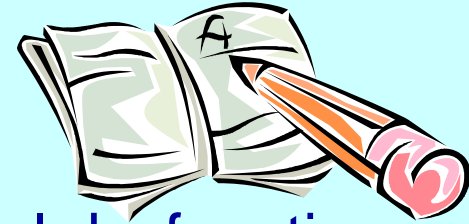
MS Impact On Sexual Function - Females



- Decreased libido,
- Altered genital sensation (including numbness, pain, burning or general discomfort),
- Decreased physical response in terms of vaginal lubrication
- Decreased frequency or intensity of orgasm.
- Non-sexual physical changes may affect sexual response such as fatigue, spasticity, bowel and bladder function, pain, and incoordination producing general impairment in mobility and function.
- Psychological Issues, Role shift, Loss, Body Image etc.

(Foley et al., 2001; Sanders et al., 2000, Smeltzer & Kelley, 1997).

MS Impact On Sexual Function - Males



- 92.1% of male MS patients reported sexual dysfunction
- erectile dysfunction
- impaired genital sensation
- decreased libido
- decreased intensity of ejaculation
- Non-sexual physical changes may affect sexual response such as fatigue, spasticity, bowel and bladder function, pain, and incoordination producing general impairment in mobility and function
- Psychological Issues, Loss, Body Image etc.


(Foley et al., 2001; Sanders et al., 2000).

Impact of Disability/illness on Couples' Sexuality - an overview:



- Impact on overall quality of life and well being
- Sex reported to be one of the most serious problems in marriages where one of the partners had a disability
- Change in sexual activity patterns (Freq, Interest, Satisfaction)
- Disability has also been shown to increase stress and affect the roles and personal boundaries experienced by couples
- Impact on marriage and divorce rates





IMPACT OF MS ON COUPLES' SEXUAL RELATIONSHIPS

The purpose of the study was to understand the lived experience of couples in terms of their sexuality where one partner has a disability (MS).

Specifically; the research focused on understanding:

- Each partner's perceptions of the impact of MS on their sexual relationship.
- What gives each partner meaning in their sexual relationship.
- What partners consider to be important disability-related factors impacting their sexual relationship.
- The coping strategies each partner is using and how these have changed since the onset of MS.

METHODS & ANALYSIS

Methods:

- A hermeneutic phenomenological approach was used in data collection and analysis.

Data collection:

- In-depth semi-structured interview

Data Analysis:

- Thematic content analysis using a constant comparative method was used

(Maykut and Morehouse 1994)

Preliminary Findings:

- The following is a summary of some of the initial results of the study.
- The analysis was done for four separate groups:
 - Group #1 – Females with M.S.
 - Group #2 - Male partners
 - Group #3 Males with MS
 - Group #4 Female Partners



Group #1 Women with MS – Results

- The women with MS lived a life of uncertainty and contradictions
- Raised doubts regarding their worthiness, attractiveness and identity
- Sex out of fear
- Acceptance and defiance
- Outward behavior did not reflect their inner state

Group #2 Male Partners – Results

- Responded with pragmatism
- MS was seen as an inconvenience
- More frustrated with partners “irrational” behavior
- Felt their wives made “mountains out of molehills.”
- Most did not feel the MS had much of an impact on their sexual relationship

Group #3 Males with MS – Results

- The MS forced the men to learn to communicate more and be more sensitive toward their relationship.
- Men didn't want to be perceived as weak.
- Sex to fulfill their partners' need (a way to express love)
- Men felt their partners were instrumental in maintaining and enhancing the relationship.
- Men avoided all forms of physical contact as they felt intimate contact should lead to sexual contact which they felt they can not fully fulfill.

Group #4 Female Partners – Results

- Female reported communication actually improved post diagnosis (men started to listen and talk).
- All forms of sexual intimacy decreased.
- They experienced guilt (needed to be the “superwoman”).
- Sacrifice-a coping strategy

Females with M.S. their lived experiences compared to their partners perceptions

Women with MS

- Overcompensation
- Taking on the “burden”
- Buffering their partner

Men

- Don't perceive much of an impact
- Are confused at why their wives act so irrationally
- “What's the big deal”

Male with M.S. their lived experience compared to their partners perceptions

Men with MS

- o Learned to communicate
- o Started to devalue sex – “sex is not that important”
- o Increased dependence on their partners - partner more in control of the relationship

Women

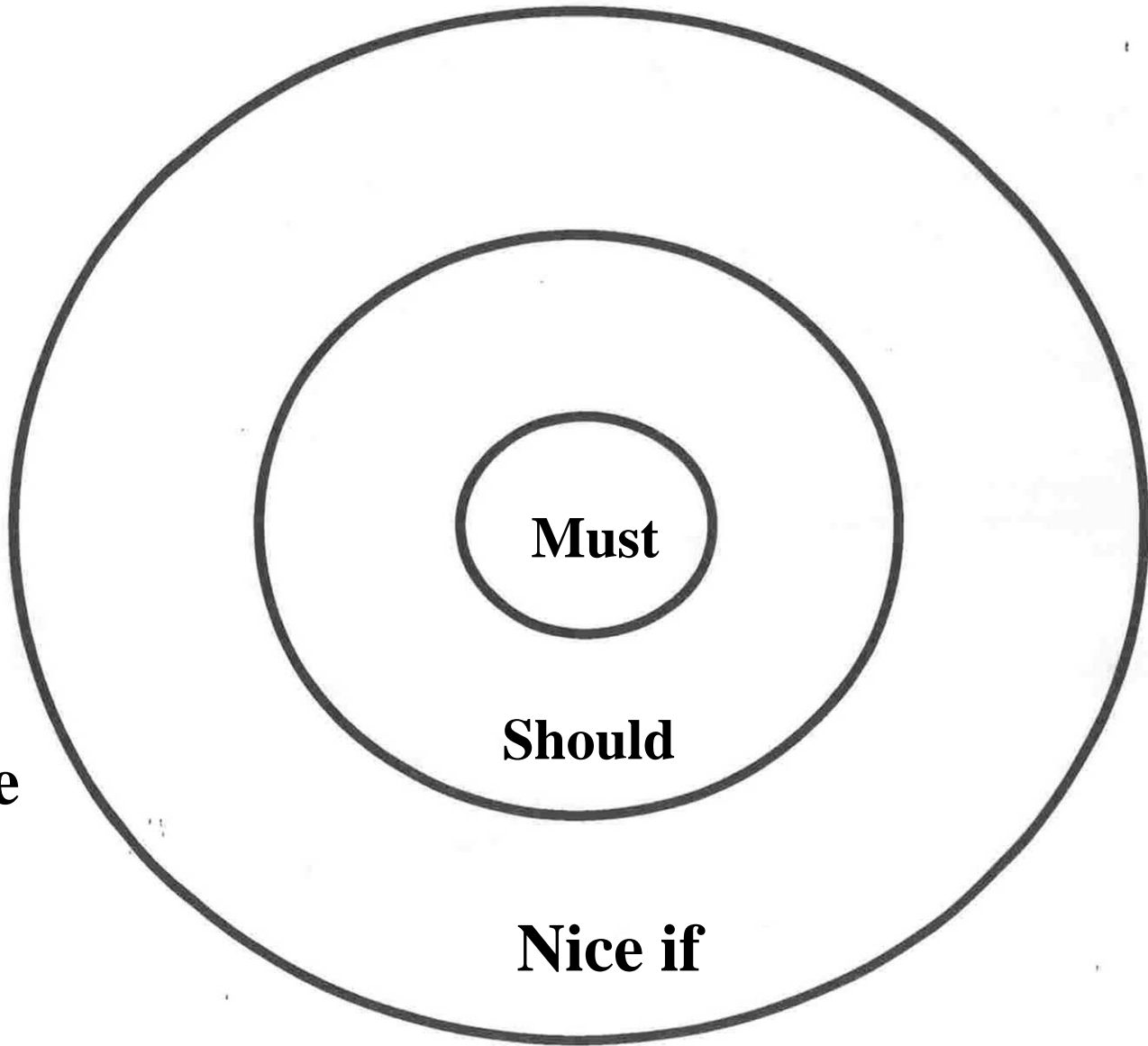
- o Taking on responsibility of the relationship
- o More active in all aspects of the relationship
- o Sacrifice!!!! Its their burden



So What Does This Mean?

- Women with MS or women who have partners with MS are more likely to take on the burden and martyr role.
- Men with MS or men who have partners with MS are more likely to be shielded for the true impact of the disease.
- Although communication was identified as very important for all groups – it was filtered.

ATTRACTION TEMPLATE



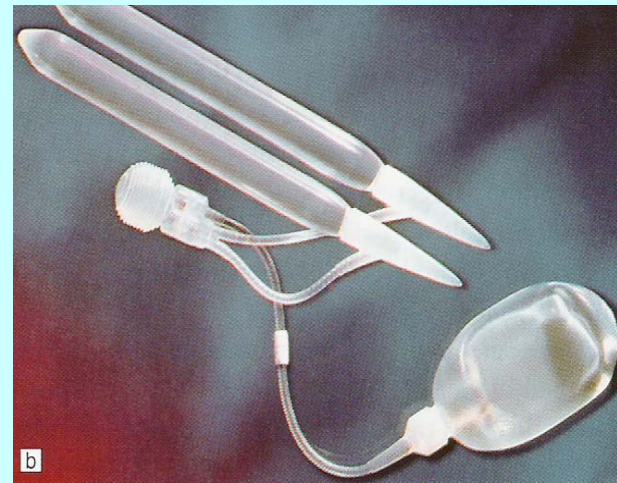
**Society's
perspective**

Management of Erectile Dysfunction

- Sildenafil (Viagra)
- Vardenafil (Levitra)
- Tadalafil (Cialis)
- Prostaglandins injection
- Vacuum erection device
- Sexual aids: vibrators, silicone rings
- Surgery – penile prosthesis
- Education and counseling

Penile Prosthesis - Inflatable

- Utilized since 1973
- 3 piece:
 - Most natural appearing erection | girth and length
 - Excellent flaccidity for optimal concealment
- 2 piece:
 - Easier implantation
 - Larger scrotal pump
- Complications:
 - Infection
 - Erosion
 - Deformities
 - Mechanical malfunction
 - Patient Dissatisfaction



Primary Sexual Dysfunction in Women

- Water soluble Lubricant
- Vibrators Self or Partner
- Kegel Exercises(pelvic tilts)
- G – Spot
- Body mapping(find other erogenous zones)
- Viagra?
- Intimacy and Communication



Coping with Loss of Libido

- Sensual and Sexual Pleasure can be Achieved without Desire!
- Avoidance causes Lack of Intimacy
- Learn how to talk Intimately, maybe at first it has to be in the dark
- Deal with Losses and Grief
- Start Over - Have Dates, explore one another like a new couple – Be a New Couple

Body Mapping Exercise



- Safe/comfortable setting/temperature
- Remove clothing
- Begin by touching top of head and systematically moving down body
- Vary pressure, speed, rhythm, pattern
- Note areas of pleasure, sensory change
- Alter touch to maximize pleasure
- Do not attempt orgasm
- Communicate with and instruct your partner

Foley, 2000

Treatment of Secondary Problems

- Spasticity: Muscle Relaxants – timing
- Pain: Carbamazepine (Tegretol) Gabapentin (Neurontin) Frozen Peas
- Bladder Management: Meds, Catheterization, Fluid management, Condom catheters
- Fatigue: Meds, Exercise, Planning
- Weakness: Alternate positions(spoon), pillows

Medications and Sexual Dysfunction

- Anticholinergics
- Antihistamines
- Anticonvulsants
- Tricyclic antidepressants (amitriptyline)
- SSRI's (prozac, paxil, etc.)
- Benzodiazepines (valium, zanax, etc)
- Beta-blockers (propranolol)

Coping with Catheters

- Ask Healthcare Provider
- Tape catheter to abdomen to prevent pulling
- Use night bag with longer tubing
- Empty bag and tape connections to prevent leaking. Men – condom over catheter
- Alter positions(spoon position)
- Catheter can be removed and reinserted if partner is instructed(don't leave out)
- Communicate, be prepared

Caregiver

- If partner provides care it is sometimes difficult to switch from caregiver to lover
- Have homecare provide the services more often and just before a planned hour of intimacy



Coping with Tertiary Sexual Dysfunction

- Talk about feelings related to role reversal, about losses, about values related to sexuality
- Body mapping to improve self-image
- Attend a couples workshop to enhance your relationship
- Learn how to talk about sex, keep the accusations out of intimate times

Coping with Tertiary Sexual Dysfunction

- Dealing with stress(anxiety)
- Couples Counseling, psychologist, clergy, etc. To help understand one another and improve communication
- Individual counseling, self-image,losses
- Anger – Are you stuck?
- Medication: sometimes a mild tranquilizer will help anxiety

Intimacy and Sexuality

- Goal is understanding one another : what each of you wants in an intimate sexual relationship
- Goal of intimacy is not always intercourse
- Sometimes intercourse is exquisite French Cuisine, sometimes it's meatloaf!
- Meatloaf is Great, especially with mashed potatoes!

Combining findings with literature:

Some common suggestions regarding intervention / strategies which may be effective in helping couples include:

1. Mutual Responsibility
2. Education and Information
3. Facilitating Communication Between Partners
4. Attitude and Behavior Changes
5. Prescription of aids, prosthesis and resources



Summary - Management Approaches

- Information & education**
- Remove communication barriers
- Acceptance - facilitate attitude change to help the participants adopt different criteria to evaluate sexuality
- Safety - physical and psychological
- Reassure - remove anxiety – Performance
- Medication management
- Improve coping skills
- Suggest alternative positions
- Assistive devices – lubricant, vibrators, pumps etc.
- Provide sex therapy - behavior change

Monga & Kerrigan (1997)



Conclusion:

- As you can see when MS strikes it needs to be addressed
- The focus of intervention should be altered depending on who you are dealing with.
- Health care providers can play an important role in enhancing the quality of life by dealing with this important issue

