Sexuality with myotonic dystrophy

Presentation by:
- Isabelle Fisette-Paulhus, M. PT
- Cynthia Gagnon, Ph.D. OT
Cynthia Gagnon, Ph.D.
- Occupational Therapist
- Professor at the Faculty of Medicine and Health Sciences at Sherbrooke University, Québec, Canada
- Full-time career award researcher
- Scientific director of the Groupe de recherche interdisciplinaire sur les maladies neuromusculaires (GRIMN)

Isabelle Fisette-Paulhus, M. PT
- Physical Therapist
- Student - master’s degree in research, Sherbrooke University
- Clinician at the continence program at the day hospital in Gatineau, Québec, Canada
- Clinical research coordinator, NeuroMuscular Centre at The Ottawa Hospital
Learning objectives

1. Attendees will be able to define important terminology related to sexual function, sexual activity, and intimate relationships.

2. Attendees will learn about two projects related to sexuality in the neuromuscular/DM community.

3. Attendees will learn some strategies for pursuing healthy, fulfilling sexual activities.
## What is sexuality?

<table>
<thead>
<tr>
<th>Includes</th>
<th>Manifests as</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biological sex</td>
<td>Thoughts</td>
</tr>
<tr>
<td>Gender identities and roles</td>
<td>Fantasies</td>
</tr>
<tr>
<td>Sexual orientation</td>
<td>Desires</td>
</tr>
<tr>
<td>Eroticism</td>
<td>Beliefs</td>
</tr>
<tr>
<td>Pleasure</td>
<td>Attitudes</td>
</tr>
<tr>
<td>Intimacy</td>
<td>Values</td>
</tr>
<tr>
<td>Love life</td>
<td>Behaviors</td>
</tr>
<tr>
<td>Reproduction</td>
<td>Practices</td>
</tr>
<tr>
<td></td>
<td>Roles</td>
</tr>
<tr>
<td></td>
<td>Relationships</td>
</tr>
</tbody>
</table>

World Health Organization, 2002
What is sexuality?

Fundamental needs

Unique

Experienced differently and importance in a person’s life varies

Evolves and changes over the course of an individual’s life.

World Health Organization, 2002
Factors influencing sexuality

- Biological
  - Hormone
  - Age
  - Disease
- Psychological and social
  - Anxiety
  - Self-image
  - Interpersonal relationships
- Economic
  - Financial resources
  - Insurance
- Political and legal
  - Laws and regulations
- Cultural and ethical
  - Openness to sexuality
- Religious and spiritual
  - Values
  - Religion
- Historical
  - Evolution between decades
  - Social prejudices
- World Health Organization, 2002
- Santé Montréal, 2016
Sexual response adapted from the model of Masters & Johnson

- Excitement
- Plateau
- Orgasm
- Resolution

Masters and Johnson, 1966
Sexual function and intimate relationships

- **Sexual function** (mental and physical functions):
  - Excitement / arousal phase: desire, libido, sexual interest
  - Plateau / preparatory phase: penile or clitoral erection, lubrication
  - Orgasmic phase: muscle contractions, ejaculation
  - Resolution phase: satisfaction, relaxation, absence of pain

- **Intimate relationships**:
  - Romantic relationships
  - Spousal relationships
  - Sexual relationships

- **Sexual activity**: caressing, masturbation, foreplay and intercourse

World Health Organization, 2001
Myotonic dystrophy

Functions and anatomic structures
- Sexual function
- Muscle function
- Function of the respiratory system
- Urinary function
- Etc.

Activities
- Sexual activities
- Mobility
- Undressing
- Etc.

Participations
- Intimate relationship

Environmental factors
- Attitudes
- Social norms
- Support

Personal factors
- Self-esteem
- Coping strategies
- Age
- Gender
How can sexual function, sexual activities and intimate relationships be affected by myotonic dystrophy?

<table>
<thead>
<tr>
<th>Sexual function:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Erectile dysfunction</td>
</tr>
<tr>
<td>• Decreased vaginal lubrication</td>
</tr>
<tr>
<td>• Pelvic floor muscle dysfunction</td>
</tr>
<tr>
<td>• Low sexual desire</td>
</tr>
<tr>
<td>• Pain during sexual activities</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other function:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Muscle weakness</td>
</tr>
<tr>
<td>• Fatigue</td>
</tr>
<tr>
<td>• Loss of mobility</td>
</tr>
<tr>
<td>• Urinary and anorectal dysfunction</td>
</tr>
<tr>
<td>• Cardiorespiratory impairments</td>
</tr>
<tr>
<td>• Etc.</td>
</tr>
</tbody>
</table>

Almost no research evidence !!!!
Project 1: Prevalence of urinary incontinence and other pelvic floor disorders in women with myotonic dystrophy type 1
Isabelle Fisette-Paulhus, PT; Mélanie Morin, PT, Ph.D.; Cynthia Gagnon, OT, Ph.D.

Data collection & analysis completed

Article in production

OBJECTIVES:

• Assess the prevalence, characteristics and impacts of urinary incontinence and other pelvic floor disorders in adult women with myotonic dystrophy type 1
• Assess the sexual function
• Explore the impact of age, phenotype, genotype, muscle weakness and number of deliveries on these symptoms
Project 1: Prevalence of urinary incontinence and other pelvic floor disorders in women with myotonic dystrophy type 1
Isabelle Fisette-Paulhus, PT; Mélanie Morin, PT, Ph.D.; Cynthia Gagnon, OT, Ph.D.

METHODS:

• Epidemiological study performed in Quebec, Canada
• Recruitment: patient registry of a neuromuscular disease’s clinic at the Jonquière Hospital (CIUSSS Saguenay-Lac-St-Jean)
• Interview using 4 validated questionnaires + general questionnaire

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women</td>
</tr>
<tr>
<td>≥ 18 years old</td>
</tr>
<tr>
<td>Confirmed diagnosis of myotonic dystrophy type 1 (DM1)</td>
</tr>
</tbody>
</table>
Project 1: Prevalence of urinary incontinence and other pelvic floor disorders in women with myotonic dystrophy type 1
Isabelle Fisette-Paulhus, PT; Mélanie Morin, PT, Ph.D.; Cynthia Gagnon, OT, Ph.D.

RESULTS:

- 80 participants
- Age: 23 to 78 years old
- 75% were sexually active

- Urinary incontinence: 60.6%
- Abdominal pain: 66.3%
- Anal incontinence: 56.3% (include stool and flatus)
- Fecal incontinence: 26.3%
- Pelvic pain: 22.5%
- Constipation: 40.0%

- Sexual dysfunction: 18.3%
  - Hypoactive sexual desire
  - Low lubrication
  - Pain or discomfort during vaginal penetration: 43.3%
    - 20% had this symptom at least half the time
Pelvic floor muscles
Project 2: Clinical practice guidelines on roles and interventions in physical therapy to promote sexuality in adults with neuromuscular disorders
Isabelle Fisette-Paulhus, PT; Cynthia Gagnon, OT, Ph.D.; Julie Fortin, M.Sc.; Annie Plourde, Ph.D.; Marjolaine Tremblay, SW, M.Sc.; Laura Girard-Côté, PT; Mélanie Morin, PT, Ph.D.

Clinical practice guidelines soon to be published
Article submitted to Physiotherapy Canada Journal

INTRODUCTION:

• Neuromuscular disorders:
  • Diseases that affect function of the muscles with alteration to the muscle itself or peripheral nerves
  • > 200 different diagnoses
  • Wide range of signs and symptoms
  • Includes myotonic dystrophy
Project 2: Clinical practice guidelines on roles and interventions in physical therapy to promote sexuality in adults with neuromuscular disorders

Isabelle Fisette-Paulhus, PT; Cynthia Gagnon, OT, Ph.D.; Julie Fortin, M.Sc.; Annie Plourde, Ph.D.; Marjolaine Tremblay, SW, M.Sc.; Laura Girard-Côté, PT; Mélanie Morin, PT, Ph.D.

Summary of the results from the Heatwole et al. (2012, 2015) studies

<table>
<thead>
<tr>
<th>Impairments/limitations</th>
<th>DM1 (n=119 to 125)</th>
<th>DM2 (n=34 to 37)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain during sex</td>
<td>15.3%</td>
<td>33.3%</td>
</tr>
<tr>
<td>Impaired sexual function</td>
<td>57.6%</td>
<td>67.6%</td>
</tr>
<tr>
<td>Limited sexual positioning</td>
<td>Not reported</td>
<td>70.6%</td>
</tr>
<tr>
<td>Decrease sexual contact</td>
<td>53.8%</td>
<td>58.8%</td>
</tr>
</tbody>
</table>

Results from the Christopher project Report to the Myotonic Dystrophy community: Sexual/intimacy problems (DM1 = 32%) vs (DM2 = 44%)

70% of people with chronic disorders present problems with their sexuality, and only 18% are able to overcome them independently.

Hagerman et al. 2019; Heatwole et al. 2012; Heatwole et al. 2015; Stewart 1976
Project 2: Clinical practice guidelines on roles and interventions in physical therapy to promote sexuality in adults with neuromuscular disorders
Isabelle Fisette-Paulhus, PT; Cynthia Gagnon, OT, Ph.D.; Julie Fortin, M.Sc.; Annie Plourde, Ph.D.; Marjolaine Tremblay, SW, M.Sc.; Laura Girard-Côté, PT; Mélanie Morin, PT, Ph.D.

60% of healthcare professionals believe that sexual difficulties should be discussed, but only 6% frequently engage the discussion

OBJECTIVES:

1. To document impairments in adults with neuromuscular disorders that can interfere with sexual activities and to propose physical therapy interventions.
2. To recommend approaches to discuss sexuality.
3. To highlight issues that require expertise in pelvic floor rehabilitation.

Gianotten et al. 2006
Interventions
Physical activity

✓ Improves mental and physical well-being
✓ Direct impact on sexual function
✓ Indirect impact on sexual activities (maintenance or improvement of function, cardiorespiratory endurance or muscle strengthening)

Physical inactivity can increase the risk of developing sexual dysfunction.

Christensen et al. 2011; Lombardi et al. 2010; Mollaioli et al. 2020; Plinta et al. 2015
Muscle weakness

• Preliminary studies show beneficial impact of exercise on muscle weakness
• Recommended having a muscle strengthening program for maintenance of capacities

• Tips to compensate for muscle weakness:
  - Modification sexual position, be creative
  - Sexual activity ≠ penetration
  - Practice position before trying it in a sexual context
  - Use furniture or sexual objects
    - Weakness in the hand is frequent in DM1: some sexual objects like vibrators are hand-free

Roussel et al. 2019; Roussel et al. 2020
Fatigue

- Determine when energy level is at highest and plans sexual activity around it
  - Mornings are usually when the energy is at the highest
- Plan rest period before and after sexual activities
- Penetration = more energy

Bardach 1995; Delaney & Donovan 2017; Kaufman et al. 2007
Contractures and reduced range of motion

✓ Stretching before sexual activities are good way to help position and stay away from injury.

✓ Heat can be applied to relax the muscles*

✓ Some adapted positions may be more favoured depending on contractures. Physical therapists can help you in finding stretching exercises and adapted positions.

*Hot showers can help reduce tension in the muscles before sexual activity, but you have to be careful if you have low blood pressure.
Erectile dysfunction

70-72% in DM1

✓ Negative impact of lifestyle habits on erectile function (obesity, physical inactivity, diet, tobacco, alcohol, drugs)

✓ Importance of pelvic floor muscle:
  ✓ Contraction of pelvic floor muscle → decreases venous return from the cavernous tissues and help erection
  ✓ Can help penetration and maintain of erection during penetration
  ✓ Partners can do contraction around the penis during anal or vaginal penetration to increase pressure and help erection

Antonini et al. 2011; Ben-Zacharia 2011; Christensen et al. 2011; Mollaioli et al. 2020; Peric et al. 2013; Smith et al. 2015

Physical therapy
- Education
- Personalized program for pelvic floor muscles
- Neurostimulation, biofeedback
# Female lubrication

<table>
<thead>
<tr>
<th>Lubricants</th>
<th>+</th>
<th>-</th>
</tr>
</thead>
<tbody>
<tr>
<td>Water based</td>
<td>- Most accessible</td>
<td>- Dry quickly, need to reapply</td>
</tr>
<tr>
<td></td>
<td>- Can be used with condoms or other sexual objects</td>
<td></td>
</tr>
<tr>
<td>Silicone</td>
<td>- Can be used in water and with condoms</td>
<td>- More expensive</td>
</tr>
<tr>
<td></td>
<td>- Longer lubrication</td>
<td>- Can’t be used with silicone products</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Difficult to wash off</td>
</tr>
<tr>
<td>Oil based</td>
<td>- Low cost</td>
<td>- Can’t be used with condoms</td>
</tr>
<tr>
<td></td>
<td>- High hydration and moisturizing</td>
<td>- Can stain clothes</td>
</tr>
</tbody>
</table>

- Bardach 1995; Lucio et al. 2014; Mercier et al. 2019; Smith et al. 2015

**Physical therapy**

- Pelvic floor muscle exercises
- Vibratory stimulation
- Transcutaneous electrical stimulation
Pain

- 86-88% in DM1 and DM2
- Importance to identify the cause of pain (tensions, myotonia, neurogenic pain, dryness, etc.)

 ✓ Schedule sexual activities at time when the pain is less intense and synchronizes with medication, level of fatigue and stress
 ✓ Relaxation and rest after and before sex can help reduce pain
 ✓ Modification in position (overload, back pain, vaginal penetration)

Physical therapy
- Pelvic pain: exercises, stretching, neuromuscular stimulation, manual therapy, biofeedback, dilatator

Breton et al. 2008; Crabtree 1997; Peric et al. 2015
Incontinence

- Lifestyle habits that can have an impact on urinary symptoms:
  - Weight loss
  - Increase physical activity
  - Smoking cessation
  - Decrease caffeine consumption
- Water intake
- Pelvic floor muscle exercises

- Emptying the bladder before sexual activity and putting a protection on the bed can decrease anxiety associated with leaks.

Physical therapy

- Education, bladder diary
- Exercises
- Neuromuscular stimulation
- Proprioceptive exercises
- Biofeedback

Bo et al. 2014; Dumoulin et al. 2018
Respiratory and cardiac implications

To reduce breathing difficulty and decrease intensity of the activities:

- Avoid sexual activity one hour after eating
- Don’t consume alcohol three hours before sexual activity
- Avoid hot, humid or cold environments
- Plan sexual activity when well rested
- Some strategies can decrease dyspnea (posture, pursed lip breathing, diaphragmatic breathing)
Positioning

- Sexual activity ≠ penetration
- Respect capacities of BOTH PARTNERS
- Take into consideration:
  - Maintain of position
  - Movement into the position
  - Transferring between position
- Adaptations, equipment: pillow, bed helper, bean bag, electric bed
- Practice positions before sexual context

Physical therapy
- Recommendations
- Education on equipment

First position: on the back

Activities possible:
- Caresses
- Masturbation
- Oral sex
- Vaginal or anal penetration

Benefits:
- Women or men
- Less effort
- Better support
Second position: on the side, face to face

Activities possible:
• Caresses
• Masturbation
• Oral sex in reverse position (69)
• Vaginal penetration

Benefits:
• Allows both partners to participate
• Less effort
• Interesting positions if both have limitations
Third position: on the side, spoon or perpendicular

Activities possible:
• Caresses
• Masturbation
• Vaginal or anal penetration

Benefits:
• For women or men
• Less effort
Fourth position: sitting

Activities possible:
- Caresses
- Masturbation
- Oral sex
- Vaginal penetration

Men sitting: partner face to face, back or side

Women sitting: possibility of moving the buttocks forward on the chair for penetration or oral sex, but this decreases the support

Benefits:
- Passive position for the person seated
- Decreases the number of transfers
Fifth position: on the abdomen

Activities possible:
• Masturbation
• Vaginal and anal penetration

Middle of the bed or edge of the bed (doggy style)

Benefits:
• Women or men (anal penetration)
• Facilitates sex with penetration

AVOID IF:
- Inability to roll over onto your back
- Severe weakness of the upper limbs
- Breathing difficulty
Sex objects

Masturbation: women

- Magic wand
- Vibrating panty
- Hands-free vibrator
- Dildo
- Massage glove
- Finger vibrator
- We vibe
- Handy harness
- Magic mount

The pictures are examples of different sexual objects. No reference is mentioned as we don’t want to encourage one specific brand or sex shop.
Sex objects

Masturbation: men

Penis stimulator

Vibrator penis ring

Male masturbator

Kneeling mount

We vibe

The pictures are examples of different sexual objects. No reference is mentioned as we don’t want to encourage one specific brand or sex shop.
Sex objects

Penetration

Thigh strap on

Ohnut

Penis sleeve

Sling and strap

The pictures are examples of different sexual objects. No reference is mentioned as we don’t want to encourage one specific brand or sex shop.
Conclusion

• Sexuality and intimacy are part of a fundamental need.

• Neuromuscular diseases can affect sexuality.

• There are many ways to adapt your sexual life.

• Future studies should focus on developing interventions for improving sexual function.
Thank you!
References

References


Myotonic Dystrophy Foundation
References


Questions ?