Supporting patients DM1 and sexuality for clinicians

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Sexuality or what are we really talking about?

- "Sexuality is a central aspect of being human throughout life, including sex, gender identities and roles, sexual orientation, erotism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviors, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. [...]

(Organisation mondiale de la santé 2006)
Sexuality .... Not a simple physical act

- Physical act
- Affection
- Love life
- Self-esteem
- Reproduction
- Couple’s life
- Family life
- Social relationships
- Sexual Identity
- Ethics
- Etc.
Physical act: to do or not to do

But what?

- Making love
- Caress
- Masturbation
- Kissing
- Hugging
- Touching
How DM1 can influence sexuality: physical part

• Muscular system
  • Decrease muscle strength
    • Difficulty/Unable to assume certain positions
    • Decrease endurance
    • Decrease ability to close hand/myotonia: masturbation/caress
  • Presence of pain
    • Difficulty/Unable to assume certain positions
    • Fear of having pain during the process
How DM1 can influence sexuality: physical part

• Central Nervous system
  • Fatigue
    • Decrease interest
    • Decrease endurance
  • Hypersomnolence
    • Decrease interest
    • Decrease opportunity
  • Apathy
    • Trouble initiating
• General cognitive functionning
  • Risk-taking behaviors
How DM1 can influence sexuality: physical part

Genito-urinary system
  • Erectile dysfunction
    • Between 24.1% and 36.7% of men
    • Medication may be given

• Gynecological problem
  • Painful menstruation

• Urinary incontinence
  • Medical consultation
  • Hygiene technique

• Intestinal problem
  • Medical consultation
  • Sexual counsellor
  • Hygiene technique
How DM1 can influence sexuality: physical part

Cardiac system
• Patient and partner may be fearful of having sexual relationships

Respiratory system
• Nocturnal ventilation
WHO DOES WHAT?
Sexual Medicine Physicians or Physiatrists (MD)

- Maximizing sexual physiology and reducing the medical issues
  - Medications
  - Pain
  - Bladder and bowel continence

- Other physicians (urologist, gynecologist, neurologist, etc) may also have valuable expertise
Occupational Therapist

• Teaching skills such as how to:
  • organize a **daily routine** to allow time and energy for sexual activities
  • manage **personal hygiene** before and during sexual activities
  • **compensate** for reduction or loss of typical body functioning in order to sexually satisfy self and/or partner
  • alter or eliminate **environmental barriers** to improve the quality of sexual activity (e.g. poor lighting, inadequate bed system etc.)

• Adapt sexual devices to meet the abilities of clients
  • adding switches
  • making ‘hands free’ options
Physiotherapist

• Educate and assist clients with skills such as:
  • transferring from wheelchair to bed
  • repositioning in bed
  • maintaining balance
  • maximizing comfort in sexual positioning alone or with partners
  • compensate for reduction or loss of typical body functioning in order to sexually satisfy self and/or partner
  • perineal reeducation (advanced practice)
Nurses

• Can assist with the execution of many of the suggestions given by the OT, PT or MD, and are critical in assisting with the overall medical management.

• Sexual Health Clinicians (SHC) are nurses specialized in the area of sexual health. They are experts in educating clients and their partners on the complex changes to sexual function as a result of chronic illness or disability, and are qualified to make specific suggestions to enhance sexual functioning and/or fertility.
Social worker/Psychologist

• Social Workers
  • Can play a large role in educating and counseling partners and families around sexual and fertility issues.
  • Can also assist with funding options for the purchase of equipment.

• Psychologists
  • Explore in depth with clients the many different emotional components of sexuality such as self esteem, assertiveness, and positive self-talk, as well as collaborate with partners and family around sexual and fertility issues.
  • Psychologists can also address trauma around sexuality.
Rehabilitation Sexual counsellors

- Not found everywhere
- University training
- Holistic approach around sexuality
« It does not exist! »

« Of course, but not my role »
Challenges

• Subject often not discussed
• What is really sexuality/preconception
• Patients expect clinicians to talk to them about it
• Healthcare professionals do not feel comfortable addressing this with their patients
  • Very few training
  • Specific resources

(Dyer 2013, Gianotten 2006, Taylor 2006)
Tabou...

- Healthcare professionals
- Patients
- Family
- Sheltered housing...
BRIDGING THE GAP

A DUAL RESPONSABILITY
How to talk about sexuality

Ex–PLISSIT

(Annon 1976, Taylor 2006)
The Extended PLISSIT Model

Self-awareness → Reflect → Review → Knowledge → Challenge assumptions

Reflect → Review → Reflect

P, LI, SS, IT

Key:
P: Permission giving
LI: Limited Information
SS: Specific Suggestions
IT: Intensive Therapy

Taylor 2006
Stage 1

PERMISSION-GIVING

WE CAN TALK ABOUT IT

• Give the permission to the patient about sexuality
• Assessment process
• Poster in the waiting room/leaflet

REASSURE

• Normalization of the topic

CLARITY

• Open direct question

Ex–PLISSIT

People with DM1 often mention that [symptoms] interfere with their sexuality.

Do you... How is your experience with this?
Opportunities for permission-giving

- New patient registration
- Contraception
- Waiting room information and poster
- Discussion around bringing the bed downstairs
- Annual evaluation: include it in the process
PERMISSION ⇔ INFORMATION

- Often linked
- Information linked to expressed needs

IMPACTS

- Impact of illness on sexuality
- Effect of treatments on sexual function

CLARIFICATION

- Clarifying misinformation, dispelling myths
- Factual information in a limited manner (leaflet, website, etc.)
Problems solving approach:

- All aspects of sexuality
- Specific suggestions related to the expressed by the patients
- Psychological aspects

Muscular weakness

To experiment sexual positions… for example, by placing yourself on the side
Advanced practice

• Training
• Not all profession
  • Physiotherapy
  • Sexual counsellor
  • Nursing
• Etc.

Niveau 1
Permission-giving

Niveau 2
Limited information

Niveau 3
Specific instructions

Stage 4
INTENSIVE THERAPY
You talk to your patient about his/her sexuality? *Write your thoughts!*

- What you have been discussing
- Good moves
- What you should not have said
- Things to do to get better
TO TALK ABOUT IS THE BEGINNING OF A GREAT SUCCESS
Références


