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Clinical Protocol: Interstitial Cystitis / Bladder Pain Syndrome (IC/BPS)

PREAMBLE

- Case definition includes:
  - Pain
    - Suprapubic pain (or pressure, discomfort) related to bladder filling
    - Pain throughout the pelvis—in the urethra, vulva, vagina, rectum
    - Extra-genital locations such as the lower abdomen and back
  - Urgency
  - Frequency
  - Worsened with:
    - Specific foods or drinks
    - Bladder filling
  - Improved with urination
  - Note:
    - Typically, IC/BPS patients void to avoid or to relieve pain
    - Patients with overactive bladder void to avoid incontinence
- The diagnosis of IC/BPS can be challenging
  - Rule out infection and other causes
  - If hematuria present, more sinister causes need to be considered
  - You may need to refer to Urology and/or Gynecology
- Can occur in males
  - Overlap with chronic prostatitis
- IC/BPS is a visceral pain syndrome and therefore central sensitization is key to symptom evolution and typically involves bladder as well as non-bladder pain generators
  - One example of this is the well-understood process of "viscero-visceral crosstalk" that results in symptoms in neighboring organs. For example:
    - Dysmenorrhea
    - Vulvodynia
    - Hypertonic Pelvic Floor Dysfunction (with its associated voiding problems)
    - IBS
  - More distal Central Sensitivity Syndromes usually co-exist (e.g., FM)
- Therapy directed toward primary pain and secondary pain generators downregulates the process of central sensitization
- Referral to Pelvic Pain Clinic or Urology is be required for the diagnosis and management of more complicated cases
- Multi-modal therapy and patient education (including self-care practices) are the key to successful management
- The treatments described below may occur one-on-one or in a group setting depending on resources Provide patient with information/dose adjustment handout
- It is expected that physicians would educate themselves about these drugs beyond the outline provided below

1. PATIENT EDUCATION

- Topics include

  - Identification of symptom triggers:
    - E.g., diet, stress, insomnia, depression, and hormone fluctuations
  - Fluid management:
    - Altering the concentration and/or volume of urine either by fluid restriction or additional hydration
    - Goldie Locks Zone: 6 – 8 cups /day (1.5 – 2 L/day)
  - Avoidance of bladder irritants:
    - E.g., acidic foods (e.g., citrus), alcoholic beverages, caffeine
    - Elimination Diet
  - Application of local heat or cold over the bladder or perineum
  - Bladder training with urge suppression
  - Avoidance of tight-fitting clothing
  - Avoidance of constipation
- Patients should keep a log/diary of symptom severity, associated disability, and response to treatments
- "The Interstitial Cystitis Survival Guide" available at Amazon.ca
- "Family and Friends" evening session
  - To register for the next event contact infoccdp@cw.bc.ca
- Incorporated into multiple offerings (e.g., handouts, web-based resources)
  - IC Patient Resources

2. PHYSICAL ACTIVITY

- Directed at central sensitization more generally and Hypertonic Pelvic Floor Dysfunction more specifically
  - Caution for patients with co-existing ME/CFS who may get worse if they overdo it.
- Relaxation techniques
- Reverse Kegel exercises
- Pelvic-floor strengthening exercises (e.g., Kegel exercises) should be avoided

3. SLEEP

- See Sleep Protocol for details

4. DIET

- Offered in group setting and individual sessions with dietitian
- Most bothersome foods:
  - Coffee (caffeinated and decaffeinated)
  - Tea (caffeinated and decaffeinated)
  - Soda
  - Alcohol
  - Citrus juices
  - Cranberry juice
  - Foods and beverages containing artificial sweeteners
  - Hot peppers and spicy foods
- Trial of an elimination diet can be helpful to identify trigger foods

5. ALTERATIVE AND COMPLIMENTARY THERAPIES

- Calcium glycerophosphate (Prelief) and quercetin show some promise

5.1 Calcium glycerophosphate (Prelief)

- Neutralizes acidic foods and improves both bladder and bowel symptoms

5.2 Quercetin

- Flavonoid, a plant pigment found in fruits, vegetables, leaves and grains
- 800 mg 20 min AC meals BID – TID
- Watch for: headache, paresthesias

6. PSYCHOLOGICAL AND BEHAVIOURAL THERAPIES

- Incorporated in core group: Living with Complex Chronic Diseases
  - Combines Education, Pacing, CBT &, Mindfulness
  - 10 weeks
- Incorporated into other groups

7. INTERVENTIONS

- Maneuvers that resolve pelvic, abdominal, and/or hip muscular trigger points, lengthen muscle contractures, and release painful scars and other connective tissue restrictions
- For example:
  - Myofascial release
  - Trigger Point Injections
- Internal referrals
- Outside referrals:
  - Change Pain Clinic
  - Muscle MD
  - Myo Clinic (Victoria)
  - Other practitioners across the province

8. MEDICATIONS

Oral Therapies

8.1 Pentosan polysulfate (Elmiron)

- The only oral medication that the FDA has approved for the management of IC
- Expensive $$$
- Modes of action:
  - Replenishment of the glycosaminoglycan layer defects
  - Antihistaminic effects on mast cells
- Is a LMWH-like compound with anticoagulant and fibrinolytic effects

  - Bleeding complications (such as ecchymosis, epistaxis, and gum bleeding) may occur
- Contraindicated in patients with hypersensitivity to related compounds (LMWHs or heparin)
- Adverse event rates are low; similar to placebo groups studied
- Failure to respond after 6 months is generally thought to be an adequate trial
- 100 mg TID 1 hour before or 2 hours after meals

8.2 Amitriptyline

- Cyclobenzaprine, another TCA, also has muscle relaxant properties
- See FM clinical protocol for prescribing instructions

8.3 Hydroxyzine (Atarax)

- An antihistamine with antianxiety and analgesic properties
- Used if patient has:
  - Significant Hx of allergies
  - Intolerance to amitriptyline
- Minimal side effects other than sedation
- Start 25 mg QHS; may increase to 50 mg

8.4 Cyclosporine A

- Immunosuppressive agent
- Used in patients intolerant or unresponsive to intravesical therapies
- A response is seen within 6 weeks
- Sustained benefits up to five years have been observed
- Rapid return of symptoms with cessation of therapy
- Usually well-tolerated
- Serious side effects:
  - Hypertension
  - Elevated serum creatinine
  - Monitor weekly for first 4 weeks of therapy then q6 months
- Watch for:
  - Gingival hyperplasia
  - Induction of facial hair growth
- Start 1.5 mg/kg/day BID
- May be reduced to 0.75 mg/kg/day after initial response

Topical Therapies

- Used in patients with associated vulvodynia
- Vulvodynia if often made worse with prolonged use of oral contraceptives
  - Should be discontinued when possible
- Compounded creams designed to down-regulate the neuro-immune upregulation (i.e., peripheral sensitization) is useful
- Examples:
  - Topical steroid ointment
  - Amitriptyline/baclofen/gabapentin (2.5% each)

Intravesical Therapies

- Refer to urology
- Various anesthetic therapeutic cocktails are used; Ingredients include:
  - Heparin
  - Bicarb
  - Lidocaine
  - Corticosteroids
  - Pentosan polysulfate (Elmiron)
- Duration of the benefit is initially short
  - Multiple installations are typically used
  - Increasing duration of the benefit often seen with ongoing treatment
- Can be used as a rescue treatment of patients with severe flare
- Many patients have such significant urethral allodynia that the placement of a catheter for instillation is simply not tolerated

9. ASSESS AND TREAT COEXISTING CENTRAL SENSITIVITY SYNDROMES

- Treatment protocols are available on our website
- Central Sensitivity Syndromes include:
  - IBS
  - Migraine
  - Tension Type Headaches
  - POTS
  - Multiple Chemical Sensitivities
  - Interstitial Cystitis
  - Pelvic Pain Syndromes
  - Irritable Larynx Syndrome
  - Restless Leg Syndrome
  - Non-cardiac Chest Pain
  - Temporomandibular Disorders
  - Myofascial Pain Syndrome
  - Central Abdominal Pain Syndrome
  - PTSD

10. ASSESS AND TREAT FOR COEXISTING ANXIETY AND MOOD DISORDERS

- Referral to psychiatrist for selected patients

Patient Resources:
http://www.bcwomens.ca/health-info/living-with-illness/living-with-complex-chronic-disease/interstitial-cystitis