Endometriosis:
A pathway to care

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Conflicts of Interest

- I receive research funding from Myovant Sciences
Objectives

• Break down comprehensive care for endometriosis into categorical pathways

• Understand the complexity of endometriosis – associated pain processes

• Find, treat, and direct patients to the appropriate interventions for care of endometriosis-associated pain, organ dysfunction, and sub-fertility
Why a pathway?

• Endometriosis is complex and confusing
  • Patients get to care too late
  • Patients do not get correct care
    • Too few conservative therapies
    • Inappropriate conservative therapies
    • Too many surgeries
    • Insufficient surgeries
  • Patients get partial care
Getting on to the pathway

- Dysmenorrhea (especially primary- or starting in teens)
- Subfertility
- Dyspareunia
- Organ dysfunction
Navigating the pathway: A few rules for the road

• There are 3 main types of endometriosis

SUPERFICIAL-
• greater association with cyclic pain
• Does not cause organ dysfunction

CYSTIC
• Cyclic pain and often ipsilateral constant pain
• Ipsilateral pain deep thrust dyspareunia

DEEP INFILTRATING
• Can cause any type organ dysfunction
• Retrocervical tenderness, nodularity
• Deep thrust dyspareunia
• Must differentiate from high tone pelvic floor

LASTLY
• Endometriosis follows no rules
• Endometriosis related pain is only partially caused by endometriosis
Chronic Pelvic Pain Source

A chronic pelvic pain source rarely occurs in isolation
A compilation of pain sources and symptoms
Endometriosis Pathway to Care

Suspected Endometriosis

- Generalized Pelvic Pain
  - Simple Dysmenorrhea
  - Pain duration throughout the month
- Organ pain and dysfunction
  - Bowel
  - Bladder
- Subfertility
  - Vagina

Complete History, Physical exam
Suspected Endometriosis

Pain duration throughout the month

Complete History, Physical exam

Involves organ systems

Simple Dysmenorrhea

Bowel

Bladder

Vagina

Subfertility

Endometriosis Pathway to Care
Simple dysmenorrhea

• Diagnosis
  • History- Painful periods, denies any other pain source or organ dysfunction
  • Imaging- pelvic US
  • Examination- pelvic floor, uterus, retrocervix, adnexa

• Treatment course
  • Menstrual suppression
    • COC, POP, vaginal ring, etonorgestrel implant, MPA injectable, LNG-IUD*
    • GnRH agonists/antagonists, danazol
  • Pelvic floor PT (as indicated)
  • Other Considerations: adenomyosis
Simple dysmenorrhea

- Simple dysmenorrhea
  - Menstrual Suppression
    - Acute and severe pain
      - GnRH especially if amenable issue
    - Non-acute
      - Long term hormonal options
  - No abnormalities
  - adenomyosis
  - cysts
    - Persistent and characteristic of endometrioma
    - Consider MRI to characterize
  - Ultrasound
    - Deep infiltrating endometriosis

ENDOMETRIOMA PATHWAY
DIE PATHWAY
Failed first attempt

- Identify reason for failure
  - Side effects
  - Incompatible belief system
  - Fear, anxiety
- Try another form of menstrual suppression
- Repeat brief history and physical exam
- Consider Diagnostic Laparoscopy (with intent to treat)
The complete history

• PAIN- intensity, duration, timing, location, radiation, better, worse
• PERIODS- regularity, pain course, onset timing, fertility plans
• URINARY- frequency, urgency, emptying, leaking, pain (with filling, with urination)
• BOWEL- constipation, diarrhea, emptying, leaking, pain (before, during, or after BM)
• SEX- entry, before/during/after, specific spot
Side note: the pelvic floor examination

• **Purpose**- to rule out **HIGH TONE PELVIC FLOOR DYSFUNCTION**

• **Symptoms** can include: dysmenorrhea, dyspareunia, urinary/bowel dysfunction (esp. Constipation, OAB, incomplete emptying)

• **AKA**
  - Pelvic Floor tension myalgia
  - Levator ani syndrome
  - Myofascial Pelvic Pain Syndrome
Making the diagnosis
Spine tenderness nt
SI joint right side tenderness
CVA tenderness nt
Leg length - equal
Pubic symphysis tenderness N
Pubic bones supra pubic right greater than left
Abdominal tenderness
Abdominal myofacial trigger points - bilateral lower quadrant - murphy's sign  Lower left rectus

Vaginal Vestibular tenderness nt
Rectal tenderness nt
Bladder base tenderness ++

Uterus mobile antverted no uterine tenderness
Retrocervical nt no nodularity
Adnexa nt

Pelvic Floor Musculature
RIGHT SIDED
Pubococcygeus 3
Iliococcygeus 3
Coccygeus 3 burning
Obturator ne

LEFT SIDED
Pubococcygeus 3 burning
Iliococcygeus ne
Coccygeus ne
Obturator ne
(Pain Scale 1 to 3, 3= extreme)

RV exam - deferred
Suspected Endometriosis

Generalized Pelvic Pain
- Simple Dysmenorrhea
- Pain duration throughout the month

Complete History, Physical exam
- Involves organ systems
  - Bowel
  - Bladder
  - Vagina
- Subfertility
Pain duration throughout the month

Endometrioma

ENDOMETRIOMA PATHWAY

Myofascial origins

High tone pelvic floor

Abdominal myofascial pain

Other pain diagnoses
- Pelvic congestion
- Neuropathic Pain
- Centralized Pain
- IC/PBS
- IBS
- Pelvic girdle syndrome
- Labral tear
- Osteitis pubis
Endometrioma

- Characterize AND confirm persistence
- Goal of treatment - fertility, pain, concern for malignancy
Asymptomatic endometrioma

• If asymptomatic,
• smaller than 8 cm and,
• no concern for malignancy...
• No action is needed
• Expectant management, follow every 6-12 months
Endometrioma and PAIN

- Rule out other causes for pain
- Consider medical interventions

- Drain
  - Limited resources OR in consultation with REI for ART

- Cystectomy
  - Best for fertility and pain

- Oophorectomy
  - Best for permanent resolution of endometrioma

POST OPERATIVE MENSTRUAL SUPPRESSION
Endometrioma and Fertility

Immediate desires
- REI
  - Cyst not in the way
    - ART
  - Cyst in the way
    - Drain then ART
- No desire for ART
  - Cystectomy

Eventual desires
- Cystectomy + menstrual suppression
Endometrioma and size alone

Endometrioma >8 cm

- Concern for malignancy
  - If desires ART
    - Cystotomy and drainage
  - If can/desire to avoid oophorectomy
- Surgery
  - Ovarian cystectomy
- Concern for ovarian destruction
  - If concern for malignancy
    - FA-125 cannot guide us here?!
  - oophorectomy

Serum CA-125 levels is a poor screening modality for EAOC. Kadan reported that CA-125 was higher in patients with EAOC compared to benign endometrioma, but did not reach statistical significance (mean 204.9 vs. 66.9 U/mL, P > 0.1).34
Endometrioma + PAIN and done with childbearing

• Should we remove both ovaries?
• We must compare apples and oranges
• Recurrence rates versus surgical menopause
  • Recurrence of pain: 62% versus 10%: hysterectomy alone with oophorectomy
  • Reoperation rates: 31% versus 3.7%: hysterectomy alone with oophorectomy
• Ovarian cancer risk. - OR 1.34 in women with endometriosis*
  • Somigliana reported no increased risk
• Menopausal status
Involves an organ system

- Can involve pain or functional deviations of an organ system
- Sometimes the cause can be directly linked to endometriosis
- Sometimes the cause is part of a complex pain syndrome

There are of course other organ systems: Catamenial locations like lung, brain Diaphragm Ureter Nerve and nerve roots
Urinary frequency
Urinary Urgency
Pain with filling
Pain with urination
Hematuria
Incomplete emptying

Bladder

Failed PFPT and hormonal suppression

MRI + cystoscopy
More cyclic in nature

Bladder Endometriosis
SURGICAL RESECTION
No abnormalities

Food sensitive, random flares, hurts with full bladder
Hunner’s ulcers
ABLATE

IC/PBS PATHWAY

Cystoscopy
No abnormalities
Bowel Pain with defecation

Pelvic floor

Rectal pain, inability to empty “constipation"

Large intestine

MRI or US

Small Intestine (commonly ileocecal)

CT/MRI enterography

Or R iliac fossa US

Cyclic vomiting (cyclic SBO)

NOTES on the appendix

Low threshold to remove
1. Visible lesion
2. Stage 3/4 endometriosis

NOTES ON SMALL BOWEL ENDO

• Menstrual suppression can eliminate symptoms
• Resection can be done without diversion, and can be curative-but risk of SBO
• Imaging is limited for diagnosis

NOTES ON LARGE BOWEL ENDO

• After menstrual suppression, dyschezia and dyspareunia often persist
• Resection can resolve symptoms
• Resection ranges from
  • Rectal shaving
  • Discoid resection
  • Segmental resection+ reanastomosis
  • Segmental resection+ reanastomosis+ileostomy
• Constipation and outlet dyschezia seem to be most predictive of rectosigmoid endometriosis

Menstrual suppression OR surgical resection

Menstrual Suppression OR surgical resection

Low threshold to remove
1. Visible lesion
2. Stage 3/4 endometriosis

Do not recommend incidental appendectomy

Do not recommend incidental appendectomy
NOTES ON UTEROSACRAL DIE
• Most common site for DIE
• Often responsible for refractory dyspareunia
• Sometimes nodularity, sometimes only tenderness
• High surgical success rate

Dyspareunia related to endometriosis
• Combination of causes
• Often related to pelvic floor
• Timing is the key to diagnosis
Finding patients that need help

• Reaching out
  • Social media
  • Advertisement
  • Hard media
  • Soft media
  • Industry

• Finding in your own system
  • Using CPT codes
Using your health system to identify patients

- In health system with:
  - # in CCF system

- In 1 year: 2288 patients with endometriosis or related symptoms in the Emergency department
  - 39 patients had endometriosis diagnosis

<table>
<thead>
<tr>
<th></th>
<th>Visits During 2018/5/1 ~ 2019/4/30</th>
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<tbody>
<tr>
<td></td>
<td>SuspEndo</td>
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<tr>
<td>Total Patients (include hospital encounter)</td>
<td>13,934</td>
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<tr>
<td>Total Visits (include hospital encounter)</td>
<td>18,858</td>
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<tr>
<td>Total Patients (exclude hospital encounter)</td>
<td>11,821</td>
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<tr>
<td>Total Visits (exclude hospital encounter)</td>
<td>16,257</td>
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<tr>
<td>Total Patients seen by OBGYN</td>
<td>8,153</td>
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<td>Total Visits seen by OBGYN</td>
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<tr>
<td>Total Patients seen by CPP Clinic</td>
<td>561</td>
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<tr>
<td>Total Visits Seen by CPP Clinic</td>
<td>776</td>
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</tbody>
</table>

Percentage (seen by OBGYN/Total patients (exclude Hospital Encount) | 68.97 | 87.58 | 69.99 |
Google trends: endometriosis

Jan 1, 2018: Advertising campaign for Orilissa™
Laparoscopic excision of endometriosis

Pelvic Floor PT

Pelvic Pain psychology

Abdominal Trigger Point Injections

Surgery: 10/11/18
Started PT appts: 12/14/18
Started Lupron: 5/8/19
Stopped PT appts: 5/30/19
Working with Darcy on anxiety: 7/3/19
Started trigger points: 8/20/19
A summary of surgical indications for endometriosis

• Failed conservative therapy for simple dysmenorrhea
• Point dyspareunia, with retrocervical tenderness/nodularity
• Large or symptomatic endometrioma
• Non-responsive AND symptomatic deep infiltrating endometriosis
• Subfertility (+/- w IVF)
Key Takeaways

• Viewing endometriosis as a pathway can guide patients to a more efficient and effective treatment course

• Endometriosis associated pain and symptomatology has a multifactorial pathogenesis and involves co-existant pain syndromes

• There are roles in endometriosis care for both conservative and radical treatment courses, many times utilizing a multifactorial approach

• Finding, diagnosing and treating endometriosis requires an understanding of general pelvic pain processes, endometriosis sub-types and a recognition of pain phenotypes and imaging courses in order to direct our patient to the most efficient and effective care
Sources


• Matorras R, Elorriaga MA, Pijoan JI, Ramón O, Rodríguez-Escudero FJ. Recurrence of endometriosis in women with bilateral adnexectomy (with or without total hysterectomy) who received hormone replacement therapy. Fertil Steril 2002;77(2):303–308


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