

## Brokengirl:

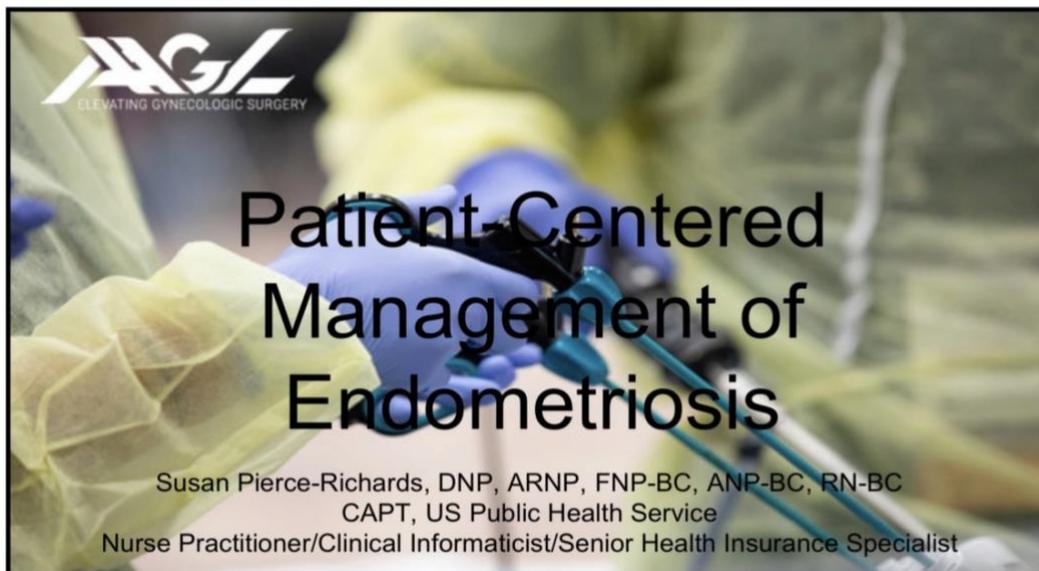
# The secret shame of chronic pelvic pain and the unseen consequences of our current care paradigm for endometriosis care

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This blog is the narrative from my portion of a panel presentation/debate on the current treatments for endometriosis related pain given on 11/13/2019 at the AAGL 2019 48<sup>th</sup> Global Congress on MIGS. I had the privilege of sharing the stage with Dr. David Redwine who has impacted countless lives through his clinical, research, and educational efforts that he continues in his “retirement.” The audience included legendary endometriosis experts and advocates Nancy Petersen, Heather Guidone, and Dr. Sallie Sarrel. [Panel Session 4: Debate: "There Will Be an Answer, Let It Be"- Expert Debate on Treatments for Endometriosis Associated Pain](#)

Disclosure: I have no financial relationships to disclose.

Disclaimer: The views presented herein do not represent the views of the Federal Government



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## Table of Contents

<b>Introduction</b> .....	<b>3</b>
<b>Brokengirl—how the current state of endometriosis care fails patients</b> .....	<b>3</b>
Teens .....	3
Twenties .....	4
Thirties .....	4
Forties .....	4
Lupron—the dementor .....	4
Excision—the light at the end of a very dark tunnel .....	5
<b>Person-centered care</b> .....	<b>5</b>
<b>The evidence-base—does it support person-centered care?</b> .....	<b>6</b>
1. Is our evidence base patient centered? .....	6
2. Are meta-analyses of randomized controlled trials (RTC) really the pinnacle of evidence? .....	6
3. Shared decision making—is it really patient centered? .....	7
4. Do we appreciate the power imbalances? .....	7
5. What happens outside of the exam room matters. ....	8
6. What about the people who can't access care or who we drove away? .....	8
<b>What is patient centered care, and what can clinicians do differently?</b> .....	<b>8</b>
1. Respect for patient's values, preferences, and needs .....	8
2. Information, communication, and education .....	8
3. Continuity and transition .....	8
4. Access to care .....	8
5. Technical skills .....	9
But what does person-centered care really look like ... and how can you be your patient's superhero? .....	9
<b>Summary</b> .....	<b>9</b>
<b>Resources</b> .....	<b>11</b>
<b>References</b> .....	<b>12</b>

## Introduction

Objectives

- Describe the impact of endometriosis on patients and the health care system<sup>1-3</sup>
- Recognize biases and limitations in the literature that impact the application of evidence in an evidence-informed, person-centered approach to care
- Identify areas of your practice where you can better engage with and empower patients

Endometriosis is a common disease, often causing pain, bowel and bladder dysfunction, and infertility, that presents a diagnostic and therapeutic challenge to clinician (Nnoaham et al., 2011). And it's costly. Estimates reach \$119 billion annually in the United States. But it's the toll on people's lives that I want you to focus on today. Their lives are interrupted by diagnostic delays, and their life trajectories are altered as endometriosis impacts every aspect of their lives (D'Hooghe, Dirksen, Dunselman, de Graaff, & Simoens, 2012; Howard, 2016). They wait even longer for effective treatment.

As the industry hotly debates theories of origin, diagnosis, symptom management, surgical approaches, drug therapies... where is the patient????

I want you think today about **a** patient—not the mean of the carefully selected subjects of a randomized controlled trial—but **a** human being, living their messy and complicated life, in a culture that does not truly empower patients...

## Brokengirl—how the current state of endometriosis care fails patients

Brokengirl... the secret shame of pelvic pain

Teens...	20s...	30s....	40s...
Dysmenorrhea	Urgency	Pelvic fullness	Bleeding x 3 years
Dyschezia	Frequency	"Hemorrhagic" cysts	<i>Hyst for bleeding – dx endometriosis</i>
Menorrhagia	Obstipation	Infertility	Nausea
Fixed uterus	<i>Stopped</i>	Flank pain	SBO sx
Dyspareunia	<i>seeking care</i>	Hematochezia	Melena
			<i>Excision + appy/LAR</i>

Symptom onset: Early teens      Time to dx: 30+ year  
Family hx of endo: M, MGM      Time on hormones pre dx: 19+ years

The story I am telling you today is mine - but it is extremely common. Nancy's Nook is an online educational community founded by Nancy Petersen, a highly respected nurse expert in endometriosis care. This community has grown from 200 to over 82,000 members [93,000 as of Feb 2020] in 7 years—most members failing "**usual**" endometriosis care.

## Teens

Like many others, my symptoms started in my early teens, were relentless and progressive. I had heavy, painful periods, and pain with bowel movements. I had an immobile uterus noted on my first pelvic exam at 18.

And once I began having sex, it was painful—until I was 45—after excision.

And I was told my symptoms were **normal**.

I was ashamed and embarrassed that I could not handle "**normal**".

## Twenties

In my 20's I developed painful urinary urgency, frequency, and worsening bowel problems. Again and again, I was told my symptoms were “**normal**” or that **I must be non-complaint** with hormonal suppression and NSAIDS.

I felt like a failure that the treatments **my providers gave me** did not work.

SO, I **stopped seeking care** for my symptoms.

I threw myself into school, work, and exercise because my choices were to cope through complete denial and pathological distraction ... **or what????**

The alternative was a very dark place...

Ironically my drug of choice, pathological workaholism and exercise, made me appear highly functional—and I was—but at a cost. Inside I was a little girl, silenced by shame and embarrassment, struggling to get through each day. I felt completely alone.

I was broken.

## Thirties

In my 30's I developed pelvic fullness (that I ignored), “hemorrhagic” cysts, infertility, flank pain, and rectal bleeding. I was urinating over 30 times per day and waking hourly at night, but my urine tests were always “**normal**” so I assumed I had a “small bladder”

## Forties

In my 40's I had a hysterectomy—but for bleeding, not pain. The relentless daily pelvic and bowel pain, urgency and frequency hadn't stopped—but I **had** stopped reporting it.

I had daily vaginal bleeding but delayed hysterectomy for 3 years because a gyn flippantly told me he would remove my ovaries and uterus because “**you don't need those anymore.**” Castration apparently is perfectly fine for **those of us born with a uterus.**

At hysterectomy, my new gyn found a fixed pelvis, bilateral endometriomas with intestinal and ureteral endometriosis. She was blindsided my silence, and lacked the skills to address the endo she found.

She was kind, humble, compassionate, and frankly horrified at the quality of life I had accepted.

Her validation impacted me profoundly and for that I am grateful. But due to the **MISinformation highway in ObGyn-land\***, she had nothing to offer me but Lupron.

\*ObGyn = Obstetrics and Gynecology

## Lupron—the dementor

Lupron (leuprolide) sucked the life out of me like a dementor. I had the brain, bones, and vagina of a 90-year-old, violent hot flashes, I smelled like a ferret, and had no joy.

And no, my symptoms did **not** improve—they actually worsened.

I developed relentless daily nausea, intermittent small bowel obstruction symptoms, and eventually had upper GI bleeding.

I was very ill and struggling to maintain hope.



- Misinformation from clinicians is rampant – hysterectomy, menopause, and pregnancy as a cure; Lupron to “kill off” remaining endometriosis, **and** being told they have “inoperable” disease (many of whom went on to have successful complete excision surgeries).
- They are offered **limited treatment options** such as “Lupron or hysterectomy” or “pregnancy or contraception.”
- In addition, they are often told that symptoms persisting **after inadequate care** are “in their heads.”

The overall experience reported by our members is **consistent with the literature** on women with chronic pain, medically unexplained symptoms, and endometriosis that describe:

- The struggle for credibility—the work to present the appropriate appearance and level of assertiveness to be taken seriously without offending clinical staff or having their symptoms psychologized.
- The stigma of menstruation and the prevalence of gender biases towards women with chronic pain, that marginalize patients in our system of care.
- Repeated invalidation that leads to self-doubt, and **shame**—many simply sever relationships with their provider and **drop out of care**.
- Being **dependent on providers who don’t understand the disease**, don’t understand its impact on them, and lack the knowledge and skills to help them.

(Gjesdal, Dysvik, & Furnes, 2018; Grundstrom, Alehagen, Kjolhede, & Bertero, 2018; Kundu, Wildgrube, Schippert, Hillemanns, & Brandes, 2015; Samulowitz, Gremyr, Eriksson, & Hensing, 2018; Werner & Malterud, 2003, 2005; Young, Fisher, & Kirkman, 2015, 2017)

These experiences are **completely demoralizing**. If you are fortunate enough to find effective care early in your disease trajectory, you may escape some of the physical sequelae—but **I am not sure your dignity is ever fully restored**.

Do I think our system is full of heartless clinicians? Of course not, but it begs the question—how can a condition so common **still be so misunderstood by so many clinicians** and does our evidence base, and its limitations, factor into this disconnect?

## The evidence-base—does it support person-centered care?

What evidence do we need to support PCC?

- Is our evidence base patient-centered?<sup>12-14</sup>
- Are meta-analyses of RCTs the best evidence?<sup>12-19</sup>
- Do we really engage in shared decision making?<sup>12, 14, 20</sup>
- Do we appreciate the power imbalances?<sup>8,9,12</sup>
- What happens outside of the exam room?<sup>12</sup>
- What about the people we don't see?<sup>12</sup>

Understand limitations and biases ... appraise carefully

Can we leverage our evidence-base to serve patients better? Should we be using different evidence—or looking at our evidence differently (Greenhalgh et al, 2015; Miles, 2018)?

There are some biases and limitations in the literature, and hence in many of our “evidence-based guidelines,” that may not be serving individual patients well.

### 1. Is our evidence base patient centered?

Much of the published literature is not actually patient centered. Patient centered outcomes research and pragmatic trials are relatively new—and most of our current evidence was born from a more paternalistic era where researchers determined the questions, the outcomes measures and the meaning of the data (Dhillon, 2019; Greenhalgh et al, 2015; Miles, 2018).

### 2. Are meta-analyses of randomized controlled trials (RTC) really the pinnacle of evidence?

RTCs are used most often in drug trials (and particularly blinded studies are not well suited to surgical trials). The RTC studies **carefully curated and narrowly defined** populations. This design may not identify less common adverse effects, and may not be generalizable to **your particular patient**. Significant publication bias is big concern that can exaggerate benefits. Publication bias is **more prevalent** in industry sponsored drug studies, and **even more prevalent** in endometriosis drug research (Dhillon, 2019; Greenhalgh, Snow, Ryan, Rees, & Salisbury, 2015; Guo et al., 2009; Guo & Groothuis, 2018; Horwitz, Charlson, & Singer, 2018; Horwitz & Singer, 2017; Koninckx et al., 2018; Koninckx, Ussia, Zupi, & Gomel, 2017; Miles, 2018).

Other types of studies that sit lower in the evidence hierarchy are also important because **they ask and answer different questions**. Qualitative studies in particular provide rich context and insight into the experiences and behaviors of patients, caregivers, and clinicians.

In the current evidence-based model, drug interventions will generally have the “most valued” evidence. But does this represent the best evidence for the best options for polymorbid, socially complex patients? Particularly those with endometriosis where publication bias in drug studies is significant and non-pharmacologic interventions, including surgery, play critical roles in management.

### 3. Shared decision making—is it really patient centered?

So what about shared decision making? It can be effective—but it is more than tool or handout AND it requires **we invest in relationships**. Clinicians need to understand the patients lived experience, and patients need to fully understand **ALL** treatment options in order to engage in thoughtful discussions about how these options fit into their lives (Geukens, Apers, Meuleman, D’Hooghe, & Dancet, 2018; Greenhalgh et al., 2015; Miles, 2018)

Post op from hysterectomy, my well-meaning gynecologist gave me choice between doing nothing—relentless daily unpredictable pain, 24/7 nausea, worsening bowel and bladder symptoms OR something—that was Lupron. I did not know there were other options—and I was desperate. I chose “something.” That was **neither shared decision making NOR informed consent**.

### 4. Do we appreciate the power imbalances?

Now, let’s talk elephant in the room. **Power**.

Working in healthcare is hard—and clinicians often feel powerless. However, as clinicians we **always** have more power than our patients

This imbalance can play out when we (often unintentionally) dismiss and psychologize symptoms, patronize and question patient’s mental capacity, and withhold information and treatment options (Greenhalgh et al., 2015; Samulowitz et al., 2018; Werner & Malterud, 2003).

And being a clinician does not immunize you to the effects of this power imbalance when **you are the patient**.

I am a doctorally prepared nurse practitioner, senior ranking officer, and educated in endometriosis—a pretty empowered position. And yet last fall, a medical resident reduced me to a weeping mess a few minutes into a consult.

I was scheduled with an attending colorectal surgeon at a military facility at the request of my urogynecologist to gain support for a referral back to my endometriosis surgical team to evaluate some bowel issues suspicious for symptomatic adhesions.

Instead of the attending, a resident came in and stood across the room with his arms crossed. He did not take a history, examine me, or allow me to see the attending—then promptly refused to write the referral because it was “unnecessary.”

**To avoid getting labeled as “difficult,”** I asked politely what symptoms should prompt my return.

**“Intractable vomiting” he said.** Hmmm, I am an active duty officer and am required to stay “deployment ready.”

I left as quickly as I could so he wouldn't see me cry. It took me 8 months to muster the emotional energy to contact my urogynecologist—who ultimately fought successfully for that referral.

Similar to recognizing privilege, if you recognize the power imbalance, you can then leverage your power **to help** your patients.

## 5. What happens outside of the exam room matters.

And we cannot ignore what happens outside of our exam rooms. The explicit and tacit knowledge that patients gain and share outside of the exam room has always factored strongly into patients' decision making but its impact is not well represented in the literature. Online communities have increased information sharing among patients and their caregivers—and we need to recognize, appreciate, and study its impact on the decision making process (Greenhalgh et al., 2015).

## 6. What about the people who can't access care or who we drove away?

Our evidence is primarily based on patients who engage with the health care system. But often the patients with the most need have significant barriers to care, or have dropped out of care, and these patients are not represented well in the literature (Greenhalgh et al., 2015).

The take home message is look for the literature that answers the questions you have **about your specific patient**, understand the **biases in** and **limitations of** the literature, and **appraise carefully...**

## What is patient centered care, and what can clinicians do differently?

What can I do differently to meet patients needs? 

Dimensions of patient centered endometriosis care<sup>20</sup>:

- Respect for patient's values, preferences, and needs<sup>6,7,8,11,14,20</sup>
- Information, communication, and education<sup>6,7,20</sup>
- Continuity and transition<sup>7,20,21</sup>
- Access to care<sup>20</sup>
- Technical skills<sup>18,20</sup>

“Evidence-based, patient-focused’ ideology”<sup>14</sup>

↓

“Evidence-informed, person-centered’ health and social care”<sup>14</sup>

So how can we be more patient-centered? Geukens and colleagues identified 5 dimensions that need improvement in endometriosis care.

### 1. Respect for patient's values, preferences, and needs

In order to respect your patients values you have to know them—to know them you have to ask, listen, and care enough to really hear.

### 2. Information, communication, and education

Communication is useless if you **perpetuate misinformation**—it is your responsibility to educate yourself, your staff, and your patients.

### 3. Continuity and transition

Make sure you are doing your part in coordinating your patient's care.

### 4. Access to care

Don't delay diagnosis and treatment—slapping a hormonal band-aid on patients does not count. You need to promptly refer if patients want or need care beyond your capabilities.

## 5. Technical skills

If you don't have the skills to find it and to remove it—refer and collaborate! Remember—getting your patients the care **they** need is what is important.

But what does person-centered care really look like ... and how can you be your patient's superhero?

I can tell you what it looked like for me:

**Superhero #1** was the diagnosing gyn who performed my hysterectomy—the one who did not fix me, but who respected my desire to keep an ovary. She was the first physician to **respect my values**—and afterward, she recognized my long silent suffering and validated my inner broken girl. It sounds absurd—but until then I did not understand that there was the possibility of, and that I was worthy of, a better quality of life. **This was immeasurably empowering.**

**Superhero #2** was my primary care provider. My primary care provider **supported me** 100% to get a consult with the excision surgeon I found and **committed to coordinating** my follow-on care. Simple, but not common enough.

**Superhero #3** was my **excision surgeon—life transforming**. Her history and exam were incredibly detailed. She communicated **what** she was doing, **why** she was doing it, **what** she was finding, and **how** that would guide her surgical approach and follow up recommendations.

She did not conflate endometriosis and pelvic pain like many do. They are not synonymous and understanding the difference is critical for both providers and patients. This was essential in setting my expectations for recovery and in openly discussing **where her skillset ended and where she would engage other clinicians in my care**. She respected my desire to keep at least part of my ovary—even if it risked a second surgery. I felt seen. I felt heard. I felt confident that whatever she did would respect my values.

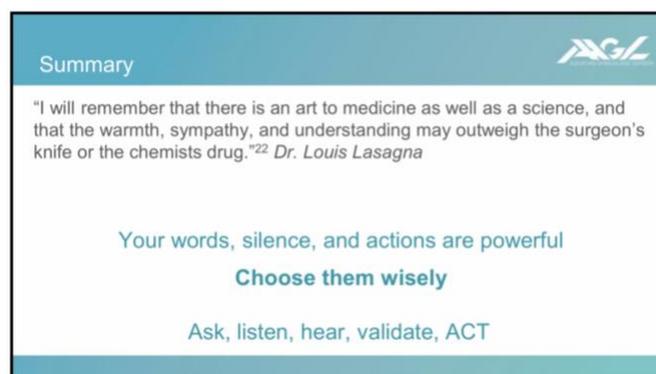
Post op, I really saw how she “got” me. I was the sole money earner of a family of four, in a fast-paced challenging job, and I ran marathons for sanity. I told her I would not take anything that made me **dopey, sleepy, fat, or constipated**. She knew telling me to stop running would compromise my primary coping strategy and source of social connection.

Most importantly, **she never made me feel like a “difficult patient.”** Yes, her surgical skills are phenomenal—but her willingness to ask, listen, and learn who I am—to appreciate **my** (horrible) experiences, to understand **what I value**, to discern **what empowers me**—is what makes her such an effective clinician.

We crafted a plan centered around **my values** and **informed by the evidence**—and included PT, injections, self-administered bladder instillations, yoga, and diet—and **no oral medications!**

Ultimately, we need to shift our care from an “**evidence-based, patient-focused**” paradigm to “**evidence-informed, person-centered health and social care.**” The shift sounds like a subtle word play, but experiencing both (as patient and provider), the latter is far more powerful and rewarding (Miles, 2018).

## Summary



Summary

"I will remember that there is an art to medicine as well as a science, and that the warmth, sympathy, and understanding may outweigh the surgeon's knife or the chemist's drug."<sup>22</sup> *Dr. Louis Lasagna*

Your words, silence, and actions are powerful  
**Choose them wisely**

Ask, listen, hear, validate, ACT

“I will remember that there is an art to medicine as well as a science, and that the warmth, sympathy, and understanding may outweigh the surgeon’s knife or the chemist’s drug” (“Physicians oaths,” n.d.).

Medicine and surgery both play a role in caring for patients, but as clinicians your **most powerful tools** are **compassion, humility, critical thinking, and collaboration**.

You do not need to be an endometriosis expert to be your patient’s superhero. Listening and validation are immeasurably therapeutic. **But being kind is not enough**. You must develop enough critical thinking to **understand your limitations, be humble enough** to accept those limitations, and **care enough** to get your patients to the care they need.

My esteemed colleagues today will talk a lot about the surgeon’s knife and the chemist’s drug.

My hope is that you see and hear this information today through a patient-centered lens—and understand that your **words**, your **silence**, and your **actions** are powerful. **Choose them wisely**

## Resources

- Nancy's Nook Endometriosis Education  
<https://www.facebook.com/groups/NancysNookEndoEd>
- Endo What  
<https://www.facebook.com/EndoWhat/>  
<https://www.endowhat.org>
- Endometriosis Research Center  
<https://www.facebook.com/EndoResCenter/>  
<https://www.endocenter.org>
- The Endometriosis Summit  
<https://www.facebook.com/The-Endometriosis-Summit-Patient-Practitioner-Town-Meeting-1456981957765827/>  
<https://theendometriosissummit.com>
- Endopaedia  
<http://endopaedia.info>

## AAGL 2019 related course materials

Endo 609 – Endometriosis The Whole Picture [ENDO-609: Didactic: Endometriosis - The Whole Picture](#)

- Endometriosis - The Patient Perspective – Heather Guidone, BCPA  
Favorite sound bite ““Enduring & Existing” isn’t the same as “Living”
- A Holistic Approach to Endometriosis. Evaluating Co-existing Conditions of Endometriosis – Iris Orbuch, MD  
Favorite visual – Timeline of current (abysmal) state of care and second timeline of what the care timeline should look like.

There will be an answer, Let it be – Expert debate on treatments for endometriosis associated pain [Panel Session 4: Debate: "There Will Be an Answer, Let It Be"- Expert Debate on Treatments for Endometriosis Associated Pain](#)

- Patient centered management of endometriosis – Susan Pierce-Richards, DNP, ARNP, FNP-BC, ANP-BC, RN-BC  
*Narrative above*
- Surgery is the only answer – David Redwine, MD  
Favorite comment during debate – “how many days a month, a year, a lifetime does a person have to have pain. It is time to treat the endometriosis!”

Endometriosis Special Interest Group

- Shannon Cohn, Filmmaker and Co-Founder of EndoWhat? <https://www.endowhat.org/who-we-are>  
Discussed ongoing upcoming endometriosis related film work, bi-partisan efforts in education and research, and partnership with AAGL to improve education of clinicians.

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