



# Endometriosis- The Patient Perspective

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First I'd like to thank the chairs Dr Orbuch, Dr Einarrson and Dr Brown and AAGL for this important opportunity.

## DISCLOSURES



- **No financial relationships to disclose**

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Quickly about me - I am the Program Director of the Center for Endometriosis Care, a board certified patient advocate, a PCORI ambassador and serve on several advisory panels, committees and boards related to endometriosis and broader health issues, including for ACOG and many others. I have no financial disclosures.

## OBJECTIVES



- Discuss necessity of patient perspective in endometriosis care/treatment;
- Review deficits in endometriosis research/treatment/support which can negatively impact patient's HRQOL;
- Articulate proactive strategies to increase engagement and improve the endometriosis patient healthcare experience.

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I've spent close to 30 yrs working in the disease space, but also have intimate experience with endometriosis, adenomyosis, fibroids and infertility. Like so many with the disease, I ultimately became an "expert by experience." I use my three decades-long journey to try and empower others and encourage them towards meaningful engagement in their own care - because no one should still be going through the same delayed diagnosis and failed interventions that I did beginning in the 80s. So my objectives today are to hopefully impart a little bit of both my personal and professional perspectives to help broaden the discussion. Gloria Steinem once said, "the final stage of healing is using what's happened to you to heal other people." I use my voice in that way to ensure others do not have to contend with the dismissal and poor care that I did.



**“Despite the existence of severe pain, often described as 'intense' or 'overwhelming', women experienced delay in receiving a diagnosis of endometriosis, and their symptoms were frequently trivialized or normalized.** This, and the limited effectiveness of treatments, affected relationships with partners and family, work, and sexual relations, although individual experiences in each area were diverse...the experience of endometriosis pervades all aspects of a woman's life. This experience is compounded by the side effects of many treatments. **Women with this disease need to be taken seriously, and not have their pain trivialized or normalized.”**

-Denny E. Women's Experience of Endometriosis. J Adv Nurs. 2004 Jun;46(6):641-8.

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When I was invited to give this talk, I initially thought, ‘what could I possibly tell the world’s best surgeons?’ But I realized, who better? You are the gatekeepers, the teachers, the mentors who will leave a legacy of improved care of those with the disease, who have the power to change the way those outside this room view and treat endometriosis. I’m not here to tell you how to perform deep excision or prevent vascular injury. I’m not going to talk about how to perform a PSN. There are no Venn diagrams or flow charts in my slides. What I am hoping for, is that you will leave here encouraged to go home and extend your advocacy outside your own ORs on behalf of your patients and those with endometriosis everywhere.



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Over the span of the 3 decades that I have been diagnosed with and working professionally in endometriosis, medicine and technology have made incredible advances. Scientific breakthroughs and innovations have transformed our world and revolutionized lives. No field has emerged more in terms of development than healthcare – and yet, endometriosis is still mired in virtually the same quagmire I fought through when I began my own personal and professional journey – if not worse.

This disease exacts a vast and painful toll on lives: significantly reduced quality of life, compromised academic and professional opportunities, impaired sexual and physical functioning, negative effects on relationships, loss of productivity, invalidation that can lead to crippling self-doubt and hopelessness, countless ineffective medical and poor surgical treatments that have perhaps worse outcomes than doing nothing. I can speak on all of that first-hand. Those who do not live with this disease - while sympathetic - can never fully comprehend the devastation that is part and parcel of endometriosis on a very visceral level.

It was Dr Barbara Levy who taught me the expression ‘we can’t boil the ocean’. It resonated, because I’ve often felt that’s what we’ve been attempting to do with this disease for decades. And yet, endometriosis remains fundamentally trapped in outdated assumptions that invariably lead to poor outcomes, and much of what is communicated about it, including in the literature and especially the media and even by highly influential endo organizations, reflects a stagnant belief system that perpetually confounds the diagnostic, treatment and support processes.

So it should come as no surprise to anyone that for far too long, we have been handcuffed by a system that makes decisions about us without us, and yes - I do mean us – a system that adequately represents neither patients nor the physicians committed to moving the disease forward. If we are to achieve real progress, we must strive towards a unified ideology that is reflective of modern concepts and which truly puts patients first. I would ask that we start consistently framing endometriosis as a systemic disease, requiring a collaborative approach that must be integrated into therapeutic concepts at symptomatic presentation in order to ensure timely diagnosis, appropriate intervention and reduce costly, unproven protocols. We must also value the patient perspective in every aspect of this disease.

## NECESSITY OF PATIENT PERSPECTIVE



### Patient Perspective is the Foundation of Patient Engagement

- “lived experience of disease and its impact on them and their caregivers, including symptomatic, intellectual, psychosocial, spiritual and goal-oriented dimensions of the disease and its treatment” [McGoon et al. 2019]
- “value”=more than just financial

### Patient Perspective is Vital

- ‘evaluating patient experience along with...effectiveness and safety of care is essential to providing a complete picture of healthcare quality’ [Agency for Healthcare Research & Quality 2017]

### Patients are the Drivers of Change - not just Objects of Change

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Patient perspective has been defined as an individual’s “lived experience of disease and its impact on them and their caregivers, including symptomatic, intellectual, psychosocial, spiritual and goal-oriented dimensions of the disease and its treatment.” Simply put, leveraging the patient’s vast practical knowledge of their endometriosis and the care system they use to improve it.

This is the very foundation of patient engagement. Those collective experiences inform everything we do in healthcare: R & D, policy change and organizational reform, and providing for improved technologies, effectiveness and safety of care. Patients must be - and largely are - the drivers of that change - not just objects of it. We must implement and reinforce improved messaging around endometriosis: namely, that patients and clinicians should work together to co-create care plans that meet not only clinical objectives, but the patient’s own goals and values.

No, we can’t boil the ocean - but by valuing patient perspective, we can change the pathways to better care.



### Paternalistic Pitfalls

- Oliver Wendell Holmes, 1871: "**Your patient has no more right to all the truth you know, than he has to all the medicine in your saddle bags...he should get only as much as is good for him**" [Smith 2004]
  - some still resist patient involvement; place emphasis on **treating endometriosis** vs. treating **person with endometriosis**
- few patients willing to accept antiquated authoritarian attitudes any longer!

### Patients Seek Autonomy in Care

- ‘the right to hold views, make choices and act based on own values and beliefs’ [Beauchamp & Childress 2009]
- want to be “understood as individual human being” [Lindberg et al. 2014]; be partners in own care

### Why Wasn’t I heard? Believed? Told about Other – Better – Options?

- and why has so little changed over the course of almost 30 years??**

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Unfortunately, since even before 1871 when Oliver Wendell Holmes told his group of medical students that "**Your patient has no more right to all the truth you know, than he has to all the medicine in your saddle bags...he should get only as much as is good for him,**" some physicians have seen little need to inform or involve their patients in the care process. Those types of clinicians tend to focus on treating **endometriosis**, but not the **person** with endometriosis. The sacred construct of “informed consent” is sometimes viewed as little more than a legal pretense or bureaucratic obstacle to be overcome as quickly as possible.

Thankfully, few if any patients are willing to accept such antiquated, authoritarian attitudes any longer. Most rightfully seek autonomy in their care - the right to hold views, make choices and act based on their own values and beliefs. They want to be seen not as a patient, but as a person. They want - much as I did - to be partners in their care, and to be given the tools necessary to give truly informed consent about treatment choices – choices based on evidence and what is right for them personally, not just a physician’s inability to offer choices or a treatment bias.

Unfortunately, such biases impacted much of my own treatment - or lack thereof - and still continue to complicate care for many today.

Fortunately, most patients are now largely aware of their widening array of options, and so they rightly expect to be involved in identifying which are best for them on an individual basis. Knowing who to operate on, when, and how - or why not - is obviously a key discussion. But the lens of the patient perspective is critical for another reason, as well. The patient experience is not often adequately reflected in the literature. As Dr Cara Jones noted, “endo’s reduction to “painful menses” has resulted in its normalization to the point of invisibility” - and as Curtis et al. wrote, "In the



#### The Literature: too Far Removed from Actual Patient Experiences?

- "...descriptors are flat and don't convey the suffering women experience." [Curtis et al. 2004]

#### Bedside Manner = Less Pain? '*Clinician-patient relationship may affect pain experienced during medical care*' [Reynolds-Losin et al. 2017]

#### Patient Experience & Expectations of Care are 'Relational' & 'Functional'

- Relational: doctors empowering patients by recognizing, respecting and including preferences; politeness, honesty, level of respect demonstrated throughout doctor-patient interactions
- Functional: effectiveness of communication across healthcare system, accessibility and continuity of care [Sirdifield et al. 2016]

#### All Dimensions of Patient Satisfaction Matter

- "women with endometriosis often have negative health care experiences; pain is normalized, minimalized or trivialized by healthcare staff..." [Bach et al. 2016]
- "...characterized by ignorance, exposure and disbelief." [Grundström et al. 2018]

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literature, endometriosis pain is often described in medical language. Medical literature includes descriptors such as pelvic pain or ovulation-like pain, which is stabbing or dull. These descriptors are flat and don't convey the suffering women experience."

It is often difficult to give voice to the shame, fear, frustrations, emotional, physical and financial consequences of this disease. It is hard for me even now, when I am on the other side personally and have worked so many years in the professional sector. Yet, when we do find the courage to vocalize our perspective, it is still far too often trivialized. And so a breakdown in the patient-physician relationship begins. That breakdown can speak to far more than just the level of patient satisfaction - some emerging data even indicates that a patient's trust in their surgeon - including both competence and warmth of interaction - may actually modulate their pain. Although this concept has not been studied in endometriosis specifically and is understudied overall, some data does reflect the importance of impression management in care. But patient experience and expectations of care go beyond just a good office visit or friendly bedside manner. They can be considered in terms of 'relational' and 'functional' aspects:

Relational aspects refer to doctors actually empowering patients through soliciting, respecting and including their preferences. Functional aspects refer to the effectiveness of communication across the healthcare system, accessibility and continuity of care. Incidentally, this should matter to more than just patients: there's a distinct correlation between patient satisfaction and the risk of being sued for malpractice.

So I would maintain that all dimensions of patient experience matter. Too many studies, for far too long, have demonstrated that those with the disease have negative healthcare experiences and their pain is normalized and even outright ignored by the medical profession.

For example, when Grundstrom et al. sought to identify and describe such encounters among those with endometriosis, a double-edged experience emerged: positive on the one hand and utterly destructive on the other, characterized by ignorance and disbelief. Conversely, when subjects felt acknowledged and confirmed, it boosted their self-esteem and greatly improved their encounters. Unfortunately, the destructive side is hardly unique, and we can - we must - all do better.



#### Universally, Patients Want...

- To be seen, heard, believed and valued as **authorities on their own narratives**
- To have access to high level, gold standard care **regardless of financial status**
- To have emphasis placed on **relief - or at least reduction - of symptoms** - not just procreative potential
- To make own choices through **truly informed consent** - not based on bias or agenda of physician
- To be treated as **partners in care**; patient-centered care/shared decision making starts with listening to - and really **hearing** us

**"Patient satisfaction with medical support is essential since it does not only strongly influence quality of life and the psychological strain associated with endometriosis, but is also related to an improving health status."**

[Lukas et al. 2018]

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Experiences of endometriosis can be unique, just as responses to treatments are. But universally, patients want the same things:

- To be seen, heard, believed and valued as authorities on their own narratives
- To have access to gold standard care regardless of financial status

- To have emphasis placed on relief - or at least reduction - of symptoms - not just procreative potential
- To make own choices through truly informed consent - not based on the bias or agenda of the prescriber/practitioner
- And to be treated as partners in care. Patient-centered care and shared decision making starts with listening to – and really hearing - individuals.

Studies have shown that patients want their doctors to take a collaborative human-first approach, communicate with their heart and mind, behave with integrity and practice competently. (Bulk et al.)



At the end of the day, WE are the only credible narrators of our experience, and we ask our perspectives to be treated with value.

If my voice had been heard early on in my journey, perhaps my body would not have required extensive restorative repair work and disease removal by an actual endo expert 1,000 miles away, after undergoing more than 20 poor surgeries in the ten years prior. Maybe I would not have been in my early twenties already struggling with the effects of poor medical suppression, some effects which last to this day. Maybe I would not have had to undergo surgical menopause after a radical hysterectomy at 27.

Please believe me when I tell you that enduring and existing is not the same thing as living. A 15 minute office visit is a mere flash into our lived experiences with this disease - but the lasting impact on our bodies of a lesion of just a few millimeters is seismic.

But the deficits in the patient perspective don't occur only in the dr's office. They happen as a result of the larger community and how this disease is viewed. How we talk about endometriosis matters – facts matter – accuracy in information matters. The propagation of misinformation everywhere leads to those ongoing barriers to quality care – dismissal of pain, lack of coordinated care, missed diagnoses, all the poor treatments patients are subjected to, poor health literacy, continued fertility valuation over quality of life and symptom eradication, continued redundancy in research, and the current hard sell by some to shun quality – and in some cases, any surgery at all - can all be life changing for those struggling here and now.

In that way, perhaps it is fair to say that the more things change, the more they stay the same from the time of my own journey with the disease, with patients continuing to struggle within a system that leads to not only poor outcomes but also financial toxicity. Not everyone can access the dedicated centers of expertise because they are uninsured, under-insured or insurance simply won't pay because of the institutional stronghold that all endometriosis treatment is viewed equal in the hands of all physicians, which is it most decidedly not.

## DEFICITS IN TREATMENT, RESEARCH & SUPPORT NEGATIVELY IMPACT HRQOL



### The More Things Change, the More they Stay the Same

- failed “standards” of care = **poor outcomes**
- dismissal, normalization= **poor outcomes**
- delay in treatment/poor treatments = **poor outcomes**
  - “[D]elay in diagnosis can be a high source of stress responsible for an important psychological impact in these patients, having a sense of misunderstanding and neglect of the medical profession” [Leroy et al. 2016]

### Continued Barriers to Universal Quality Care for All = **poor outcomes**

- lack of proper coding, insurance red tape, lack of coverage leads to financial toxicity

### Fertility Valuation over Quality of Life/Pain Eradication: **Why??**

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The true costs of these flawed standards for patients and their families are incalculable.



### Poor Health Literacy

- generational inability to discriminate between normal/abnormal; need to inform early, inform correctly

### Redundant Research

- Heavy focus on repurposing existing therapies; ‘industry sponsored research brings pro-industry results’
- must end “innovation drought” [Guo & Groothuis 2018]
- “None of the evaluated RCTs met all the methodological criteria, none had only a low risk of bias and provided sufficient details on methods and randomization to allow for the reproduction and replication of the study” [Capraş et al. 2019]

### No Incentive to Improve Quality of Treatment for Endometriosis

- those dedicated to endometriosis care poorly represented at institutional levels
- system largely rewards approach of untreated/poorly treated disease
- financial ties, agendas, bureaucratic red tape must not continue to drive standard of care!

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In addition to, and as a result of, those failed standards, there continue to be no incentives to perform dedicated, subspecialty care for the disease. Instead, we have a system of financial ties, agendas of influence and bureaucratic red tape that continually drive the narrative.

It is time for the true stakeholders to take back the disease from the hands of bureaucracy, back from the architects of the anti \*quality\* surgery movement, and put it in the hands of the patients and professionals who live with and have dedicated their lives to properly and accurately diagnosing and treating it. We all need a seat at the table wherever endometriosis care and research are being discussed to ensure our voices are heard, from the structuring and implementation of organizational processes to clinical trial design to standards of care to treatment choice to access to quality help.

## PROACTIVE STRATEGIES TO IMPROVE EXPERIENCE



### Personalized Medicine

- evaluate / encourage narrative which details not just symptoms, but also functional burden/psychosocial impact as well as objectives of treatment
- encourage/be receptive to patient perspective; incorporate views into management
- inform patients about ALL possible therapies - let them participate in decision-making process and gain control over own management [Lukas et al. 2018]

**[Patients] “are looking for highly personalized, simple and connected experiences that place them squarely in charge and make them feel empowered. They want to be heard, understood and accompanied by friends, family and healthcare experts as they traverse their health journey, all while receiving the highest levels of quality care.”**

-Geeta Wilson [Gingess 2019]

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So how do we improve a broken system? Personalized medicine may be the guide, which evaluates and encourages narratives that detail not only symptoms, but a ‘wholistic’ experience of the individual’s illness in terms of functional burden and psychosocial impact - as well as their goals and objectives for treatment. Physicians should encourage their patients to express their perspectives, be receptive to and attempt to comprehend and incorporate those views into management.



### Accurate Education Matters!

- perception that society at large, including many clinicians, **lack awareness and accurate knowledge about endometriosis** is distressing factor for many [Kundu et al. 2015]
- share what you know/challenge misinformation wherever it appears

### Judicious & Timely Referrals - Collaborative Care Enhances Patient Experience

- referrals to multidimensional teams: address physical, clinical, psychological, social and educational needs; tertiary referral centers with interprofessional networks in place can offer access to optimal management
- long-term, patient-focused, multidisciplinary chronic care model [Agarwal & Foster 2019]
  - pain, psychology, gastroenterology, urology, expert surgeons, pelvic physical therapy, integrative medicine e.g. acupuncture, nutrition, mind-body
- connect with institutions, groups and other resources that can enhance and support engagement efforts [Moen 2017]
  - but...caveat emptor!

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And again, the perception - correctly - that society at large, including some clinicians, lack awareness and accurate knowledge about endometriosis is an incredibly distressing factor for many.

It should not have taken over twenty surgeries and countless failed therapies which have had a lasting, highly negative impact on my life, for me to finally find an endometriosis specialist on my own thousands of miles away - yet that’s still routinely happening today. We must overcome the dearth of accurate information about this disease and ensure that we correct and challenge the myths and misinformation wherever we see them, including from endometriosis foundations and academic centers.

Data also indicates that many doctors are reportedly not to open to second opinions, and patients routinely criticize the lack of cooperation with other specialists. So, timely referrals to multidimensional teams that can address physical, clinical, psychological, social and educational needs of patients are critical. Tertiary referral centers with interprofessional networks in place can offer access to optimal management. Incidentally, quality care also cuts healthcare cost burdens.

And please, connect your patients with institutions, groups and other resources that could enhance and support their engagement. But you must also simultaneously warn about the risk of outdated or inaccurate information which can delay proper treatment, is expensive and perhaps even dangerous.



"The most important thing when planning a patient's treatment for endometriosis is to **LISTEN TO THEM.**"

-Ken Sinervo, MD MSc FRCSC ACGE



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This is not just my perspective or story, but that of millions who have been demeaned by the system at some point in their journey. The institutional failures surrounding endometriosis are very present, very real and very impactful on those seeking care today, just as they were 30 years ago for me.

## IN SUMMARY...



### Patient Perspective is Cornerstone of Quality Care

- being heard/believed would have **accelerated access to quality care**

### When in Doubt, Refer Them Out

- it is unethical to deny any treatment (unless strong medical indication to do so)
- **earlier referral** to a subspecialist may have had life-changing impact on long-term outcomes

### "Enduring & Existing" isn't the Same as "Living"

- the impact on our bodies of **a lesion of just a few millimeters is seismic**
- 20 minute office visit is mere flash into lived experience

### Consequences for Decisions Made About Us without Us

- we need allies and advocates for change from the **inside the broken system**

### Continue to Break Barriers & Move Forward to Achieve/Effect Real Change

- valuing patient perspectives
- disseminating correct education
- sharing legacy of expertise through training – **be both learner and teacher**

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However, I have EVERY hope, and remain encouraged, that if we work together to better educate society about early intervention and goldstandard surgery combined with multidisciplinary, integrative treatments that address the whole person from a big picture perspective, and change our culture of misinformation and societal bias against endometriosis, we can continue to make positive strides.



**"[When patients] participate more actively in the process of medical care, we can create a new healthcare system with higher quality services, better outcomes, lower costs, fewer medical mistakes, and happier, healthier patients. We must make this the new gold standard of healthcare quality and the ultimate goal of all our improvement efforts:**

**Not better hospitals.**

**Not better physician practices.**

**Not more sophisticated electronic medical systems.**

**Happier, healthier patients."**

-Dr Charles Safran [Ferguson 2007]

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I am the beneficiary of all those who have moved the needle and fought to be agents of change for decades and I'm honored to have had the opportunity to be both student and teacher in the tireless fight to increase endometriosis awareness, expand the fundamental pathways towards better diagnosis and management, and achieve better policies in this disease. We have made strides and we can – and will - continue to do so.

To that end, I would like to acknowledge Dr Ken Sinervo, Dr Robert Albee, Dr Harry Reich and countless other international endo champions out there, both still practicing and those retired, as well as people like my friends Dr Arrington and the Drs Orbuch, who have stood unwaveringly on the side of their own patients. In particular, I'd also like to acknowledge the lifetime works of Dr David Redwine, for being continually unafraid to disrupt the status quo, to argue against flawed public doctrine, even when doing so has drawn the ire of his colleagues, and for still striving to advance quality care today. All of your efforts reverberate internationally.

I would also like to recognize AAGL for leading the way among professional societies with a focus on true quality care and advances in endometriosis surgery. Change must continue, but we can only improve if the patient perspective is incorporated and embraced, and more importantly, valued more than industry influence and elitist tribalism that pervades so much of endometriosis care and research, perhaps even more so now than when I began my journey. No, we can't boil the ocean, but we can make strides for a better future by working together for the greater good.

Often we hear the sentiment, stay in your lane. I would respectfully suggest that we can share the road. By featuring the patient perspective at every step of our work, disseminating correct education, and sharing a legacy of proper training to achieve and effect real change in endometriosis, we have the opportunity to unravel the enduring mysteries of this disease so that the next generation doesn't need to scream to be heard. I would ask that as gatekeepers and the best physicians in the world, you help lead that charge. As Samuel Taylor Coleridge once said, she (or he) is the best physician who is the most ingenious inspirer of hope.

Thank you for this opportunity, and thank you for giving hope to your own patients.

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