



The art of medicine

Medical misinformation and the internet: a call to arms

Almost 16 years ago my family and I were deposited on the other side of the stethoscope. Pregnant with triplets, my membranes ruptured at almost 23 weeks and I delivered my first son who I elected not to resuscitate. I managed to stay pregnant until 26 weeks when I developed chorioamnionitis and delivery was required. My sons Oliver and Victor had a long road out of the neonatal intensive-care unit. They both had bronchopulmonary dysplasia. Oliver also had a cardiac defect unrelated to prematurity that needed surgery, and Victor had cerebral palsy. There were lots of other diagnoses as well: congenital hypothyroidism, retinopathy of prematurity, and severe gastro-oesophageal reflux.

Oh, the reflux. Even now I curse that word. Victor vomited out of his nose after every feed. The vomiting often triggered apnoea that required resuscitation and, as he was on oxygen, quickly changing his clogged tubing. I slept with him upright in a chair for more than a year. I was aware this deviated from every infant sleep guideline, and yet what was I to do? No doctor or feeding therapist had provided me with an alternative. Each visit to a specialist was increasingly emotional. Medicine responded to my distress by ratcheting up the intensity of interventions. Non-formulary prescriptions. An endoscopy. Finally, surgery was offered. I wanted surgery to fix this. I really did, but as an obstetrician-gynaecologist and pain medicine physician I was aware of the phenomenon of physicians responding to emotional distress with surgery. If a condition is big and terrible then surely only a big response will suffice, and nowhere in medicine is the show as grand as the operating room.

Instead of booking the appointment with the paediatric surgeon, I searched PubMed for articles on infant gastro-oesophageal reflux and found an expert at a university where I knew people. I wrote an e-mail, shamelessly name dropped,

and sent it out into the ether. Moments after I hit send I felt foolish. But I was desperate. And to my surprise she replied. What a kindness to extend. She wondered if Victor was growing well, I was managing his apnoeic episodes, and he hadn't had pneumonia why exactly he needed surgery? She endorsed how hard it must be, but in a kind way she made me understand the distress was mostly mine.

Something about her brief but friendly confidence helped in a way that even now I struggle to explain. That feeling of floundering in medical chaos and being pulled back to order by an unknown expert never left me. Why had I not been able to find a concise summary online that spoke to me that same way? It was not for want of trying.

I'd started with what I as a physician knew were medical sites with accurate information, such as the National Library of Medicine and the American Academy of Pediatrics, but what I found didn't meet my needs medically as my son's condition was complex. Perhaps even more importantly, they didn't meet my emotional needs. And so I ended up where the language resonated and I felt understood—on blogs and sites that sold products. And the confidence, well, it was intoxicating. I bought special pillows, thickening agents, elemental formulas, prescription medications, and a litany of other even more dubious therapies. I kept trying these interventions in an increasingly desperate and decreasingly scientific series of permutations and combinations.

If I had first found that sensible information from a noted expert in a way that I could hear might things have been different? Might I never have experienced distress from trying so many useless therapies? Might I have not shown up in the panic that led to surgery being suggested? How could the library of literally all things be right there and yet the critical piece of information I needed be impossible to locate?

Clearly, we needed a better medical internet. So, I decided to help fix it. I started blogging to help parents navigate the gauntlet of prematurity, but greeted with so much misinformation and disinformation about vaccines I began to think about my own field, gynaecology. What disastrous information were my patients finding online?

Vulvovaginal mayhem seemed everywhere. An Augean stables of articles and social media posts. The vulva apparently one wrong pair of underwear away from chaos and the vagina one cookie from meltdown. Words such as natural and pure, used to control a woman's sexuality, now weaponised by the wellness-industrial complex to sell useless, yet expensive so-called toxin-free products.

There was not just misinformation and disinformation about medical care. Practical day-to-day things, not typically addressed by medicine, were especially ripe for



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abuse—for example, how to select menstrual pads or pubic hair grooming. And many sites contained even greater dangers, notably, exposure to anti-vaccine or other medical conspiracy theories.

We have huge gaps in medicine—in both the science and how we communicate, especially in women's health—but much of what I found when I first started my online quest and what I still find today is exploiting those deficiencies, not fixing them.

In the early days of medical blogging and tweeting, I was looked down on by those who found my direct to public approach unprofessional. "Separate your personal and professional", they said, as if professionalism was the public thinking that doctors were not real people. "Being on social media could be construed as direct medical advice", they warned. But I didn't care. The health of the public is a physician's concern.

It is hard for people to wade through the quagmire that is the medical internet. Bad information is everywhere, fear sells, and the lure of the cure is real. In our 24/7 news cycle a misleading medical story can spawn many erroneous articles. Sometimes the content is actually accurate, but the headlines are incorrect. And let's face it many of us, doctors included, don't always read to the end of a story.

We also all mistake repetition for accuracy, a phenomenon called the illusory truth effect. And social media, with retweets and reposts, is the very model of repetition.

It can be hard to distinguish fact from fiction when they are both presented as valid conversations, especially when bias isn't disclosed. Even quality articles can have click bait advertisements. I thought how I still use textbooks when I want to divorce myself from the cacophony that can be the internet, so why shouldn't everyone have that same privilege? So I decided to write *The Vagina Bible*, a textbook for the public with clear, concise information for fact checking that was free of online distractions. My desire to empower people with medical knowledge has also led to a forthcoming series called *Jensplaining* for Canada's public broadcaster's CBC Gem streaming service. The show is definitely an apple cider vinegar free zone.

The more I see fake medical news, the more I realise we need to use all mediums and media to tackle it. The glut of medical misinformation is real and it harms. It turns people away from vaccines, fluoride, and leads them to useless products. And don't underestimate the weight of "it can't hurt, so why not?" advice. Whether it is useless underwear changes or forgoing all sugar, it compounds desperation when it is ineffective. And snake oil peddlers are always standing by with a confidence we evidence-based practitioners can only dream to emulate.

Everything we read and share builds the internet, so we in medicine should especially take that to heart. One barrier I hear from medical professionals about engaging online is that it seems so overwhelming. How does one even try?

Find good medical content and post it on Facebook, Twitter, or the social media platform that works best for you. Even in a small circle of friends and family you can make a difference. If you read something accurate, well sourced, and bias free click the like button. The more clicks the greater the chance that piece will appear favourably in an algorithm. Ignore bad pieces—social extinction is the best strategy.

Guiding your patients to accurate information is also important. Find good online resources and offer them as handouts or e-mail the links directly if you can do that securely. Your patients are looking online, whether they tell you or not. Offering them curated content from trusted sites, such as the National Health Service in the UK or professional medical societies, validates their search efforts and I believe it makes people more likely to share with their health-care provider what they found online.

Create content, be it quality medical research in a journal or opinion pieces for the lay press. You can even study the impact of medical information found online.

Is getting involved directly online just not your thing? Everyone should learn the following four basic rules of internet health hygiene. The first is never read the comments as ad-hominem attacks beneath the content can lead people to question the very facts that were just presented. The second is avoid sharing bad information—even in jest. We are all primed to remember the fantastical and sadly medical truths are usually stodgy. Also, sharing makes the bad content more popular algorithmically speaking. The third is don't get information from anyone selling product. Bias has an impact. And finally, steer clear of content from practitioners who are against vaccination or who recommend homeopathy.

We in science are the people who developed surfactant, the measles vaccine, and safe blood transfusions. We created anaesthesia, highly active antiretroviral therapy, and newborn screening for thyroid disease. We know how to do great things with science. Helping people have access to quality information so they can make informed decisions is also one of those great things, because you can only be empowered with your health if you are accurately informed.

Is fixing the medical internet daunting? I suppose, but when your membranes rupture at almost 23 weeks and yet you have two young men smiling at you because of science it is not possible to say such a thing is too hard. And it is simply not acceptable to me that quality research that can save lives and reduce suffering could be undone by a medical conspiracy theorist or a celebrity looking to sell supplements. Come join me in building a better medical internet.

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Jen Gunter is the author of *The Vagina Bible* to be published in the USA, Canada, and the UK on Aug 27, 2019.

Further reading

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