

How Dr Google Is Impacting Parental Medical Decision Making



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KEYWORDS

• Internet • Evidence-based information • Social media • Self-management

KEY POINTS

- The use of online search engines to find health-related information is commonplace.
- Non-evidence-based Web sites include misinformation and advice regarding unproven alternative therapies, pseudoscientific explanations, and personal anecdotes.
- Medical professionals need to have awareness of misconceptions that interfere with parental medical decision making and be prepared to actively discuss this during clinical encounters.

INTRODUCTION

The patient-provider relationship is sacred. Patients trust their physicians with intimate details surrounding their health and relay concerns they may not even be comfortable discussing with their spouse. In return, physicians protect their patient's privacy and offer information and advice to help them achieve optimal health outcomes. Shared medical decision making relies on trust from both ends of this relationship. However, what happens when patients go outside this relationship to obtain information pertaining to their own care, or that of their children? What happens when patients or parents feel their physician is not listening to their concerns or offering options that are incompatible with their personal belief systems? Patients cannot be faulted for searching for medical information online. After all, we live in a world connected in real time and society functions through use of the Internet, social media, and constant access to handheld devices. However, when the information patients seek turns out to be incorrect, or even harmful, this can not only damage the patient-provider relationship but also lead patients to seek non-evidence-based promises of miracle cures, costly treatments, or unnecessary testing. If physicians and medical professionals are to continue to help patients and parents achieve the best health outcomes, then they will need to

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evolve. This evolution begins by appreciating the various types of misinformation that impacts medical decision making and developing approaches to address this during individual clinical encounters.

DR GOOGLE WILL SEE YOU NOW

There are many reasons patients or parents may seek medical information online, starting with easy, immediate access to information 24 hours a day, 7 days a week and at their convenience. It is simply much easier to type in a few key words on a search engine than try to call a physician's office, leave a message, and wait for a reply. Well-child visits with a pediatrician typically take place every few months during the first 2 years of life, but then generally occur only once a year thereafter. During the months between visits, children will exhibit a range of normal developmental changes, childhood illnesses, and other symptoms that may raise concern from parents. Rashes, stomach pains, changes to bowel habits, sleep disruptions, behavioral changes, and upper respiratory infections are all normal expected parts of childhood but are also common sources of parental concern. A visit to the pediatrician may provide reassurance, but this necessitates time off work and school, copayments, and travel. It is simply much easier for parents to take their questions online through search engines or social media groups.

Problems arise when parents type their queries into search engines such as Google. These search engines use various algorithms to display results with the top search items often reflecting the most popular sites, or those that have paid to appear at the top of the list. It is natural to assume that the sites that appear at the top of a page are the most important and even the most accurate. Unfortunately, this is rarely the case. There is no regulation of any Web sites in regards to vetting the medical information they provide, a concept that many people may not understand. People commonly assume that prominent physicians such as Mehmet Oz, also known as Dr Oz, are trustworthy and that their advice is accurate and evidence based. After all, why would a major television network give Dr Oz a syndicated talk show unless he was trustworthy? Unfortunately, non-evidence-based approaches and alternative medicine products are frequently discussed and promoted through the Dr Oz show, which has led to congressional hearings and discussion from policymakers regarding the need for more accountability.¹

All medical professionals should spend time perusing the Internet to acquaint themselves with the information, and more importantly, misinformation that their patients are encountering online. It can be as easy as typing common questions encountered in the clinical setting into a search engine and then going through the sites that appear. It is known that two-thirds of adults will search for health-related information online and not just for themselves but also for friends or family members as well.² The information they discover will influence how they perceive their own health and may lead to inaccurate self-diagnosis, use of non-evidence-based and costly at-home testing kits, inappropriate expectations regarding treatment outcomes, and ultimately, dissatisfaction with the care they receive from "traditional" Western medicine. If medical professionals can better understand where their patients are coming from in regards to this type of information, they can address this during clinical encounters and offer anticipatory guidance as well as words of caution regarding online searches. Lastly, medical professionals should also be familiar with the evidence surrounding the same types of searches, including what is available through peer-reviewed published research and clinical guidelines. There is often a large discrepancy between information found on Google compared with PubMed. For instance, at the time of this writing, a search

for the term “artificial red dye allergy” in Google yields 5.1 million results, whereas the same search in PubMed yields 3 results, none of which are relevant or actually demonstrate that this is a proven (or plausible) diagnosis.

MISCONCEPTIONS SURROUNDING ALLERGIC CONDITIONS

Allergic conditions are particularly susceptible to misinformation, pseudoscience, nonvalidated testing, and anecdotes describing success rates from treatment that far surpasses anything reported in peer-reviewed literature. Atopic dermatitis, asthma, allergic rhinitis, food allergy, and drug allergy are all very common conditions that impact millions of people. Children are particularly susceptible, and parents can easily become frustrated owing to a lack of any current cure for their child with atopic dermatitis, asthma, or food allergies. These conditions are known to have significant psychosocial consequences, including poor sleep, missed school (or work for parents), and behavioral changes, and can lead to bullying.³ In addition, food allergies can be potentially life threatening, and the number one fear expressed by parents of children with peanut allergy is that their child may die from accidental exposure, including from trace amounts.⁴ Because of the highly emotional nature of these concerns, these parents are particularly susceptible to seeking alternative approaches and spending money, time, and emotional investments on nonvalidated testing or treatment options.

Patient or parent testimonials touting the benefits of non-evidence-based treatment approaches are rampant on Web sites, and particularly on social media. Medical professionals are well versed in the important differences between anecdotes and evidence, but the lay public often equates the two. Anecdotes can provide powerful and emotional stories that relay tales of miracle cures or improvement through various means. These personal stories do not serve as evidence and may have no applicability to anyone else’s health. First, there is no proof that these stories are true or actually happened. Even if true, anecdotes are highly subject to multiple forms of bias, and important pertinent details are often neglected or ignored. Almost all chronic medical conditions exhibit a normal pattern of waxing and waning symptoms, which is frustrating for parents and patients. This also allows for misattributing association with causality. For instance, if someone with atopic dermatitis exhibits a flare of symptoms during the winter months or while acutely ill and decides to eliminate gluten from their diet at the same time, they can easily misattribute their gluten avoidance as the “treatment” when their skin ultimately improves. Should they choose to share their story online or with the social media followers, then others will inappropriately encounter advice on how a gluten-free diet can treat atopic dermatitis.

Table 1 lists a few examples of nonvalidated tests or treatment options found online that pertain to common allergic conditions. These examples are constantly changing, often matching whatever new fad or celebrity testimonial is currently en vogue. Given

Table 1
Examples of nonvalidated testing and treatment options found online

Diagnostic Testing	Treatment Options
Immunoglobulin G tests for food allergy or sensitivity	Chiropractic adjustments
Provocation-neutralization	Himalayan salt therapy for asthma
Applied kinesiology	Nambudripad’s allergy elimination technique
Cytotoxic testing	Lifestyle eating and performance
Electrodermal analysis	
Chemical analysis of hair and urine	

their public profile, actors, actresses, and musicians often have very large platforms and can reach millions of people from across the world. Regardless of the fact that most celebrities lack any education, training, or experience that would give them any qualifications whatsoever to dispense medical advice, this has not prevented many celebrities from influencing the medical decision making of their fans. Actress Gwyneth Paltrow founded a company, Goop, that promotes various forms of wellness and medical advice targeting women. Subscribers encounter non-evidence-based advice touting the benefits of cleanses for weight loss, jade eggs for improved sexual performance, and bee venom for treatment of wrinkles. Another actress and former Playboy model, Jenny McCarthy, has used her popularity to actively promote the harms of childhood vaccines and used the personal story of her son's autism to reinforce the common misconception (despite sound evidence to the contrary) that vaccines cause autism. The President of the United States, Donald Trump, has also publicly declared vaccines to be harmful and has even stated that physicians are engaging in a conspiracy to harm their patients. Due in part to these endorsements, the antivaccine movement has gained significant traction across the world and has led to recent measles outbreaks in multiple countries, including the United States, a country in which measles was officially eradicated in 2000.⁵ In early 2019, the World Health Organization listed vaccine hesitancy as one of the top 10 threats to global health.⁶ Needless to say, celebrities and politicians who publicly dispense incorrect medical advice absolutely impact the decision making of patients.

LOW HEALTH LITERACY

Health literacy refers to the capacity of someone to understand, interpret, and apply medical information to self-management skills. This is more than just the ability to read. Health literacy encompasses the ability to make effective decisions pertaining to one's own medical care. Only 12% of adults in the United States are deemed to have proficient health literacy.⁷ Patients with low health literacy are less likely to receive annual influenza vaccines, schedule and appear for routine medical appointments, and take medication as directed by their prescription.⁸ All together, this contributes to suboptimal health outcomes and increased risk for hospitalization.

There are validated instruments available to determine each patient's or parent's level of health literacy. However, use of these questionnaires is time consuming and can disrupt clinic flow, which makes them challenging to implement in routine clinical practice. Even if formal instruments are not used, medical providers can still improve their understanding of health literacy and address this with patients during each visit. Elderly patients and those who speak English as a second language are at increased risk to have low health literacy.⁹ However, any patient who has difficulty filling out questionnaires pertaining to their medical history, who cannot accurately recount their medication prescriptions, or who appears to be confused when discussing medical information warrants additional attention. With heightened awareness, medical professionals can actively monitor for warning signs of low health literacy and address this during the visit.

The concepts surrounding low health literacy are important given its prevalence and also how it can impact patient and parental decision making pertaining to the information they encounter online. People with low health literacy are more susceptible to the common misinformation tactics found through online searches for medical information. They will be less likely to recognize deliberate misinformation from those selling products and more susceptible to fanciful claims and pseudoscientific explanations. If medical professionals can improve their own recognition of low health literacy among

their patients, then they can actively address this when discussing treatment recommendations or issues pertaining to self-management. There are simple tools that can be used to improve retention of important medical information after the visit. The Ask-Me-3 questions¹⁰ encompass 3 questions that assess a patient's understanding of their self-management plan:

1. What is my main problem?
2. What do I need to do (about the problem)?
3. Why is it important for me to do this?

It would be remarkable if every patient could answer these simple questions at the conclusion of each medical visit. Another method called the Teachback Method relies on the patient to reiterate the medical information given to them during their visit. By using the Teachback Method, medical professionals are forced to prioritize the information they give, keep the information simple, and make it pertinent. Then, if the patient cannot accurately reiterate the information they are given, the onus is on the provider to take another approach or use a different explanation. This ensures that the person doing the educating meets the learner where they are at in regards to their level of understanding and ability to understand. For example, an allergist may wish to educate a parent of a newly diagnosed asthmatic child with all the information pertaining to the immunopathology surrounding their asthma, association with other atopic conditions, and range of available treatment options. However, the message the parent may most benefit from at this visit is likely much more simple, along the lines of: "Your child has asthma, which causes his airways to be irritated and have recurrent episodes of tightening. Albuterol is a medicine that works very quickly to reverse that tightening when it occurs and should be used as soon as he has persistent cough, difficulty breathing, or wakes at night due to cough. The way we give albuterol is very important, so we're going to review the proper technique and practice with you today."

LOW SCIENCE LITERACY

The ability to trust and understand science is another area where celebrities and policymakers influence the opinions of the general public. Frustration often mounts from patients and the general public because of the ever-changing evidence and clinical guidelines. As evidence accumulates, it often changes the understanding of underlying disease pathogenesis, prognosis, and best approaches to treatment. An example pertaining to pediatric allergy pertains to advice surrounding the timing of introduction of allergenic foods, particularly peanut. In 2000, the American Academy of Pediatrics (AAP) recommended avoiding cow's milk until 1 year of age, egg until 2 years of age, and peanut, tree nuts, and seafood until 3 years of age.¹¹ This recommendation was based on expert opinion and the understanding at the time that avoiding exposure may prevent the development of food allergy. Within just 8 years, the AAP removed that advice and offered a general recommendation that those foods do not need to be avoided, but did not include an active recommendation to introduce these foods. In 2015, the Learning Early About Peanut study demonstrated for the first time that early introduction of peanut into the diet of infants at risk to develop peanut allergy (moderate to severe eczema and/or egg allergy) before 12 months of age AND ongoing ingestion at least 3 times a week up to the age of 5 years old dramatically reduced the development of peanut allergy compared with infants who avoided any peanut ingestion.¹² This prompted the publication of new guidelines in 2017 that recommend active introduction of age-appropriate peanut products to all infants around 4 to 6 months of age, followed by ongoing ingestion, with risk stratification

and provisions for peanut immunoglobulin E testing before introduction for infants with moderate to severe eczema and/or egg allergy.¹³ Ultimately, within 17 years, the recommendations surrounding the timing and manner of introducing peanut into an infant's diet changed dramatically. Allergists and medical professionals view this as an excellent example of scientific achievement and progress. This is how science and clinical guidelines should evolve; this is proof that the system is working. However, parents and those with low science literacy may view this as another reason to distrust science and even physicians. After all, if we cannot make up our mind about something like when to feed babies peanut, then how can they trust anything else we have to say?

In addition, distrust of evidence leads to climate change denialism, vaccine hesitancy, belief that genetically modified organisms are unhealthy, and even that the Earth is flat. It is important for medical professionals to be aware of low science literacy because this will be present among the patients and parents who come to the office every day. A researcher poses a question and systematically attempts to identify evidence that answers that question, giving equal weight to evidence in support of and against the hypothesis. However, many online searches, particularly by those with low science literacy, start with someone thinking they know the answer (or mistaking their opinion as fact) and then seeking Web sites or resources that reinforce their already formulated beliefs. This is confirmation bias and another contributing factor that influences how parents make medical decisions pertaining to their child's care.

MEDIA HEADLINES

Health-related topics often generate interest, and media outlets are constantly searching for the latest publications or presentations at national meetings. Unfortunately, the headlines are often inaccurate, and copyright editors choose phrasing that is more likely to generate Web site clicks and shares and less likely to be scientifically accurate. It is impossible to accurately describe the nuances of a peer-reviewed study, such as inclusion/exclusion criteria, methodology, results, limitations, and findings in 1 headline, yet people often use the headlines alone and never even read the article (which often misconstrues the research as well). An astonishing 59% of links shared on Twitter are never even read by the person sharing them with others.¹⁴ Thus, media reports and catchy headlines that misinterpret, overstate, or confuse research findings can be easily misinterpreted. Medical professionals can set a Google alert for articles related to any topic of interest and receive a current and updated array of examples, which can be valuable for addressing with patients. In addition, medical professionals should take the time to identify recent popular medical headlines, *then* read the article, and *then* locate and read the actual research study. More often than not, the information provided in the article is either missing the mark in regards to overall study findings or cherry picked 1 particular aspect that was deemed more popular or likely to generate interest while ignoring important study limitations or additional findings. This approach can offer valuable insight into how parents formulate their own medical decisions.

COGNITIVE BIAS

Everyone has cognitive biases, which are systematic patterns that deviate from the norm and interfere with their ability to make rational decisions. Health care professionals who have a thorough understanding of cognitive biases and how they can dramatically impact one's perception of reality will easily recognize these during patient encounters and throughout online searches. This can help not only better

understand online behavior but also offer a unique advantage during personal interactions. If medical professionals can understand and identify the common faults in how people make decisions related to their health, they can point these out, provide a rational explanation, and ideally assist medical decision making.

Cognitive biases lead people to create their own personal subjective reality, which can dictate behavior. As one can imagine, if everyone is viewing the world according to their own perception, this can lead to false conclusions that lie well outside proven facts, science, and reality. It behooves health care professionals to appreciate the wide range of viewpoints, biases, and alternate perceptions of reality that are disseminated online and particularly how this can influence parental attitudes and decision making.

PSEUDOSCIENCE 101

The boundary between science and pseudoscience is often murky. Pseudoscience essentially consists of statements, beliefs, or practices that are claimed to be both scientific and factual, but are incompatible with the scientific method. Online searches for medical information offer a perfect platform for attention-grabbing headlines and pseudoscientific explanations for unproven diagnostic testing or treatment options to gain traction and widespread appeal. Those headlines that claim black mold causes hidden toxicity, the benefits of detoxes and cleanses, or how gluten causes leaky-gut syndrome: those are pseudoscience 101. Why does the public fall for this, often to the point of spending large amounts of money for treatment options or programs that are not supported by any evidence? Cognitive biases contribute, but another phenomenon may be contributing to this as well and is rooted in poor communication skills by medical professionals.

Traditionally, science has been communicated to the public by those in academics, who, to the average person, may seem elitist, nerdy, or disconnected. However, scientists and health care professionals have generally missed the mark when trying to communicate health-related information to the general public. It is known that people are searching online for health-related information. As such, this space has been filled by professionals who overreach their qualifications, such as chiropractors, homeopaths, naturopaths, and other alternative medicine providers (plus the occasional board-certified physician who has crossed over to the dark side of pedaling pseudoscience in the name of profit). These individuals have traditionally excelled at communicating and listening to patients, which, in turn, makes them seem more trustworthy and believable. Although some of these individuals deliberately dispense misinformation in an attempt to profit from their services, many are subject to the Dunning-Kruger effect and are merely explaining things in a way they were actually taught in their alternative medicine education. They simply do not know what they do not know and fill in the gaps with thought processes that are often not physiologically plausible and rarely supported by evidence. Regardless of intent, this is an important arena that contributes to the vast array of misinformation online, confuses patients and the public, and by muddying the waters, ultimately leads to decreased trust in qualified health care professionals who are dispensing evidence-based information.

Unfortunately, modern medicine has failed to find a cure, and in some cases effective treatment, for many chronic conditions. Patients can easily become frustrated when health care professionals dismiss their chronic ailments and concerns or fail to provide any relief. It is only natural for them to turn to unproven therapies in the quest to find relief from their struggles. This is where they can be taken advantage of through promises of magical cures or providers who claim to know the “cause”

of their complaints (occasionally with disparaging remarks about how medical schools do not teach the “right” information). Chronic Lyme disease, chelation therapy, vaccine toxicity, toxic mold syndrome, electromagnetic sensitivity, and bogus cancer treatments are just a few areas where pseudoscience prevails. Harm occurs when patients forego proven evidence-based treatment options in favor of unproven therapies, spend significant amounts of money, and experience side effects, at times severe, from pursuing this path. This is one of the most profound reasons health care professionals should disseminate evidence-based information through social media: to try to reach some of these patients and prevent their descent into the realm of pseudoscience.

Use of specific wording, conspiracy-fueled rejection of evidence-based recommendations, and cherry-picked data from research studies performed in laboratory animals or presented as abstracts at scientific meetings but not published in peer-reviewed journals are a few tactics used by those peddling pseudoscience. Health care professionals can assist patients and the public in identifying and avoiding pseudoscience by promoting positive messaging on social media and raising awareness.

HOW MEDICAL PROFESSIONALS CAN REGAIN TRUST

By recognizing that patients and parents are going online to search for health information, medical professionals can actively discuss this at each clinical encounter. This should be actively discussed in a nonthreatening manner and offer acknowledgment that this occurs. Providers should allow for questions to be raised, even if they stem from areas that are far outside the plausible realm, and appreciate that most patients *want* to hear proper evidence-based information to assist their medical decision making.

Medical providers can use this example phrasing as an opening to this discussion: “I realize you have likely spent some time searching for information online. There are many great resources available that offer evidence-based information. Unfortunately, there are also many non-evidenced sources that provide incorrect, and possibly harmful, information. Please feel free to ask me any questions about the information you have read, particularly if it differs significantly from the information I provide to you. If you’d like, I am happy to provide you with a list of trusted resources that provide vetted information. I do recommend caution if you encounter personal stories or information surrounding treatment that sounds too good to be true, as that is often the case.”

Although all of this can serve as a source of frustration for medical professionals, it is important to embrace how the world has become so interactive and the multiple benefits that online resources provide. Providers who fail to adapt may be seen as old fashioned or less trustworthy by patients. As society evolves, the millennial generation will get older and start to have children of their own. It behooves providers to interact with these individuals in a manner to which they are accustomed. Although mid to older generations of physicians and medical providers may recall growing up in a world with rotary telephones, they must appreciate that younger generations have only known an online world. If the valued patient-provider relationship is to be resurrected, then providers must evolve as well.

SUMMARY

Now more than ever, it is important for medical professionals to appreciate the sheer amount of health information available online. It is even more important to appreciate the sheer amount of misinformation available as well. By actively spending time online searching for information from the patient perspective, providers will gain a new

understanding of where their patients and parents of their patients are coming from. This knowledge can then translate to individual conversations in the clinical setting and can assist decision making.

REFERENCES

1. Tilburt JC, Allyse M, Hafferty FW. The case of Dr. Oz: ethics, evidence, and does professional self-regulation work? *AMA J Ethics* 2017;19(2):199–206.
2. Lawhon L. New survey reveals importance of online health communities. Philadelphia: Health Union, LLC; 2016. Available at: health-union.com/news/online-health-experience-survey/.
3. Herbert L, Shemesh E, Bender B. Clinical management of psychosocial concerns related to food allergy. *J Allergy Clin Immunol Pract* 2016;4(2):205–13.
4. DunnGalvin A, Dubois AE, Flokstra-de Blok BM, et al. The effects of food allergy on quality of life. *Chem Immunol Allergy* 2015;101:235–52.
5. Olive JK, Hotez PJ, Damania A, et al. Correction: the state of the antivaccine movement in the United States: a focused examination of nonmedical exemptions in states and counties. *PLoS Med* 2018;15(7):e1002616.
6. Ten threats to global health in 2019. Available at: <https://www.who.int/emergencies/ten-threats-to-global-health-in-2019>. Accessed March 15, 2019.
7. Kirsch IS, Jungeblut A, Jenkins L, et al. Adult literacy in America: a first look at the results of the national adult literacy survey (NALS). Washington, DC: National Center for Education Statistics, U.S. Department of Education; 1993.
8. Scott TL, Gazmararian JA, Williams MV, et al. Health literacy and preventive health care use among Medicare enrollees in a managed care organization. *Med Care* 2002;40(5):395–404.
9. National Center for Education Statistics. The health literacy of America's adults: results from the 2003 national assessment of adult literacy. Washington, DC: U.S. Department of Education; 2006.
10. Michalopoulou G, Falzarano P, Arfken C, et al. Implementing Ask Me 3 to improve African American patient satisfaction and perceptions of physician cultural competency. *J Cult Divers* 2010;17(2):62–7.
11. Kleinman RE. American Academy of Pediatrics recommendations for complementary feeding. *Pediatrics* 2000;106(Suppl 4):1274.
12. Du Toit G, Roberts G, Sayre PH, et al. Randomized trial of peanut consumption in infants at risk for peanut allergy. *N Engl J Med* 2015;372(9):803–13.
13. Togias A, Cooper SF, Acebal ML, et al. Addendum guidelines for the prevention of peanut allergy in the United States: report of the National Institute of Allergy and Infectious Diseases-sponsored expert panel. *J Allergy Clin Immunol* 2017; 139(1):29–44.
14. Gabelkov M, Ramachandran A, Chaintreau A, et al. Social clicks: what and who gets read on twitter? ACM SIGMETRICS/IFIP performance 2016, HAL archives. Jun 2016 2016. Antibes Juan-les-Pins, (France).