

April 2018 <u>http://PatientSafetyAmerica.com</u>

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<u>*Question*</u>: According to a 2018 Centers for Disease Control report, in U.S. women ages 15 to 44 years, how much did the use of attention deficit/hyperactivity disorder (ADHD) drugs increase from 2003 to 2015? <u>a)</u> none b) 100% c) 200% d) 300% e) 400% f) 500%

Book Review: The 60-Minute Guide to Health Literacy – A Common Sense Approach to Informed Decision Making

Author: Jo Kline, JD

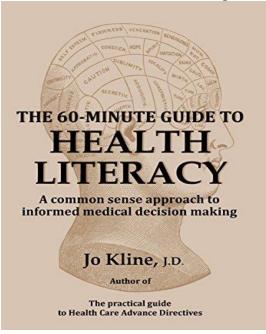
This comprehensive, yet compact book does exactly what its title suggests – it addresses the lack of common sense when it comes to dealing with difficult decisions that are part of obtaining optimal health care until death relieves us of that task. Having learned the lessons of this book the hard

way when my son was dying, I appreciate the importance of its wisdom and forethought. I kept mentally nodding, "That's right, that's right." As I started reading the reasons for Ms. Kline's book, I felt as if she was "hugging" me because it is likely that any reader of her book is seeking guidance in hard times. A hug is in order.

Her chapters generally trace the path of life. She exposes the reader to a brief tutorial on the rights of patients to have autonomy – control of one's destiny. But,

the following chapters (2-7), warn the reader that autonomy is meaningless if one has no idea how their destiny can be controlled. You must know where to get trustworthy help, how to interface with your care team, and how to engage your clinician in shared-decision making. Her message comes through clearly, "You must control the situation when you are facing a serious illness and be prepared to share intelligently in decisions." Chapters 8-11 focus on speedbumps along the road to care in a system that is not necessarily focused on your best interests. What does it mean to need or be a caregiver? How does one reduce the risk of serious illness and deal with medications that may be prescribed too often? What is the difference between urgent care and emergency care?

Chapters 12-14 deal with the reality that one day we are all likely to face a life-threatening disease. Ms. Kline gives a wonderfully simple tutorial on probability and absolute risk. Palliative



care does not mean the end is near, but as the end of life approaches, how does one avoid suffering? What sort of "last days" do you or your loved one want?

You may want to leave a "piece of yourself" for generations to ponder; this she calls an "ethical will." Personally, I treasure some of the wisdom and stories my parents wrote down as the latter decades of their lives unfolded. I also treasure the words my son wrote in his journal as he endured Air Force Officer's Basic Training a few months

before he died. His maturity and clarity of thinking were evident in his words.

This is an extremely well written book that should be considered by anyone dealing with challenging health-care decisions. Getting optimal care in the U.S. system can be difficult because of perverse incentives, so know what you are up against, know how to take control, and know that there will be uncertainties. I'll easily give this book 5 stars. About \$15 on Amazon. Kindle, \$10.

Lung Cancer Screening – When is it Medical Billing – Welcome to a Mess Worthwhile? <u>Two experts</u> looked at issues in

Sometimes in medicine it seems that the more we know, the more we realize that we have a lot more to learn. If you are or have been a smoker, should you be screened for lung cancer? Are you prepared to deal with incidental findings and with the disease if they are found? These questions were addressed in a couple of articles in the medical journals I read. Two MDs wrote about the ways that harm from screening populations that are unlikely to benefit may be created. Current recommendations are that CT scanning is warranted for those from 55 to 80 years old with a history of 30 pack-years or more of smoking and have quit in the past 15 years. The authors assert that screening has been used too much in low-risk populations, leading to troublesome, incidental findings. The authors note that the lung-cancer detection rate is not all that high even in the high risk group, and that group still gets too many incidental findings. In the end, the authors call for research to better discern who will, and who will not, benefit from screening. I would also assert that patient preferences should play a role in the decision to screen or not.

Another article authored by a hand-full of experts attempted to partially accomplish what the first asked for. That group performed risk-targeted lung cancer screening by dividing about 53,000 patients into 5 groups depending on a complicated method to predict their risk of lung cancer. The patients were given low-dose CT scans or chest radiographs (control). The median follow-up time was 6 ¹/₂ years. Comparing the quality-adjusted-lifeyears (QALY) gained between the lowest-risk and highest risk groups, the difference was only 2.4 years. The cost of the QALY's gained ranged from \$53,000 to \$75,000. The norm for insurance payment is typically about \$100,000 per QALY. The authors conclude that any gains from screening are "attenuated and modest" in terms of QALY gains and cost effectiveness. The study is quite complex. Perhaps an expert could distil some guidance for patients on whether to be screened or not. If I had been a smoker, I would calculate my risk of lung cancer using a decision screening tool, such as the one from Memorial Sloane Kettering Cancer Center. I would not assume that the tool is unbiased.

Two experts looked at issues in the way medical bills are created for the delivery of care. They pointed out that the medical industry is far behind other industries with its methods, and then "The unnecessarily complex, they note that fragmented, and inefficient system of billing, coding, and claims negotiations in the US health care system employs enough people to populate small nations just to ensure that health care organizations and clinicians are reimbursed for their services." The authors opine that this costs about a half trillion dollars per year, 80% of which is wasted. If you have been trapped between factions trying to get your money or pay arcane bills, then you understand how broken the billing system has become. Even health care professionals struggle to understand their own medical bills.



The authors propose that electronic health records could be adjusted to reduce the complexity. They also note that as consumers are asked to pay more of their healthcare costs, they are going to push back. The authors also point out that patients should know how much they will owe at the time of service. I opine that the time is now to push hard on cost transparency. Consumers buy nothing else in total darkness. It is long past due for consumers of healthcare to demand full cost transparency.

Medical Devices in the Real World

The Food and Drug Administration (FDA) is charged with walking a thin line between clearing devices that may be useful to patients and clearing devices that may cause harm – and this using data that are often limited. Please see last month's book review on Danger within Us for further perspective on device harm. What the authors of a perspective in the New England Journal of Medicine propose is use of real-world data to determine the safety and effectiveness of medical devices cleared for marketing. I might note that this turns patients, in whom the device is inserted, into guinea pigs. To do this effectively, there will need to be adequate statistical methods to deal with the hodge-podge of real-world data, and there will have to be better reporting of adverse effects to the FDA. Real-world data might also be used to expand the use of a given device, but there again, the patient becomes a guinea pig. In the end, the authors seem to fall back on the need for better pre-marketing data to facilitate wellfounded decisions by the FDA. They cite the example of a radio-frequency ablation of kidney nerves to control hypertension. This was approved in Europe, but a U.S. study ultimately proved that this invasive technique was no better than medications.

The message here for patients is to know the pedigree of any device that is proposed for use in your body. You may not get a second chance if it proves to be as dangerous as some cleared or approved devices. There is a natural bias to suppose that newer is better. This is often not true in the medical-device world.

Price Transparency

It is an open secret that finding prices for medical services is little more than a roll of the dice. A team of 7 experts set out to demonstrate in clear terms what we patient-consumers already know. The team looked at the <u>cost of 4 procedural</u> <u>interventions</u>: upper GI endoscopy, brain MRI, cholesterol panel, and hip replacement. They searched the web using the search term "cost of (intervention) in (city)." They searched in 8 cities, identifying a total of 234 sites that provided geographically relevant, price transparency for each intervention. Overall, less than 20% of the "price transparency" sites initially inspected offered useful information. Prices varied widely for any given location and intervention. The authors offered as an example the prices in Chicago. The ranges in price were as follows: upper GI endoscopy \$875-\$3958, brain MRI \$230-\$1950, cholesterol panel \$25-\$100, and hip replacement \$27,000 – \$80,671. Of course, it was unclear how insurance would impact the out-ofpocket costs. The authors noted that most transparency sites required a subscription. They opined that there is "substantial room for improvement." Of course, the wise consumer would like to know the quality of the intervention. One does not negotiate a price for a car, and then discover that he was negotiating for a used Yugo rather than a new Cadillac.

Clinical Decision Making

One of the current trends in medicine is called "shared-decision making." The idea being that a fully informed patient and her clinician engage in a thorough discussion of the options available for treatment of the patient. In the context of medication use, an MD asks whether this approach is likely to lead to optimal choices given the uncertainty inherent in most choices. According to the author, the choices clinicians make are driven by simplicity of information offered by drug company representatives, recent adverse events associated with the drug, and fear of causing harm from rare side effects. On the patient side, adherence to taking a medication may be influenced by costs. The author calls for more research as it applies to decision making in healthcare.

I would disagree with some of the author's opinions. An empowered patient-consumer of drugs can question the clinician and do research to determine lots of information about a proposed prescription. I remember my high-school-educated mother, armed with her copy of *Worst Pills Best Pills*, managed to get doctors at Mayo Clinic and Johns Hopkins University Hospital arguing about the appropriate medication for her. She was highly mistrustful of medical care, and always did her homework.

Low-dose Aspirin for Patients with Previous PCI Undergoing non-cardiac Surgery

In this case "PCI" refers to Percutaneous Coronary Intervention, which is the placement of stents in coronary arteries. This is a very common procedure. An editorial in the *Annals of Internal Medicine* surveyed the data on whether <u>low dose</u> <u>aspirin</u> should be continued or prescribed anew in patients that have had stents put in and are about to undergo a non-cardiac, surgical procedure.



Like many things in medicine, it's complicated. Since low-dose aspirin poses a bleeding risk, it is not recommended for previous PCI patients that are about to undergo a procedure in which bleeding risk is high. An empowered patient that has had a PCI will ask his surgeon about use of aspirin if non-cardiac surgery is recommended.

Right-to-Try Legislation

This kindly sounding title belies the darkness behind this bad legislation. Two experts writing in the *New England Journal of Medicine* explain that the legislation allows patients with life-threatening illness to ask a drug company to provide a drug that has completed Phase 1 trials of safety and efficacy (early in the testing process). It does several potentially harmful things. A route already exists for

Answer to question: (c or d) 344%, source: https://www.cdc.gov/mmwr/volumes/67/wr/mm6702a3.htm?s_cid=mm6702a3_w

desperate patients to try investigational drugs, but this happens with some oversight by the FDA. The <u>Right to Try</u> bill removes this oversight, leaving patients at additional risk for harm. The legislation would also block any accountability on the part of the drug maker or physician involved for harm caused to patients. It could also draw patients away from structured clinical trials that have the potential to produce quality data on risk and benefit. At the time of this writing, the House has passed a Rightto-Try bill that is similar to the one passed by the Senate. If this thing passes, as seems likely, patient advocates must increase their vigilance when investigational drugs are involved in care of patients with life-threatening disease.

Patient Pages from Medical Journals

When should a patient that fell in an assisted-living facility be transported to the ER? <u>http://annals.org/aim/fullarticle/2666272/transport-emergency-department-assisted-living-residents-who-fall</u>

Sports-related concussions:

https://jamanetwork.com/journals/jama/fullarticle/26 71029

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