Las condiciones no son causas útiles

Cobo / Ventura

problems with media coverage and how to do better

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The two basic ingredients of good decision making are facts and values. Facts refer to the available choices and the likely outcomes of their choices. Values refer to how much people care about the different outcomes and the associated tradeoffs (e.g., the potential benefits and harms, costs and inconveniences of their choices). People can only make good decision when they have the facts and some clarity about their values.

This simple model of decision making highlights a basic problem: without the facts, people cannot possibly make good decisions. They may make a lucky decision and have a good outcome, but not an informed decision consistent with their values.

When it comes to medical care, people see lots of messages. Unfortunately, many do not provide the facts. Consider this colon cancer screening advertisement from Sloan Kettering –a major cancer hospital in New York– which ran in the *New York Times* (fig. 1). This ad does not present facts, it presents fear. It says be afraid: you may feel healthy, but guess what, you may have colon cancer. It says you can never feel safe because even when you seem well you may really be sick. The ad is also highly exaggerated

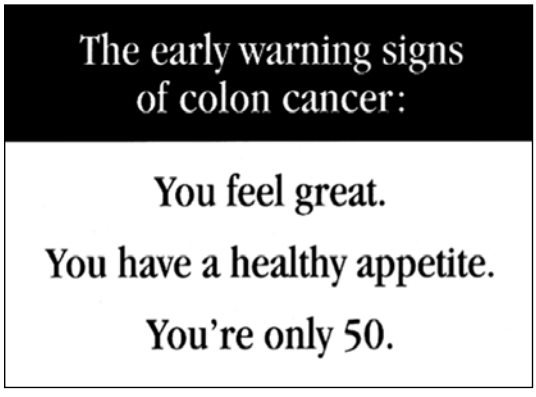

Figure 1.

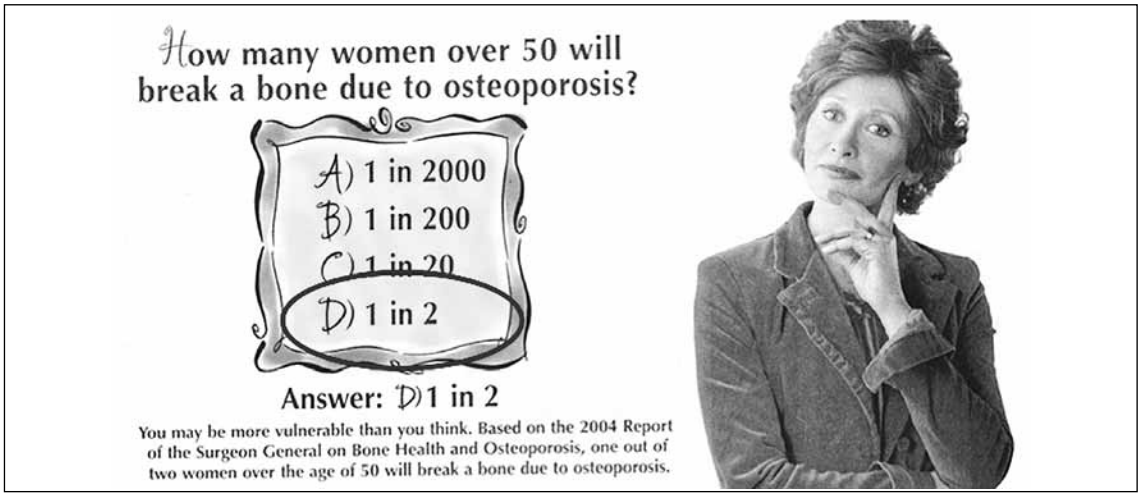

Figure 2.

since most 50 year olds who feel great and have a healthy appetite do not have –and will not get– colon cancer. For example, on average, a 50-year-old man has a 3 out of 1,000 chance of being diagnosed with colon cancer in the next 10 years and 1 out of 1,000 chance of dying from it.

Or consider this direct-to-consumer advertisement (fig. 2) promoting a drug for osteoporosis –thinning of bones (only the US and New Zealand permit direct to consumer advertising of prescription drugs– in the US, citizens are exposed to over $4 billion of these ads each year, ten times the FDA's budget for evaluating new drugs).

This ad looks like it presents facts –but it is an illusion of facts. The "1 in 2" number greatly exaggerates a woman's risk of fracture. The "1 in 2" number includes both fractures that hurt (and cause problems) and fractures that are small (which can only be seen on x-rays and never cause symptoms or problems). But most importantly, the vast majority of fractures from osteoporosis occur among women 75 and older –not among women 50 to 75. The message in the fine print reveals the true purpose of the ad: to make women feel vulnerable and afraid. The print under the numbers says: *"You may be more vulnerable than you think"* (Fig. 2).

That a drug company might exaggerate risk to sell a product is not so surprising. Seeing the same tactic from a disease awareness group is. The Light of Life Foundation (a disease awareness group founded by a thyroid cancer survivor) ran a series of ads to promote thyroid cancer screening (fig. 3).

The ad depicts Rachel, age 14, "the day before she was diagnosed with thyroid cancer".

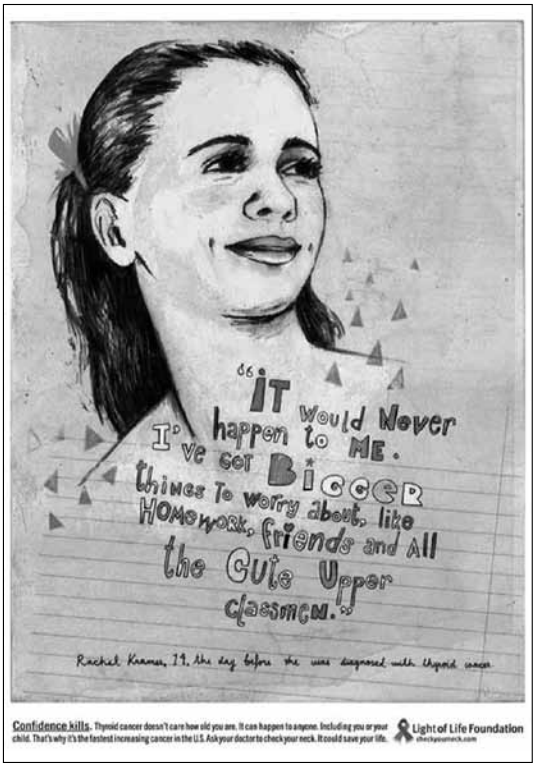

Figure 3.

Rachel says: *"It would never happen to me. I've got bigger things to worry about like homework, friends and all the cute upper classmen".* And the ad's bottom line reads *"Confidence kills: Thyroid cancer doesn't care how old you are. It can happen to anyone. Including you or your child".* We think this use of "facts" to generate fear in young people and their parents is actually cruel. A 15-year-old girl's chance of getting thyroid cancer in the next 10 years is less than 1 out of 1,000 and the chance of dying from it about 1 out a million. Because the disease is so rare, no professional medical organization recommends thyroid cancer screening for young girls.

The prior three messages share a pattern: using hype to generate extreme fear. But many messages go in the opposite direction. They use hype to generate extreme hope.

In December 2003, the cover of the magazine, U.S. News and World Report, declared "The end of heart disease" (which as of this writing in 2013 remains the biggest killer in the United States). Extreme hope also comes from leaders of our most esteemed organizations. During the U.S. National Institutes of Health budget hearings in 2005, a senator asked Dr. Von Eschenbach, the director of the National Cancer Institute at the time, *"What is going to happen by 2015 as you project it?"* The directors responded, *"No one who hears the words 'You have cancer', will suffer or die from the disease. We will prevent and eliminate the outcome"*.[1] Unfortunately, despite receiving their requested budget, the National Cancer Institute is, of course, nowhere near eliminating suffering or death from cancer.

The most effective "message" strategy is to use fear and hope together: exaggerate a risk to make people feel vulnerable and then exaggerate the benefit of what you have to offer (or sell) to reduce that risk. The advertisement (fig. 4) for abdominal aneurysm surgery from Mount Sinai (a major academic medical center in New York) illustrates the power of this strategy.

The ad makes two statements. One generates fear: an aneurysm is a death sentence. The other generates hope: Mount Sinai can offer a pardon. But both statements are highly exaggerated. Most aneurysms that are found are very

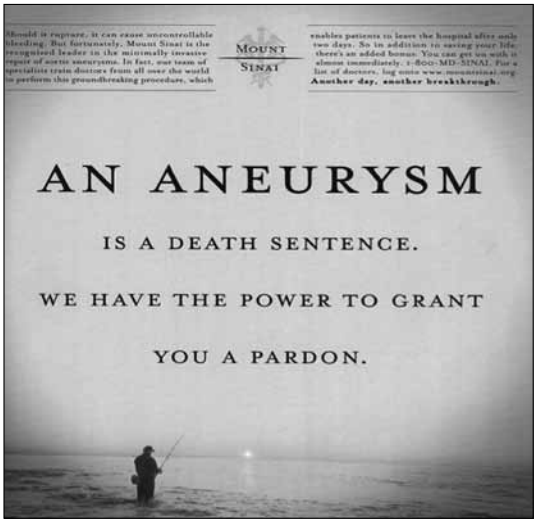

Figure 4.

small and will never grow large enough to cause problems –let alone death. And a few people will die from the surgery –not exactly a pardon.

The problem is that messages exaggerating disease risk and treatment benefit are everywhere. The problem is that these messages cause harm. They generate anxiety and undermine the public's sense of well-being and resilience. As a result, they may prompt too much exposure to medical care which may not help and can really hurt people. And repeated exposure to exaggeration may leave the public cynical: they may stop paying attention to health messages altogether.

It is easy to understand why there is so much exaggeration. Manufacturers (drug, technology) need to sell their products. Academic institutions need publicity to raise funds. Meeting organizers need to attract scientists, advertisers and sponsors. Researchers need to show results to advance their careers. Media outlets compete for stories, advertisers, and readers (or viewers). And journalists compete for the front page –or the most e-mailed story. This is a recipe for exaggeration because so many self-interests are served by being associated with research perceived to be new, big and important.

If the diagnosis is exaggeration, we think the prescription is healthy skepticism. We all need to push back and see through exaggeration to avoid being manipulated by messages that make

us too scared or too hopeful. This is especially important for journalists. The media's power to amplify and disseminate messages makes journalists a prime target for exaggeration.

Journalists' sources exaggerate

Exaggeration often begins with journalist's sources. Researchers do this when they suggest their findings apply to more people than they really do. Or when they are too certain about inherently weak science and fail to acknowledge study limitations. One way this plays out is through researcher quotes, a feature seen in almost all press releases. In a systematic review of press releases issued by academic medical centers, we judged one-quarter of researcher quotes as "exaggerated".[2] For example, in a press release titled "Scientists inhibit cancer gene. Potential therapy for up to 30% of human tumors", the lead investigator, said, "the implication is that a drug therapy could be developed to reduce tumors caused by Ras without significant side effects". The researcher greatly exaggerated the implications of this study since it only involved skin cancer in mice (no human testing for efficacy or safety had been done).

In the same systematic review, we documented other problems with the press releases –the most direct way that academic medical centers communicate with journalists.[2] Over one-third of the press releases failed to quantify the main result. When results were quantified, over half used formats known to exaggerate the magnitude of findings (for example, giving a relative change without providing the base rate). Despite the fact that all studies have limitations, few press releases mentioned them.

Many press releases promoted animal or lab research and specifically claimed that these studies were relevant to human health. Nearly all (98%) failed to caution about problems translating such research to humans. The need for caution was highlighted in a systematic review of "high profile" animal studies.[3] On average, it took 14 years to translate the animal research into human testing. And only one-third of animal studies translated into successful interventions in randomized trials of humans. Moving from animals to humans is a slow and uncertain process.

After finding similar problems in medical journal press releases, we interviewed press officers at major medical journals to better understand how releases are written. The interviews gave us insight into why press releases can be so problematic. None of the journals had data presentation standards for press releases. Nor did any require a statement about study limitations.[4]

Medical journals, academic medical centers and researchers –all important sources for journalists– contribute to the problems with health news. We now look at how these problems play out in what is actually reported in the media. We focus specifically on reporting in two high-risk zones for exaggeration: scientific meeting presentations and disease mongering.

Too much, too soon: media reporting on scientific meetings

Reporters routinely cover scientific meetings. These meetings, sponsored by large professional organizations, have two purposes: they are a forum for scientists to present work to colleagues and represent an engine for generating media coverage. In fact, the effort courting the media is often greater than the effort in vetting the sciences. In 2002 (when we conducted a study of media coverage of scientific meetings), the Society for Neuroscience received 15,000 abstracts for presentation and accepted 100% of them (the only criteria for acceptance was membership of one of the authors).[5] The only review conducted by the Neuroscience organization was to determine which abstracts would be promoted to the media.

Scientific meeting research is typically preliminary, may have limited relevance to human health, and has generally undergone limited –if any– peer review (i.e., reviewers typically have access only to the abstract –not the full manuscript). Nevertheless, research presented at scientific meetings is often big news.

To gauge the quality of these reports, we did a content analysis of news stories after five major scientific meetings (World AIDS, American Society of Clinical Oncology, Radiological Society

of North America, American Heart Association and the Society for Neuroscience).[6] We identified 174 newspaper stories (34 on the front page) and 13 national radio or television stories in the 2 months after the meeting. These stories appeared in 50 major news outlets, including eight of the top ten circulation U.S. newspapers. The bottom line was that there was lots of room for improvement. Basic study facts were often missing: one-third of the news stories failed to report the study size; about half did not state the study design and 40% did not quantify the main result. Cautions about studies with obvious limitations were also missing: all failed to caution about assuming the results of animal or cell research apply to human health, 69% failed to caution that in uncontrolled studies you cannot know if the intervention caused the finding and over half failed to caution about the instability of results from small (less than 30 patient) studies.

Remarkably, the most important caution about scientific meeting research –that it is preliminary, unpublished, not the final study results– was missing from all but one news story. This caution matters because preliminary work does not always pan out. Result change and fatal flaws emerge. These problems are reflected in the publication fate of scientific meeting research which garnered high profile media coverage. While half of this research is published in high-impact medical journals in the next 3 year, one quarter is published in low-impact journals and another quarter is never published.[5] This finding was the same for meeting research that covered on the front page of the newspaper. Dr. Richard Klausner, the former director of the National Cancer Institute, captured this phenomenon even better than the numbers: *"I'm pretty well plugged in to what's going on in research," he remarked. "I hear on the news "Major breakthrough in cancer!" And I think, Gee, I haven't heard anything major recently. Then I listen to the broadcast and realize that I've never heard of this breakthrough. And then I never hear of it again."*

The media and disease mongering

It is hard to avoid becoming sick. If you sleep too little at night, you have insomnia. But if you sleep too much during the day, you have excessive daytime sleepiness syndrome. If you have trouble paying attention, you have attention deficit disorder. But if you pay too much attention, you have obsessive-compulsive disorder. And if you have any blood sugar, blood pressure or even any bones, you may have pre-diabetes, pre-hypertension or osteopenia.

Diagnosis is expanding. We are turning ordinary experiences (such as transient sleep problems, sadness) into disease and turning risk factors into diseases themselves (such as high cholesterol, a risk factor for the heart attack is now a diagnosis itself with its own ICD9 code, etc.). And in either case, lowering the cutoff necessary for the diagnosis can expand an existing disease.[7] The late 1990's the threshold for being "overweight" was changed from a body mass index ≥25 kg/m^2 instead of ≥27 kg/m^2.[8]

Expanding diagnosis reflects a fundamental problem in medicine: how do we define sickness? Most medical phenomena exist on a spectrum. At one end, people are overtly sick. At the other end, people are perfectly well. A narrow definition of sickness –drawing the line closest to "overtly sick"– labels the few people with the diagnosis. The advantage is that the definition focuses on the sickest people –those who stand to benefit the most from treatment. The disadvantage is that we miss some people who might benefit. Ideally, we would draw the line based on the benefits and harms to patients. In reality, many forces –drug companies, device manufacturers and doctors– are pushing the line to create broader and broader definitions of sickness. Whether or not it helps patients, broadening disease definitions serves other interests.

Disease mongering is the effort to convince people that they are "sick" and need a medical treatment for this sickness. This means creating very broad definitions of disease and conducting disease awareness campaigns to raise undue concern about the prevalence and severity of "disease" to capture the biggest market. Disease mongering implies that this is being done for reasons other than the patient's interest.

The problem is that disease mongering can really make people sick. The anxiety, sick role from

the diagnosis and side effects from treatment can be worse than the disease. The primary culprits are drug companies who conduct disease promotion campaigns, run direct-to-consumer drug ads, fund disease advocacy groups, subsidize physician education (CME, etc.) and pay for clinical trials. But the facilitator is the news media. They are a highly visible source of health information for consumers (and physicians and policymakers). Because the news is more credible than advertisements, it is met with less skepticism. To avoid being co-opted into the process, journalists need to know how to recognize the signs and symptoms of disease mongering.

Case study: a drug in search of a new use and how the media helped

Years ago, GlaxoSmithKline developed a drug called *Requip*. It was a drug for Parkinson's disease, but not a very successful –a third line drug– and it was going off-patent. There were some reports that *Requip* could be used for an obscure movement disorder called Ekbom's syndrome (now known as restless legs syndrome). We are going to show how GlaxoSmithKline extended Requip's patent protection by turning this obscure disorder into –according to their direct to consumer drug ads– a "recognized medical condition. One shared by nearly 1 in 10 U.S. adults".[9]

The story actually began in the late 90's, when the International Restless Legs Foundation (a group of mostly industry funded scientists) created the definition of restless legs syndrome.[10] To have the diagnosis, a patient must have each of the four standard criteria:

1) An urge to move the legs due to an unpleasant feeling in the legs.

2) Onset or worsening of symptoms when at rest or not moving around frequently.

3) Partial or complete relief by movement (e.g., walking) for as long as the movement continues.

4) Symptoms which occur primarily at night and which can interfere with sleep or rest.

Treatment is reserved for those with moderate-severe symptoms judged by frequency.

In 2003, GlaxoSmithKline sought FDA approval of *Requip* for restless legs. FDA review generally takes about one year. Toward the end of this period, GlaxoSmithKline began launching a press campaign, beginning with press releases from presentations at the American Academy of Neurology meeting and a press releases from a company funded (and unpublished survey): "New survey reveals common yet under recognized disorder –restless legs– is keeping America awake at night". But FDA refused to approve the drug because the submitted studies were too short (12 weeks) raising questions about long term safety. The drug was finally approved in 2005 after Glaxo submitted a "long-term" study of 36 weeks. With approval, the drug company sought to "push restless legs syndrome into the consciousness of doctors and consumers alike" and began a 27 million U.S. dollar direct-to-consumer advertising campaign. Within a year, drug sales increased from $97 to $146 million.

To explore the role of the news media, we looked at coverage of *Requip* during the campaign.[9] We identified and rated the 33 news stories that appeared in major newspapers. Two-thirds of news stories simply repeated the "nearly 1 in 10 U.S. adults" prevalence estimates asserted in the drug company ads (a more critical reading of the prevalence studies suggests that <3% might need treatment, although even this number is likely to be an overestimate). Three-quarters of news stories discussed the extreme physical and emotional aspects (typically with a patient anecdote), yet none presented any anecdote of mild disease. Forty-five percent blamed doctors for being unaware of the diagnosis (e.g., "relatively few doctors know about restless legs. This is the most common disorder your doctor has never heard of") or suggested that patients were unaware they were sick. One quarter referred readers to checklists for self-diagnosis and for, for more information, to the "not for profit" Restless Legs Foundation. While the Foundation is "not for profit", its annual report discloses that, by far, the major funder is GlaxoSmithKline –the makers of *Requip*. Glaxo is the only gold medal

donor listed (defined as a minimum of a quarter of a million dollars –Pfizer, who had another restless legs drug in development was listed as a bronze medal donor). No news report mentioned entanglement between Glaxo (or Pfizer) and the Foundation. None of the news stories mentioned the possibility that there might be too much diagnosis.

Did the media accurately portray the benefits and harms of *Requip*? Not exactly. Among the 15 stories that mentioned Requip specifically, 45% only discussed the benefit of the drug with an anecdote and 33% used "miracle" language (for example, literally quoting a patient as saying "[*Requip*] has been a miracle drug for me"). Only one story quantified the benefit. The best estimate of the benefit of *Requip* comes from the 12-week randomized trial that was part of the basis of FDA approval. For the primary outcome (average improvement on the International Restless legs symptom score), the *Requip* group improved by 14 points vs. 10 point improvement in the placebo group, a net 4-point improvement on a 40-point scale. Is a change of this magnitude a "miracle"? Understanding what the 4-point change means is a challenge. Would patients notice it (power calculations in approval trials asserted 3 and 6 points as meaningful changes)? The study also looked at whether clinicians rated patients as "very much" or "much" improved: 73% of the *Requip* group improved compared to 57% of the placebo group –so only 16% of patients improved because of *Requip*.

Media reporting of the harms of *Requip* was also poor: only about one quarter mentioned any harm. But *Requip* has important side effects: nausea (40% vs. 8% placebo), dizziness (11% vs. 5%), somnolence (12% vs. 6%), and fatigue (8% vs. 4%). Increased chance of somnolence and fatigue undermine the rationale for the drug's use since much of the push for treating restless legs is how it is "keeping America awake at night". How useful is a treatment that improves restless legs symptoms for a minority of patients if it leaves almost as many feeling more tired and more fatigued. For some patients, in fact, the problem of tiredness was so severe that FDA required that *Requip* include a warning in the ad that "*Requip* has been associated with sedating effects, including somnolence and the possibility of falling asleep while engaged in activities of daily living".

In summary, the media did aid and abet disease mongering efforts. While restless legs syndrome is just one example, there is no reason to think other disease promotions would be covered any differently. Journalists can do better by being skeptical when new –or expanded– diseases are being promoted to them. More specifically, they can (and should) question prevalence estimates, present the full spectrum of disease, question the idea that more diagnosis is always better and quantify the benefits and harms of the new treatment. To help them do so, it is helpful to consult experts without financial or professional conflicts of interest (a list of "Industry-independent experts" is available at: http://www.healthnewsreview.org/toolkit/independent-experts/).

Conclusion

Problems with media coverage can have important consequences for the public. People may become too enthusiastic about new and marginally effective interventions and too certain about findings based on weak science. There are a number of ways for journalists help readers get the facts. One way is to report numbers. When journalists quantify the chance of disease and the benefits and harms of treatment, the public can appreciate the actual magnitude of the risks they face and decide whether the benefits of interventions outweigh the harms. Journalists should also routinely note important study limitations to help inoculate the public against believing that we know more than we do, and constrain unrealistic expectations. The tip sheets [see Apéndice, p. 75] we have developed provide cautions specific to common study limitations. Journalists with a healthy skepticism will promote a healthier public.

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