What A Doctor Calls A Condition Can Affect How We Decide To Treat It

By Katherine Hobson

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Want to see a group of parents shudder? Whisper that your kid has "pinkeye." That one little word evokes images of ocular goop cutting a swath through a pre-K class like a lion through a herd of gazelles.

And as it turns out, how that eye grossness is labeled can make parents feel differently about how they'd want it treated in their own child. A study published last year looked at parents' reactions to a hypothetical scenario in which a doctor describes a child's symptoms of the viral form of conjunctivitis¹

Conjunctivitis can also be caused by a bacterial infection or by allergies.

as either "pinkeye" or an "eye infection." Participants also saw a photo of an afflicted eye.

When parents were told the child had an "eye infection" and that antibiotics were unlikely to help (because it was probably viral), their interest in the drugs declined. But when they heard "pinkeye," parents still wanted antibiotics, even when they were told the drugs weren't necessary. The finding suggests that word choice has consequences, especially given the overuse of antibiotics and the emergence of antibiotic-resistant bacteria. Compared to those who heard "eye infection," parents who heard "pinkeye" also thought the condition was more contagious and weren't as likely to believe that their kid could attend child care.

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The study is part of an emerging body of research investigating how the words used to describe a disease or a condition can influence how patients feel about treatment options. "The words we use around health and diagnosis are incredibly powerful," said Kirsten McCaffery, a behavioral scientist at the School of Public Health at the University of Sydney Medical School in Australia. She's an author of a new review of the research on this topic, which comes at a time of growing concern about overdiagnosis. Overdiagnosis occurs when people are diagnosed with a disease that never would have threatened their health or life. In most cases, they're treated, sometimes aggressively. If the language used to describe a condition makes patients more likely to opt for the most aggressive treatment, that could make the overdiagnosis problem worse.

For example, one study looked at the effects of labeling a baby's crying and regurgitation as gastroesophageal reflux disease (GERD). Real parents were asked for their reaction to a hypothetical situation in which their infant was spitting up and crying, but was otherwise healthy. Those told that their infants had GERD were more interested in treating the problem with drugs even though they were unlikely to help than parents whose babies' symptoms weren't labeled with a medical diagnosis. GERD is of interest because of concern about the overuse of proton pump inhibitors to treat reflux in babies. Another study, whose authors include McCaffery, found that women given a hypothetical diagnosis of polycystic ovary syndrome had a greater intention to have an ultrasound and thought their condition was more severe than those told that they had a "hormonal imbalance." Some experts worry that the condition is being overdiagnosed; depending on the diagnostic criteria used, up to 20 percent of women of reproductive age may qualify as having polycystic ovary syndrome.

But language doesn't just influence the risk of unnecessary tests and treatments; the women labeled as having the syndrome also felt worse about themselves. When people are told that they have a disease, they may start thinking of themselves as abnormal or sick. This shift in mindset can change their behavior or sense of well-being, even if all that's changed is the label that's been applied to them. People told that they have hypertension, for example, started missing days of work more often once they found out, mostly because of self-reported illness that wasn't explained by changes in blood pressure or medication.

Labels are particularly consequential in oncology, where the stakes are very high. Hearing the words "you have cancer" can fundamentally change someone's self-identity. That's one reason researchers are debating which abnormal cells should be called cancer. It's a discussion that comes amid a rising awareness that at least some people are getting aggressive, potentially harmful treatments for lesions that aren't likely to hurt them.

Ductal carcinoma in situ (DCIS) — a diagnosis made when abnormal cells are detected in the breast's milk ducts — is one example. These cells have the potential to progress to invasive breast cancer, but many never do. Yet even though studies don't suggest that double mastectomies improve the long-term outcome for most cases, some women are getting them. The best way to treat DCIS remains a matter of debate and a personal decision on the part of the patient, but fear may bias the choices that people

make.

A study in the review shows that treatment preferences change when DCIS is described as a "noninvasive cancer," "breast lesion" or "abnormal cells." The word "cancer" seems to lead women to opt for surgical treatments, at least in hypothetical scenarios.

In 2012, the National Cancer Institute convened a group of experts who proposed changing the name of precancerous cells like ductal carcinoma in situ to indolent lesion of epithelial origin. There's precedent for removing the world "carcinoma" from low-risk tumors. In 1998, the World Health Organization did that with certain kinds of bladder tumors that only rarely progressed to invasive cancer. Similarly, some abnormal cervical cells are now referred to as low-grade lesions instead of cancer, and the change has led more patients to opt for watchful waiting rather than invasive procedures. Importantly, this switch in treatment has not increased the number of lesions ultimately diagnosed as invasive cancer. Last year, a panel of pathologists and other experts suggested that "encapsulated follicular variant of papillary thyroid carcinoma" become "noninvasive follicular thyroid neoplasm with papillary-like nuclear features." Both names are a mouthful, but the new one is missing the word carcinoma, and the hope is that this will help doctors and patients feel more comfortable treating it with less aggressive means.

Labels like "cancer" can make people scared, said psychologist Laura Scherer of the University of Missouri, an author on the pinkeye and reflux studies. Diagnostic labels can also trigger preconceived ideas about what needs to be done: Cancer always needs to be cut out immediately. GERD involves stomach acid, and there are drugs for that. Pinkeye is super-contagious, so my kid can't go to day care. Scherer's work suggests that changing the names of some conditions might help patients break out of these preconceptions.

Some research suggests that language is more important when people know less about the condition. A small study published in July looked at how urgently people would seek care for hypothetical health scenarios. Whether a condition was described in medical lingo or lay language didn't seem to matter for familiar conditions like heart attack — "myocardial infarction" in medicalese. But for newly medicalized conditions that people didn't know much about, the more technical-sounding term was

associated with a greater sense of urgency. For example, people were more likely to seek more urgent care for "androgenic alopecia" than "male pattern baldness." But in general, research hasn't nailed down precisely why some terms prompt people to say they'd want treatment and others not.

For now, simply being aware that terminology can influence your choices may prompt you to focus less on the name of the condition and more on the questions you should ask about it. How serious is this problem? What are the treatment options, and what are their risks and benefits? My child has caught pinkeye multiple times, but I've become a lot less freaked out about it since our pediatrician told me her preferred terminology: a cold in the eye.

Footnotes

1. Conjunctivitis can also be caused by a bacterial infection or by allergies.