Spinning the Genome

why science hype matters

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ABSTRACT There is a growing body of literature that describes both the degree to which science is hyped and how and why that hype happens. *Hype* can be described as an inappropriate exaggeration of the significance or potential value of a particular study or area of science. Evidence tells us that this spin happens throughout the science translation process. There is hype in research grants, peer-reviewed publications, scientific abstracts, institutional press releases, media representations, and, of course, in the associated marketing of a new product. There is also evidence that it has played a particularly significant role in the area of genetic research. Science hype is a complex phenomenon that involves many actors. And it is, at least to some degree, the result of systemic pressures imbedded in the current incentives associated with biomedical research. This article reviews what the evidence says about the sources of hype, the social and scientific harms, and what can be done to nudge us in the right direction.

Genetic research attracts significant attention from the popular press, and often these representations are less than ideal, skewing toward hyperbole

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and promises of near-future benefits. Indeed, revolutionary language has permeated public discourse since the start of the Human Genome Project (HGP) in the early 1990s. If the near constant parade of enthusiastic headlines is to be believed, we have been in the midst of a "genetic revolution" for over three decades, yet, the promised revolutionary changes never fully materialize, at least not to the extent envisioned by the proselytizers (Evans et al. 2011). The revolution is always just around the corner. Moreover, the nature and impact of the promised revolution is in constant flux. First it was going to be a gene therapy revolution, then a revolution centered on highly penetrant, predictive, and actionable disease risk genes. And now the revolution has taken the form of personalized medicine (or precision medicine). As the science evolves and the reality sinks in that stated promises cannot be fulfilled, the terms of the genetic revolution will further evolve. The hype continues.

In this commentary I explore the phenomenon of science hype surrounding genetic research and review the numerous social forces and research trends that have allowed it to become such a pernicious problem. Additionally, I briefly consider the various harms associated with the hype and how we may begin to address the problem.

Hype Happens

Even if a relatively circumscribed definition of hype is utilized—such as the inappropriate exaggeration of the state or potential benefits of an area of science—there are few who would deny science hype is a common phenomenon. Indeed, it can be argued that it is a natural part of the research process. Enthusiasm and optimistic predictions of near-future applications are required in order to mobilize the scientific community and potential funders, both public and private. This is particularly so in areas like genomics, where large amounts of sustained funding are required in order to achieve the hoped for scientific and translational goals. In addition, it is completely understandable that the researchers represent their results with passion and confidence. It is, after all, often their life's work.

And, of course, the popular press is, at the core, an entertainment industry that has the goal of making health and research stories compelling and readable. But, as science writer Andrea Rinaldi (2012) has noted, "walking the line between 'selling' a story and 'hyping' it far beyond the evidence is no easy task" (303). It is, then, understandable that reporting can often slip into the realm of exaggeration.

So, science hype is neither new nor surprising (Caulfield and Condit 2012). But there are reasons to believe that the phenomenon has been intensifying, and that it is having a more detrimental impact than in the past. Recent studies show an upswing in the use of hyperbolic discourse and spin in research publications (Chiu, Grundy, and Bero 2017). A 2015 study by Vinkers, Tijdink, and Otte, for example, explored the use of positive language in scientific abstracts. They found

that over a four-decade period—from 1974 to 2014—the frequency of positive words increased from 2 to 17.5%, an increase of 880%. Similarly, a 2016 study by Abola and Prasad analyzed how superlatives—that is, inflated language—are used to describe cancer research in the news. Not only are terms like "breakthrough," "game changer," "miracle," "cure," "home run," and "revolutionary" common, they found that they are often utilized in media reports even in the absence of clinical data.

And a growing body of literature has uncovered ample examples of exaggerated science in a broad range of biomedical fields. In the area of stem cell research—a topic our team has explored for over a decade—it has been found that there is hype in relation to both the potential benefits associated with the science and the timeframe for when clinical applications are expected to reach patients (Kamenova and Caulfield 2015; Rachul, Rasko, and Caulfield 2017). Others have found science hype to be a problem in a range of other areas including microbiome research, nanotechnology, infectious disease, immunotherapy, epigenetics, neuroenhancement, and mindfulness, to name but a few (Greener 2016; Healio 2016; Hanage 2014; Johnson 2010; Juengst et al. 2014; Partridge et al. 2011; Van Dam et al. 2017).

Of course, many studies over the past few decades have found a similar trend in the context of genetic research (Ostergren et al. 2015). In a study I did with my colleague, Tania Bubela, of over 600 newspaper articles about genetic research, we saw a consistent downplaying of potential risks and limitations and an emphasis on the potential benefits, a theme that has been consistent across a range of emerging genomic technologies (Caulfield and Bubela 2004). For example, a 2015 study of pharmacogenomics stories in the news media found that the "majority of articles over-stated the benefits of pharmacogenetic testing while paying less attention to the associated risks" (Almomani et al. 2015). A 2016 study of media representations of noninvasive prenatal testing came to a similar conclusion, finding that the "media emphasized the benefits and readiness of the technology, while overlooking uncertainty associated with its clinical use" (Kamenova et al. 2016). And our team's 2018 study of 774 newspaper articles on personalized medicine found an overwhelming emphasis on benefits over risks, limitations, or ethical concerns (Marcon, Bieber, and Caulfield 2018). Similar studies, some done by our research team, have found newspapers also hype the potential benefits of genomic biobanks and nutrigenomic testing (Bubela and Taylor 2008; Ogbogu et al. 2014).

Additionally, it is worth noting where hype happens. While studies have consistently found that general news sources—the primary source of science information for most in the general public—hype science, emerging research finds, no surprise, a similar trend exists within social media (Funk, Gottfield, and Mitchell 2017; Groshek and Bronda 2016).

Sources of Hype

I have been researching the topic of science hype since the late 1990s (Caulfield 2000). Since then I have had the opportunity to engage with hundreds of people, in both the research community and the general public, on this topic. This has given me the opportunity to get a sense of where people think science hype comes from. Who is to blame? The answer is almost always the same: the media. Of course, the reality is much more complex. While the popular press plays a role, they are only one part of a complex hype pipeline (Caulfield and Condit 2012). Indeed, the sources of science hype are numerous. And there is a complex and dynamic interplay between many of the actors, including the research funders, scientists, research institutions, the media, patients, and, of course, the public.

It could be argued that in some fields, including genetics, the hype starts well before the first research grants are written. In the 1980s, when researchers were lobbying for a large envelope of federal funding for the Human Genome Project (HGP), the idea was sold to politicians on the back of a promise of near-future revolutionary technologies and cures. After the funding started to flow, Francis Collins, who was the director of the HGP, called the initiative "the most important organized scientific effort that humankind has ever attempted. It dwarfs going to the moon" (Shreeve 1999, 55). That is a lot of hype. Naturally, that kind of language helps to frame how researchers, institutions, and the public talk about the field and their work. Expectations must be met, and funding must be maintained. In a research environment increasingly dominated by big science initiatives that compete with each other for long-term funding (I once had a senior, well-known genetics researcher tell me to stop criticizing the clinical value of personalized medicine or the money will go to stem cells) and intensifying commercialization pressure (research is increasingly framed as an engine of economic growth; Caulfield and Ogbogu 2015), it is no surprise that it now seems the norm to build research areas on a foundation of overpromise—where every emerging area of biomedicine is a revolution that will transform public health, patient care and the economy (Caulfield 2010).

This hype-infused vision of near-future benefit is further institutionalized at the stage of grant writing. If researchers want money, they must play to the expectations created by the initial, big-science ask to government. And they must do so in a hyper-competitive environment, fully aware that their grant-writing colleagues, against whom they will be measured, will also be playing to the heightened expectations. If funding is to be obtained, they must embrace the hype. Given these system pressures, it is no surprise that researchers often stretch the truth, particularly about the social impact of the work, in order to help secure research funding. A 2017 study involved anonymous interviews with senior researchers about the research grant process and, in particular, the writing of the future impact part of applications (Chubb and Watermeyer 2017). Many of the

interviewees admitted to flat-out lying, noting that their predictions of near-future impact were "charades" and "made-up stories" that were stated merely to help them "get the money" (Matthews 2016). The authors of the study came to the harsh conclusion that the unrelenting pressure to produce impressive outcomes "is resulting in impact sensationalism and the corruption of academics as custodians of truth" (Chubb and Watermeyer 2017).

The distortion of science also happens in the laboratory and during the writing up of results. There is a rich body of literature explicating the innumerable biases—large and small—that influence the execution of the research and the publication of results, virtually all of which cause a further emphasis on benefits and overly optimistic projections of clinical translation. I won't review the science behind these well-known forces, but it is worth mentioning some of the more overt, and less known, ways in which hype is injected into the representation and publication of research results. Numerous studies have found, for example, that abstracts—which, other than the title, are the most commonly read part of an article (Bastian 2014)—are often written in excessively optimistic terms (Chiu, Grundy, and Bero 2017). A 1999 analysis of the abstracts in the top medical journals found spin to exist in all the publications, ranging from 18% to as high as 68% of the total number of abstracts. A 2017 scoping review of the existing literature on this point found that 39% of biomedical abstracts had at least some degree of spin (Li et al. 2017). Some studies put the rate much higher. For example, an analysis of the spine research literature found that, over a 10-year period, 75% of the articles had at least one discrepancy between the main manuscript and the abstract (Lehmen et al. 2014).

Once a study is published, the next step along the hype pipeline is the press release, a document that is usually written by the research institution's public relations department with varying degrees of input from the associated researchers. As with abstracts, the available evidence tells us that there is a significant amount of hype in these documents (Woloshin et al. 2009). This is, of course, no surprise. There are strong incentives for research institutions to promote the work done by their academics. Heightened exposure in the popular press can help increase the public profile of an institution, facilitate support from government, and help attract private donations. Still, from the perspective of knowledge translation, hyped press releases can hardly be viewed as a constructive influence. Indeed, if forced to pick an instrument most responsible for science hype in media, it might be reasonable to point a finger at the institutional press release. A 2014 study by Sumner and colleagues analyzed 462 press releases on biomedical and health-related issues and compared them to the associated peer-reviewed article and the related articles in the popular press. They found that 40% contained exaggerated health advice, 33% had exaggerated causal claims, and 36% contained exaggerated inferences about animal studies. More important, the study found that this hype was translated into the popular press. In other words, it is often the institutional

press release—and not journalistic interpretation—that is the primary source of the science hype.

The idea that scientists and research institutions are a primary source of the hype in the media has been suggested by other studies. For example, a content analysis of newspaper stories on stem cell research found significant hype about how soon the research would be translated into the clinic, with almost 70% of the articles stating it would occur within five to ten years, or sooner (Kamenova and Caulfield 2015). This study also found that the dominant voice behind these highly optimistic timelines was the scientific community. Still, there is no doubt that the media also introduces another level of hype. A study of media reports of cancer genetics research found that while institutional press releases injected hype, media reports injected even more (Brechman, Lee, and Cappella 2011). In addition, in the context of genetics, the popular press seems to be a significant contributor to a particular kind of deterministic hype—that is, overemphasizing the strength or influence of genes on human traits and disease (Caulfield and Condit 2012).

Of course, the news media is also responsible for the tone and content of the relevant headlines. (Editors, not the relevant journalist, write headlines.) And—no surprise—there is a significant amount of science hype to be found in this most visible part of a news article. A 2004 study of the headlines associated with newspaper stories about genetic discoveries found that "the headlines were twice as likely as newspaper stories to moderately or highly exaggerate the claims made in the source science article" (Caulfield and Bubela 2004, 55). While this may seem an obvious conclusion, it shouldn't be forgotten that most people don't read beyond the headlines (Cillizza 2014). Whether reading an article on a smart phone, on Facebook, or on a Twitter feed, the headline is what is read first, and it has an impact. Headlines shape how people interpret the article, steering readers toward a particular understanding of the information (Ecker et al. 2014). The power of the headline has intensified in the era of social media, where most people share news articles without reading beyond the title. A 2016 study of over 2.8 million Twitter shares found that most people (59%) never open the associated hyperlink (Gabielkov et al. 2016). In other words, most people share news based solely on the information in the headline. In the context of health news, this means that what is getting the most distribution and attention is the assertions of "breakthroughs," "revolutions," and "cures" that dominate the headlines rhetoric.

It is important to recognize that much of science hype happens without intention or even conscious effort. While there is, no doubt, at least some overt lying or knowingly deployed hyperbole, much of the hype is the result of subtle pressures and incentive structures that nudge all the actors in the knowledge production pipeline toward exaggeration. Even the press offices at research institutions rarely believe that their press releases are representing science inappropri-

ately. An interesting qualitative study by Samuel, Williams, and Gardner (2017) involved interviews with senior press officers at numerous research institutions in the UK. They asked the press officers about press releases related to news stories about fMRI research—which, from an objective point-of-view, clearly seemed hyped. Contrary to what an empirical analysis found concerning the news reports' tendency to exaggerate relevant fMRI benefits (Samuel and Kitzinger 2013), the press officers felt that both the press releases and associated news articles were appropriately balanced and accurate. This is because, Samuel, Williams, and Gardner conclude, press officers define hype and balance differently due to their professional vision. They don't see their work as producing inappropriate exaggeration of the science, but, rather, as the responsible execution of their professional role within the broader institution.

Once a hyped narrative hits the popular press it can become ubiquitous, normalized, and increasingly resistant to critical appraisal. If a hyped message is repeated enough, it becomes a truism that is regurgitated by the popular press without any effort to reflect on the accuracy of the original claims. A study I did with my colleagues Christen Rachel and John Rasko on news media representations of platelet rich plasma (PRP) therapy highlights how this can play out (Rachul, Rasko, and Caulfield 2017). We analyzed 307 articles and found that the therapy is almost always portrayed as routine (66.4%) or cutting edge (21.8%). PRP is rarely described experimental (11.7%)—which is, in fact, the most accurate description. More important, these stories were almost always about celebrities and sports stars (75%) and often referenced PRP in a manner that assumed the therapy was effective. Indeed, when it was a sports story, 82.8% of the articles framed PRP as routine, and only 5.2% as experimental. This phenomenon—which we termed "implicit hype"—happens in the realm of personalized medicine too. The idea that consumer products should be personalized in order to maximize benefit is taken as a given. The media talks about genetically personalized skin creams, hair products, diets, and workout routines as if, despite a lack of evidence to support the claims, it is accepted by all concerned that this kind of individualized approach is more effective than existing, more generalizable, strategies (Gayle 2018; Rahman 2014).

There are, of course, may other forces that contribute to the spinning of research in the public domain, including, inter alia, the scientific bandwagon, the hot stuff bias, and the emergence of predatory journals, which facilitate the spread of poor and overly optimistic science (Catalogue of Bias Collaboration 2017; Caulfield and Condit 2012). Taken together, there is the potential for the injection of hype throughout the research and publication process. And since all of the actors are complicit collaborators—that is, they all benefit, at least in the short term, from the production of an enthusiastic message—there are few, if any, social forces moderating the messaging.

Recognizing that Hype Matters

We have seen that there is growing recognition that hype is ubiquitous and that the sources of hype are numerous, interrelated, and complex. But there is also growing recognition that it can cause real harm, including potentially eroding public trust and support for science; inappropriately skewing research priorities and the allocation of resources and funding; creating unrealistic expectations of benefit for patients; facilitating the premature uptake of expensive and potentially harmful emerging technologies by health systems; misinforming policy and ethics debates; and accelerating the marketing and utilization of unproven therapies (Bubela 2006; Caulfield 2016; Caulfield et al. 2016; Diamandis and Li 2016; Evans et al. 2011; Martin, Brown, and Turner 2008; Master and Resnik 2013; Petersen and Krisjansen 2015).

More broadly, hype may also have an impact on how we think about health and deal with disease. In the context of personalized medicine, for example, the unrelenting hype may result in a capturing of research funds and health-care resources in a manner that has long-term implications for public health policy, causing an inappropriate shift toward individualized (and usually less successful and equitable and more ethically fraught) approaches to health and away from society level interventions (Adams et al. 2016; Árnason 2012; Tedstone 2016). Jack James (2014), a professor of psychology at Reykjavík University, nicely summarizes this issue:

> A mix of excessive confidence in personalised medicine, high expectations of benefits, perceived commercial opportunities, and insufficient attention to harmful consequences has the potential to ''colonise the future'' of healthcare, wherein attention and resources are captured at the expense of alternative behavioural and social pathways that have the potential to effect greater improvements in population health.

Countering science hype will not be easy. But recognizing that there are forces that twist the message throughout the research process—from advocating for funding to the publishing of peer-reviewed papers to the writing of media stories—is an important start. Each step along the hype pipeline may require a unique policy response. We may, for example, want to think about ways to ensure abstracts and press releases are more balanced and accurate. And we could explore strategies to counter hype that emerges in the popular press and on social media. More ambitiously, there are reasons to consider how we might shift the incentive structure that underpins the scientific process. The profoundly competitive nature of academic research invites the injection of hyperbole and the overpromise of near-future benefit. What can be done, if anything, to counter the negative consequences of this competitive environment?

More research on the nature and scope of the hype problem is necessary to inform the development of policy responses. Still, given the magnitude and potential ramifications, there are steps that should be taken immediately. A good place to start: frame the knowing hyping of research as an unethical departure from the norms of science. In 2016 the International Society for Stem Cell Research published new research guidelines. In response to the growing concern about science hype, the new guidelines, which I was involved in writing, include a section on science communication that requires the research community to "promote accurate, balanced, and responsive public representations" of their work. The guidelines also suggest that it is the responsibility of researchers to monitor how their work is represented in the public sphere and to work with the communication experts at their institutions to create information resources that "do not underplay risks and uncertainties." The guidelines seek to make the avoidance of hype a standard part of knowledge translation, noting that "care should be exercised throughout the science communication process, including in the presentation of results, the promotion of research and translation activities, the use of social media, and any communication with print and broadcast media."

Being excited about new science and emerging technologies is understandable. Enthusiasm can help to build teams, raise funds, and create the momentum necessary to make big, challenging research initiatives happen. Science isn't easy, and a bit of cheerleading can be a good thing. But when enthusiasm slips into misrepresentation, it helps no one—at least in the long term.

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