Health Misinformation and the Power of Narrative Messaging in the Public Sphere

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I. Introduction

There is growing recognition that numerous social, economic and academic pressures can have a negative impact on representations of biomedical research. Empirical evidence indicates spin or interpretive bias is injected throughout the knowledge production process, including at the stage of grant writing, in the execution of the research, and in the production of the relevant manuscripts and institutional press releases [Boutron and Ravaud, 2018; Caulfield and Condit, 2012; Yavchitz et al., 2012]. The popular press, marketing forces, and online media also play significant roles in misrepresenting biomedical research [Caulfield and Condit, 2012; Kamenova, Reshef, and Caulfield, 2014; Turner and Knoepfler, 2016; Van Atteveldt, Van Aalderen-Smeets, Jacobi, and Ruigrok, 2014]. Here, the wilful or unintended dissemination of misinformation through increasingly interactive media platforms also stands as a very real and growing concern [Anderson and Rainie, 2017; Edelman, 2018] and presents a significant challenge to generating rational, evidence-based conversations about biomedicine generally, and its benefits and risks, in particular.

Exacerbating these forces, numerous trends have emerged which further problematize the science communication landscape, especially in the context of health. In this commentary, we review several of the forces playing an increasingly pernicious role in how information is interpreted, shared and used. In particular, we focus on the role that narrative plays in communicating science and misinformation to explore how aspects of narrative are used in different social contexts and communication environments. While most people have an inherent understanding of storytelling, narrative has been defined as a type of communication that "describes the cause-and-effect relationships between events that take place over a particular time period that impact particular characters" [Dahlstrom, 2014]. Narrative is a powerful tool that can enhance engagement and understanding of both truths and falsehoods [Glaser, Garsoffky, and Schwan, 2009]. Online, and specifically in the context of misinformation (e.g. conspiracy narratives, pseudoscience, etc.), research has shown that the construction and dissemination of narratives requires the efforts of numerous participants with differing levels of engagement [Introne, Yildirim, Iandoli, Decook, J, and Elzeini, 2018]. It is dynamic, incorporating numerous discursive elements (multiple sources, hashtags, hyperlinks, memes, etc.) as well as flexible, adopting and discarding both story elements and participants as time passes [Introne, Yildirim, Iandoli, Decook, J, and Elzeini, 2018].

This commentary is not meant to be a comprehensive survey of emerging health communication developments or an exhaustive account of the role that narrative plays in that context. Rather, we highlight elements that have increasingly troubled health communication in recent times, and present creative responses that may help counter the negative trends. Indeed, as we will see, traditional methods of communication have in many ways failed the public, and changes in approach are required.

II. Online Communities

Much has been written about the growing influence of social media on public discourse, including in the context of health [Smailhodzic, Hooijsma, Boonstra, and Langley, 2016]. While traditional news outlets – such as newspapers – remain the dominant source of science information [Funk, Gottfried, and Mitchell, 2017], social media platforms, including Facebook, Twitter, Instagram, YouTube and Reddit, have become important sources of health information and sites for public engagement and community-building [Centola, 2010; De Choudhury and De, 2014; De Choudhury, Morris, and White, 2014; Fernández-Luque and Bau, 2015; Guilbeault, Becker, and Centola, 2018] . Studies show younger generations are more willing to share health information about themselves online than older generations, and people of all generations increasingly go online to seek others with similar health concerns or conditions for information and support [Graham, Cobb, and Cobb, 2016]. All age groups in North America use social media heavily [Gruzd, Jacobson, Mai, and Dubois, 2018; Smith and Anderson, 2018], so the influence of social networking platforms is likely to grow.

We know, however, that the health and science information on these platforms is often problematic [Antheunis, Tates, and Nieboer, 2013; Madathil, Rivera-Rodriguez, Greenstein, and Gramopadhye, 2015]. Research has found, for example, that social media

are used to spread harmful health messages, including, to cite just a few examples, antivaccine rhetoric [Dunn, Leask, Zhou, Mandl, and Coiera, 2015; Tomeny, Vargo, and El-Toukhy, 2017], misinformation about the Zika virus [Sharma, Yadav, Yadav, and Ferdinand, 2017] and Lyme disease [Basch et al., 2017], as well as Ebola-related prevention and treatment strategies [Oyeyemi, Gabarron, and Wynn, 2014]. Alarmingly, a 2018 study of millions of Twitter interactions over a ten-year period found that falsehoods diffused "farther, faster, deeper and more broadly" than the truth [Vosoughi, Roy, and Aral, 2018]. And while some recent research has indicated notions of the "echo chamber" might be overstated [Dubois and Blank, 2018; Flaxman, Goel, and Rao, 2013], online environments do exhibit polarization characteristics and are spaces where misinformation can spread virally [Del Vicario et al., 2016]. Information dissemination through the public is incredibly complex. While offline interactions in community settings such as clubs, organizations and social groups still carry significant weight, social media also clearly impacts bioscience communication. This impact affects not only the general public but also research funding and policy [Chafe, Born, Slutsky, and Laupacis, 2011; Pullman, Zarzeczny, and Picard, 2013].

Social media consists of diverse communication ecosystems, shaped by the algorithmic logistics of each particular platform, use by varied demographics, and the resulting creation of unique communication trends and patterns. A core component shared by these ecosystems is the dynamic of "social homophily", which explains how people more commonly associate, and are more influenced by, those similar to themselves [Centola, 2010; Guilbeault et al., 2018; McPherson, Smith-Lovin, and Cook, 2001; Sunstein, 2017]. The clustering of individuals online into various communities places importance on the role that public intellectuals, celebrities, or influencers can play in knowledge transmission [Caulfield, 2015; Freberg, Graham, McGaughey, and Freberg, 2011; Khamis, Ang, and Welling, 2017], while platform algorithms are also becoming increasingly influential in shaping how information circulates [Muchnik, Aral, and Taylor, 2013; Striphas, 2016].

In more contentious social contexts, groups or communities invested in shaping public perceptions around particular topics can form, and at times, sharp divisions can emerge between various groups with differing perspectives. For example, research has shown that invested parties can create "discourse coalitions" [Hajer, 2002; Metze and Dodge, 2016], making use of communal terms and arguments to promote their causes [Attwell, Smith, and Ward, 2018; Marcon and Caulfield, 2017; Smart, 2011; Yardi and Boyd, 2010]. Here, heuristics such as confirmation bias [Stanovich and West, 2000] and information avoidance [Golman, Hagmann, and Loewenstein, 2017] can enforce established beliefs. Research has shown there is polarization between antagonistic discourse communities [Schmidt, Zollo, Scala, Betsch, and Quattrociocchi, 2018; Sunstein, 2017; Yardi and Boyd, 2010], raising questions about how to get differing groups to communicate effectively and also, importantly, how to accurately and truthfully disseminate information to all groups [Lazer et al., 2018; Sunstein, 2017; Yardi and Boyd, 2010]. This matter is becoming increasingly complicated with the rise of misinformation, which, in the modern media landscape, has taken on the popular reference or label of "fake news" [Lazer et al., 2018; Silverman, 2016] . Research has

also shown that fake news impacts everyone – even those who know the information to be false [Fazio, Brashier, Payne, and Marsh, 2015]. Indeed, mere exposure to information can influence belief [Jolley and Douglas, 2014] and repeated exposures can strengthen perceptions of authenticity [Henkel and Mattson, 2011; Pennycook, Cannon, and Rand, 2018]. Online bots (software robots) are also playing a role by taking advantage of platforms' algorithms to promote particular stories, events or narratives, drown out others, and influence online social ecosystems in ways that will require ongoing monitoring and research [Ferrara, Varol, Davis, Menczer, and Flammini, 2016; Lazer et al., 2018; McKelvey and Dubois, 2017].

A growing body of literature suggests that narratives can have tremendous sway. Across disciplines, studies have shown how narratives facilitate recall [Dahlstrom, 2014; Neimand, 2018] and spur emotional responses [Aldama, 2015; Barraza and Zak, 2009; Morgan, Movius, and Cody, 2009; Yoo, Kreuter, Lai, and Fu, 2014; Zak, 2015], which in turn can increase empathy [Barraza and Zak, 2009; Dahlstrom, 2014; Yoo et al., 2014] and perceptions of a source's trustworthiness [Cialdini, 2007; Farmer, McKay, and Tsakiris, 2014]. Narratives therefore possess some power of persuasion [Braddock and Dillard, 2016; Cialdini, 2007; Jones and Crow, 2017], whether that be to solidify one's membership in a particular identity group [Jones and Crow, 2017; Neimand, 2018] or merely to draw one towards a particular perspective [Braddock and Dillard, 2016]. Recent research has shown how misinformation, and even credible information interpreted and then skewed in a particular manner, can serve as a means of substantiating a particular narrative [Introne et al., 2018]. As a result, a narrative can gain strength from the supportive "evidence" it creates and draws upon [Introne et al., 2018].

Social media platforms have become powerful tools for sharing narratives about therapies [Du, Rachul, Guo, and Caulfield, 2016], experiences [Han and Wiley, 2013] and emerging science. Social media also allows individuals to form parasocial relationships or "digital buddies" [Yuksel and Labrecque, 2016], which may heighten the influence of messaging [Chung and Cho, 2017] and strengthen social homophily. Indeed, research has noted that "a person like you" is just as credible a source of information as an academic or technical expert [Edelman, 2017]. Not all participation in online communities is necessarily negative. For instance, a platform like patientslikeme® allows individuals with similar conditions to share experiences and receive support, which in turn can help them cope with depression and overcome social stigma [De Choudhury et al., 2014; Graham et al., 2016; Griffiths et al., 2015]. However, when narratives generate emotional and empathetic responses on social media, both the source and the information presented can gain authority and traction, regardless of how reliable or accurate they may be [Morgan et al., 2009].

III. Implicit Hype and "Scienceploitation"

The phenomenon of science hype – the exaggeration or excessive promotion of scientific developments and applications – is getting more attention from the scientific community [Marcon, Bieber, and Caulfield, 2018; Master and Resnik, 2013] and popular media[Wetsman, 2018]. The sources of this hype are complex and interrelated, and they

exist throughout the knowledge production pipeline [Caulfield and Condit, 2012]. Science hype can cause a range of social issues, including, *inter alia*, eroding public trust [Master and Resnik, 2013] , confusing policy debates [Pullman et al., 2013], and facilitating the premature implementation of technologies and the marketing of unproven therapies [Caulfield, Sipp, Murry, Daley, and Kimmelman, 2016; Petersen and Krisjansen, 2015]. While the problems with explicit hype are increasingly recognized, we are now seeing the growth of a more subtle form of hype.

The popular press, for example, sometimes presents emerging therapies in a manner that implies efficacy [Rachul, Rasko, and Caulfield, 2017]. This "implicit hype" occurs when unproven or even disproven interventions are presented as routine and/or uncontroversial in media reports. For example, recent research about the media portrayal of platelet rich plasma (PRP), an unproven therapy for various ailments including musculoskeletal injuries, found that it was most commonly covered in sports-related stories, and specifically in relation to elite athletes using the therapy as part of injury recovery or performance preparation [Rachul et al., 2017]. The therapy was portrayed as routine, and its use by elite athletes may imply that it is a cutting edge treatment [Rachul et al., 2017].[81] But given the actual state of research surrounding PRP [Engebretsen et al., 2010; Moraes, Lenza, Tamaoki, Faloppa, and Belloti, 2014], these representations are implicit hype. These stories may have significant sway with the public as they combine high exposure (story about a professional athlete in popular media), an interesting narrative (athlete recovering from injury), and a suggestion that an emerging therapy is efficacious. Since narrative communication is persuasive, this implicit hype may be more resonant with most audiences than typical communications about the unproven nature of a therapy.

Another issue is that of pseudoscience, that is to say theories, assertions or interventions that claim or appear to be scientific but are not. Pseudoscientific phraseology is too often accepted in popular media without any critical reflection. A recent study of Spanish science journalists found that only 44.9% agreed that pseudoscientific information in the media is dangerous, with many respondents dismissing concern or expressing apathy as to the effects of false messaging in the media [Cortiñas-Rovira, Alonso-Marcos, Pont-Sorribes, and Escribà-Sales, 2015]. Journalistic apathy the distinction between science and pseudoscience can only further hinder public understanding of novel health or biomedical developments, especially in cases where the l public only has basic knowledge about the topic at hand.

There are also explicit marketing strategies that leverage hype. Recent research has shown, for example, that some complementary and alternative medicine (CAM) providers combine hype and stem cell language in their marketing for both unproven stem cell therapies and other pseudoscientific products and therapies [Murdoch, Zarzeczny, and Caulfield, 2018]. For instance, the language of quantum physics [Szeto, Tomlinson, and Smart, 2018], genetics [Caulfield et al., 2015], and microbiome research [Bowles, 2017] have been used to market therapies that have not been scientifically tested. By capturing the interest around the scientific domain of stem cells, marketers can increase the attractiveness of, and exposure to, their products – even if they have no actual relation to stem cells. This phenomenon, which we call "scienceploitation", occurs

in many contexts but is understudied [Murdoch et al., 2018]. Because this type of misrepresentation uses language that can confer scientific legitimacy, it can be particularly difficult to address, especially if it is accompanied by other tokens of legitimacy (e.g., reference to publications in predatory journals or registered clinical trials) [Sipp et al., 2017] and is part of a broader, memorable narrative.

IV. Patients in the Public Sphere

Patients are also harnessing the power of the narrative to promote public awareness, build community and raise money and a profile for certain therapies. For example, the use of online crowdfunding has recently grown at an explosive rate [Massolution, 2015; Young and Scheinberg, 2017]. Health related crowdfunding has proven to be a highly competitive affair, and campaign leaders often attempt to construct "worthy bodies" that justify or morally compel donation [Paulus and Roberts, 2017]. In this way, the creation of powerful and compelling narratives is a key aspect of successful crowdfunding [Berliner and Kenworthy, 2017; Kim, Hong, and Karahalios, 2018; Kim, Kong, Karahalios, Fu, and Hong, 2016]. A similar effect can occur with public solicitation for organ donation, where patients can be judged not only on their personal appearance but also the biographical narratives they create to engender sympathy [McGee, 2005; Neidich, Neidich, Cooper, and Bramstedt, 2012].

Narratives often include information about the interventions sought and their efficacy, creating problems when these interventions are unproven or pseudoscientific. Indeed, recent research has shown that the narratives of crowdfunding campaigns for unproven stem cell therapies "underemphasize risks", "exaggerate the efficacy" and "convey potentially misleading messages about stem-cell based interventions" [Snyder, Turner and, Crooks, 2018].

These examples show another way in which persuasive narratives can mislead. Marketing can extend into the personal narratives of individuals seeking aid, as campaigns often propagate the marketing language of the clinics where treatment is sought [Snyder et al., 2018]. This can act as a legitimizing force for unproven interventions, and legitimacy is subsequently reinforced when popular media outlets publish uncritical human-interest stories about such campaigns [Murdoch, Marcon, Downie, and Caulfield, forthcoming].

V. Policy Options

As noted, science communication is happening in the context of a research pipeline full of hype [Caulfield and Condit, 2012], a media environment rife with ambiguity and false balance [Clarke. 2008; Dixon and Clarke, 2012; Friedman, Dunwoody, and Rogers, 2012], and an online environment marred by fake news [Lazer et al., 2018; Silverman, 2016]. Meanwhile, the potential sway of the misinformation is often heightened by the use of engaging narratives. These forces add to the complexity of crafting effective, evidence-based policy responses. Complicating things further is the reality that not all audiences are impacted by narratives in the same manner or to the same degree. Some

research has shown, for example, that audiences engaging a topic peripherally are more likely to find testimonials more convincing and persuasive than those highly motivated to engage the topic and analyze the information [Braverman, 2008]. With a wide range of audiences encountering numerous and diverse topics in popular media at any given time, the role of narrative is likely having some impact on how the public makes sense of biomedical issues – particularly in the contexts of nascent, developing science and health topics about which little is known.

Addressing the spread of misinformation through persuasive narratives seems essential, though it will not be easy. Many of the entities that twist information operate over the Internet. When online sources and communities come under fire, they can quickly and easily spring up in a new form elsewhere. The law can be an unwieldy, slow and overly blunt tool in the face of amorphous messaging and shifting actors. Still, existing legal and regulatory tools can have important roles to play in the right contexts. We must better enforce existing truth in advertising law, which can act to curb misrepresentations in marketing and the proliferation of unproven and disproven treatments [Murdoch et al., 2018; Ogbogu, 2015; Sipp et al., 2017]. Given this is a complaint driven regulatory framework, non-profit organizations and individuals can play an important role, as we have seen, for example, with recent claims of false advertising made against Goop by the non-profit group Truth in Advertising [Helmore, 2017]. The law of negligent and fraudulent misrepresentation is also useful for all manner of claims that are false and relied upon [Caulfield, Ogbogu, and Robertson, 2015]. And when health care professionals are involved, as is often the case [Murdoch, Carr, and Caulfield, 2016], governing regulatory bodies should take steps against members who breach practice norms through the provision of misleading information [Zarzeczny A, Caulfield T, Ogbogu U., et al. 2014; Munsie and Hyun, 2014].

Despite these useful avenues, law and policy have limits. They can be slow, expensive, and, when government action is needed, constrained by political considerations. As such, more informal policy responses should also be considered. Individual public advocacy, at both the grassroots level and among prominent experts, can have a significant effect [Abbott, 2015; Phillips, 2017; Scientific American (Editors), 2018)]. For example, David Stephan, whose son died of meningitis in 2016 after his parents treated him solely with "natural remedies", was removed as a keynote speaker from a wellness exposition in Western Canada after backlash on Twitter caused many corporate event sponsors to threaten to pull out if he was left on the program [Mattern, 2018]. One important aspect of this success story was the timeliness of the critical response online. Real time social media interventions that rapidly counter misinformation are needed to ensure that belief systems founded on misinformation do not take hold [Tomeny et al., 2017]. Codified standards, norms, and guidelines in the scientific community defining appropriate media engagement – as some scientific societies have begun to develop [International Society for Stem Cell Research, 2016] – are imperative to encourage a sense of responsibility to engage with misinformation in the public sphere and correct it.

Importantly, it should also be possible to use a narrative communication style to improve public understanding of evidence-based medicine, both through social media and more

traditional avenues. The power of social media and the impact of narrative are prevalent and strong, so there is an imperative to strategically draw on their advantages to counter some of their more problematic applications. For example, research has shown that narratives presenting the ramifications of not vaccinating – specifically children's suffering from preventable illness – can have a real impact on intention to vaccinate [Shelby and Ernst, 2013; Capurro, Greenberg, Dubé and Driedger, 2018]. Additionally, clear and definitive statements with a narrative component, made by respected and trusted voices will prove highly useful, and also provide dependable resources upon which journalists can rely.

Opinion editorials offer another useful pathway for narrative communication – indeed, recent research has found them to have an influence on public perception [Coppock, Ekins, and Kirby, 2018]. That said, science writing could also benefit from narrative style, if applied in a manner that does not compromise the truthfulness and comprehensiveness of the content [Perrault, 2013]. We shouldn't use narratives to fight anecdote with anecdote. Rather, narratives can serve as a vehicle to communicate science and relevant science-informed policy in a more engaging and digestible manner. The spread of misinformation causes real harm. Unfortunately, countering this noise is growing increasingly more complex and challenging. It will require the use of a host of science communication tools and strategies, including the creative use of narratives.

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