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Résumé de l'article

De nombreuses pressions sociales, économiques et académiques peuvent avoir un impact négatif sur les représentations de la recherche biomédicale. Nous passons en revue plusieurs des éléments qui jouent un rôle de plus en plus pernicieux dans l'interprétation, le partage et l'utilisation de l'information sur la santé et les sciences; ce qui nous mène à nous intéresser au rôle du récit. Par conséquent, nous explorons comment les aspects narratifs sont utilisés dans divers contextes sociaux et environnements de communication, puis présentons des réponses novatrices susceptibles de contribuer à contrer les tendances négatives. Comme les méthodes de communication traditionnelles ont échoué à bien des égards auprès du public, des changements d'approche s'imposent, dont l'utilisation novatrice des récits.

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COMMENTAIRE CRITIQUE / CRITICAL COMMENTARY (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

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

Timothy Caulfield¹, Alessandro R. Marcon², Blake Murdoch², Jasmine M. Brown³, Sarah Tinker Perrault⁴, Jonathan Jarry⁵, Jeremy Snyder⁶, Samantha J. Anthony⁷, Stephanie Brooks⁸, Zubin Master⁹, Christen Rachul¹⁰, Ubaka Ogbogu¹¹, Joshua Greenberg¹², Amy Zarzeczny¹³, Robyn Hyde-Lay²

Résumé

De nombreuses pressions sociales, économiques et académiques peuvent avoir un impact négatif sur les représentations de la recherche biomédicale. Nous passons en revue plusieurs des éléments qui jouent un rôle de plus en plus pernicieux dans l'interprétation, le partage et l'utilisation de l'information sur la santé et les sciences; ce qui nous mène à nous intéresser au rôle du récit. Par conséquent, nous explorons comment les aspects narratifs sont utilisés dans divers contextes sociaux et environnements de communication, puis présentons des réponses novatrices susceptibles de contrer les tendances négatives. Comme les méthodes de communication traditionnelles ont échoué à bien des égards auprès du public, des changements d'approche s'imposent, dont l'utilisation novatrice des récits.

Mots-clés

communication en santé, communication scientifique, réseaux sociaux, récit, santé publique

Abstract

Numerous social, economic, and academic pressures can have a negative impact on representations of biomedical research. We review several of the forces playing an increasingly pernicious role in how health and science information is interpreted, shared, and used, drawing discussions towards the role of narrative. In turn, we explore how aspects of narrative are used in different social contexts and communication environments, and present creative responses that may help counter the negative trends. As traditional methods of communication have in many ways failed the public, changes in approach are required, including the creative use of narratives.

Keywords

health communication, science communication, social media, narrative, public health

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 [1-3]. The popular press, marketing forces, and online media also play significant roles in misrepresenting biomedical research [2,4-6]. Here, the wilful or unintended dissemination of misinformation through increasingly interactive media platforms also stands as a very real and growing concern [7,8] 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 complicate 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” [9]. Narrative is a powerful tool that can enhance engagement and understanding of both truths and falsehoods [10]. Online, and specifically in the context of misinformation (e.g., conspiracy narratives, pseudoscience), research has shown that the construction and dissemination of narratives requires the efforts of numerous participants with differing levels of engagement [11]. 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 [11].

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. While many of the concerns and ideas presented herein are broadly relevant across many jurisdictions with advanced communication infrastructures, our focus is on the United States and Canada. 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.

Online Communities

Much has been written about the growing influence of social media on public discourse, including in the context of health [12]. While traditional news outlets, such as newspapers, remain the dominant source of science information [13], 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 [14-18]. Studies show younger generations are increasingly willing to share personal health information online, and people of all generations increasingly go online to seek

others with similar health concerns or conditions for information and support [19]. All age groups in North America use social media heavily [20,21], so the influence of social networking platforms will continue to be significant.

We know, however, that the health and science information on these platforms is often problematic [22,23]. Research has found, for example, that social media are used to spread harmful health messages, including, to cite just a few examples, antivaccine rhetoric [24,25], misinformation about the Zika virus [26] and Lyme disease [27], as well as Ebola-related prevention and treatment strategies [28]. Studies have also shown that falsehoods can diffuse “farther, faster, deeper and more broadly” than the truth [29], and while notions of the “echo chamber” might be overstated [17,30], online environments do exhibit polarization characteristics where misinformation can spread virally [31].

Social media also clearly affects bioscience communication, and this influences not only the general public’s understanding of health and science information but also research funding allocation and policy development [32-34]. Clinicians, scientists and funding institutions can all experience pressure to fund research or change policy in response to social media advocacy. For example, roughly 10 years ago a large online community advocated in Canada for an unproven and scientifically implausible intervention for multiple sclerosis called “liberation therapy”, based on anecdotal evidence that it could generate life-altering improvements for people afflicted by the condition [32]. This pressure led the Canadian Institutes of Health Research in 2010 to convene an expert panel on the topic [32,33], and allocate funds to conduct research, the resulting data of which showed the treatment to be ineffective [35].

Social media consists of diverse communication ecosystems, shaped by the algorithmic logistics of each particular platform. A core component shared by these ecosystems is “social homophily”: how people more commonly associate and are more influenced by those similar to themselves [14,18,36,37]. The clustering of individuals online into various communities highlights the role that algorithms as well as public intellectuals, celebrities, or influencers can play in knowledge transmission [38-42]. In more contentious social contexts, sharp divisions can emerge between various groups, resulting in the creation of “discourse coalitions” [43,44], where communal terms and arguments are used to promote perspectives [45-48]. Here, heuristics such as confirmation bias [49] and information avoidance [50] work towards enforcing rather than questioning established beliefs. Research has shown there is polarization between antagonistic discourse communities [37,48,51], raising questions about how to transmit accurate information through groups with differing perspectives [37,48,52]. This matter is becoming increasingly complicated with the rise of misinformation, or “fake news” [52,53]. Research has also shown that fake news affects everyone – even those who know the information to be false [54]. Indeed, mere exposure to information can influence belief [55] and repeated exposures can strengthen perceptions of authenticity [56,57]. 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 [52,58,59]. Continued research of online discourse is required, including on platforms such as Instagram, Reddit, YouTube, and blogs. These popular spaces exhibit novel and powerful uses of narrative and pose numerous methodological challenges, requiring collaborative interdisciplinary approaches.

A growing body of literature suggests that narratives can have tremendous sway. Across disciplines, studies have shown how narratives facilitate recall [9,60] and spur emotional responses [61-65], which in turn can increase empathy [9,60,62] and perceptions of a source’s trustworthiness [66,67]. Narratives therefore possess some power of persuasion [66,68,69], whether that be to solidify one’s membership in a particular identity group [60,69] or merely to draw one towards a particular perspective [68]. 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 [11]. As a result, a narrative can gain strength from the supportive “evidence” it creates and draws upon [11]. Social media platforms have become powerful tools for sharing narratives about therapies [70], experiences [71] and emerging science. Social media also allows individuals to form parasocial relationships [72], which may heighten the influence of messaging [73] 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 [74].

Not all participation in online communities is necessarily negative. Research has shown how interactive online networks can help to connect individuals seeking similar health information or dealing with similar conditions. Benefits from this connectivity include sharing information and receiving support, which in turn can help individuals consider health strategies or treatment options, build social networks, cope with depression, and overcome social stigma [16,19,75,76]. For example, Mumsnet.com, based in the UK, has approximately 5 million monthly visitors, who use the website to discuss a range of motherhood topics including miscarriage and breastfeeding [75]. On the platform [patientslikeme](https://www.patientslikeme.com)®, with over 600,000 members with nearly 3,000 different conditions, 30% of patients with epilepsy did not know someone with epilepsy prior to using the site [75]. Research has also shown that on a general non-health specific platform like Instagram, women congregate around breastfeeding related hashtags and images, creating supportive networks [77]. Questions remain, however, around the accuracy of information, especially when highly-personal narratives are generated and circulated [63]. Specifically in the case of vaccines, it is now well-known that anti-vaccination perspectives exist and are propagated through social media sites like YouTube and Facebook, the latter of which includes organized groups dedicated to this cause [78-81].

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 [82,83] and popular media [84]. The sources of this hype are complex and

interrelated, and they exist throughout the knowledge production pipeline [2]. Science hype can cause a range of social issues, including, *inter alia*, eroding public trust [83], confusing policy debates [35], and facilitating the premature implementation of technologies and the marketing of unproven therapies [85,86]. 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 [87]. 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 [87]. The therapy was portrayed as routine, and its use by elite athletes may imply that it is a cutting edge treatment [87]. But given the actual state of research surrounding PRP [88,89], these representations are implicit hype. These stories may have significant sway with the public as they combine high exposure (a story about a professional athlete in popular media), an interesting narrative (an 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 [90]. Journalistic apathy concerning the distinction between science and pseudoscience can only further hinder public understanding of novel health or biomedical developments, especially in cases where the 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 [91]. For instance, the language of quantum physics [92], genetics [93], and microbiome research [94] 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 [91]. 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) [95] and is part of a broader, memorable narrative.

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 [96,97]. 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 [98]. In this way, the creation of powerful and compelling narratives is a key aspect of successful crowdfunding [99-101]. 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 [102,103].

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” [104].

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 [104]. 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 [105].

Policy Options

As noted, science communication is happening in the context of a research translation process prone to hype [2], a media environment rife with ambiguity and false balance [106-108], and an online environment marred by inaccurate news [52,53]. 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 affected 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 [109]. 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 [85,91,110]. 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 [111]. The law of negligent and fraudulent misrepresentation is also useful for all manner of claims that are false and relied upon [112]. And when health care professionals are involved, as is often the case [113], governing regulatory bodies should take steps against members who breach practice norms through the provision of misleading information [114,115].

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 [116-118]. 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 [119]. 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 [25]. Codified standards, norms, and guidelines in the scientific community defining appropriate media engagement – as some scientific societies have begun to develop [120] – are imperative to encourage a sense of responsibility to engage with and correct misinformation in the public sphere. Further, influential and reputable voices from various communities need to persistently encourage responses from powerful social media platforms regarding their influential role in information dissemination [121]. Some positive responses from platforms are already evident [81,122,123], but these need continual monitoring. It also necessary for public health initiatives to move beyond the monitoring of online communities and begin developing ways to engage effectively with them, especially those existing on established and popular platforms outside of traditional public health institutions and practices.

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. To do so effectively will require health and science communicators to recognize the important research around “virality” [124-126] in terms of both information dissemination and interaction with platform algorithms, and to design communication strategies that use these findings to their benefit. Examples of this type of messaging are already evident [127] and can be drawn upon to experiment with new approaches. Further, scientists and science communicators new to social media should learn tactics and strategies from successful colleagues. The power of social media and the impact of narrative are prevalent and strong, so there is an imperative to strategically draw upon 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 [128,129]. 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 [130]. 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 [131]. We should not use narratives to fight anecdote with anecdote. Rather, narratives can serve as a vehicle not only to communicate science and relevant science-informed policy in a more engaging and digestible manner but to foster an understanding around “the process and credibility of scientific reasoning” [132]. 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.

Policy and communication responses

Legal and Policy tools

- Better enforcement of existing truth in advertising law, and/or improvements thereto
- Regulatory policy change and enforcement for health professionals spreading misinformation
- Policy outlining rules for and encouraging expert media engagement and the use of narrative
- Litigation

Social Tools

- Advocacy by non-profit organizations (e.g., litigation against Goop)
- Advocacy by individuals (official complaints, social media activism)
- Expert engagement in the popular press and on social media to counter misinformation
- Encouragement of social media companies to combat misinformation by modifying platforms
- Opinion editorials
- Use of creative communication strategies that utilize narratives, art, video, etc.
- Support and adoption of further research on effective communication strategies

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