Medical Communications and Writing for Patients

Dear All,

As I write this, at least some of us are likely to still be in some form of lockdown or quarantine. I pray that you and your families are all managing to stay as sane as possible, and I sincerely hope that you all stay safe and healthy.

In this first edition of 2021's *Medical Writing*, I am delighted to present a piece from Filippo Vitale and colleagues. This is a truly fascinating article that discusses how we have communicated science and scientific facts throughout history and how changes in society have affected how this is done and the outcomes that this has produced.

I found this article extremely thought-provoking (and at times a sad reflection of where we have come to as a global society) as the authors document and explain concepts like "clickbait" and "fake news". Whilst it was truly educational to understand the evolution of these concepts, I totally echo the authors' call to arms in their plea for us to be more aware of these phenomena and to do our utmost to counter them. As medical writers, we are uniquely placed to do this, and I consider it our duty to do so. What a way to start a new year!

In the meantime, stay safe and sane wherever you are, and see you in the next issue!

Bestest,
Lisa

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PUS, PEST, and clickbait: An exploration of scientific COmmunication and VIral Divulgation

The evolution of scientific communication and changes in society have led to the construction of a Public Engagement with Science and Technology (PEST) communications model. This model arose out of the perceived limitations of the "PUS" model, which was based on "public understanding of science" rather than an active engagement. In the PEST model, the general public is given the power of decision maker over scientific issues with a strong social impact. However, scientific communication has subsequently had to deal with the increasingly pervasive development of "network communication", in which scientific content suffers a significant distortion. Phenomena like "clickbait" (featuring a headline capable of triggering a level of curiosity in the reader that induces him/her to click on a link to open its contents) and fake news must be countered if the general public are to receive robust scientific facts.

Scientific communication from 1660 to today

The founding act of the first scientific society dates back to November 28, 1660, in London in the middle of the Enlightenment era. It was the Englishman John Evelyn who, together with other scholars, coordinated the establishment of the Royal Society. In his writing, in the form of a diary, Evelyn paid particular attention to the objectivity of the narrative (*Diary of the Fires and the Plague of London, Bray)*.[1] Already in 1665, the first issue of *Philosophical Transactions of the Royal Society* shows that scientific accreditation practices were established, which are still in force today and which we know as *peer reviewing*. From 1665 on, this particular practice spread gradually in other countries. In 1751, "planches", illustrated figures to facilitate the understanding of hypotheses and theories to a culturally oriented audience, were used for the first time in the *Encyclopedie ou Dictionnaire raisonné des sciences, des arts and des métiers*. In the nineteenth century, with the "*feuilleton scientifique*", the daily press began to deal with the dissemination of scientific content to the "average reader". It was the beginning of scientific dissemination. With the progressive refinement of technical equipment and research tools, the research process and dissemination of results became easier and quicker, and medical research results and scientific knowledge increased rapidly. The increasing complexity of the scientific content meant that scientific results were not easily understood by the general public. Rather, the difficulties of understanding scientific concepts caused confusion and diminished interest. With this came a new figure: the scientific journalist whose task was not only to simplify the scientific concepts, but to work at a linguistic level required to produce a widely accessible "translation" for the general public. Therefore "scientific communication", both intra-epistemic (between experts) and extra-epistemic (between competent specialists and general users), became itself a scientific domain with its own integrity as an object of research (in this way moving from the communication of science to the "science of communication"). In the 1940s, we witness the first introduction of the "Hypodermic Needle Theory".[2] For the first time what was initially intended as an opportunity, that of training and informing the general public, was seen as a power. The public was considered an inert mass that is easily penetrated by the media, which behaves like a hypodermic needle or magic bullet.[3,4] The general population is thus influenced in its behaviour and ideas by the propagandistic translation of some scientific concepts, deliberately manipulated or "injected" by the media.

This vertical relationship between the representatives of scientific knowledge and the general public over time and in response to the various subsequent sociopolitical changes, was replaced by a horizontal interaction model. In this new approach, the source of knowledge (scientists) and the object of disclosure (general public) were linked by the continuous return effects of the communication process.

In 1985, the Royal Society, with the publication of the Bodmer Report,[5] signalled the dangerous deterioration of the relationship between science and the general public. The countermeasures taken were aimed at the mutual recognition between the two fields, Knowledge and Information, of the laws and rules that

Box 1. Public Understanding of Science Model (PUS, Deficit Model)

- Unidirectional flow of information
- Mass audience, intended as a passive agglomeration with restricted cultural background
- Simplified, trivialised scientific information
- The flow of information oriented on cultural and cognitive social gaps, hypothesised, or measured

Box 2. Public Engagement with Science and Technology Model (PEST)

- Bidirectional flow of information
- Strong interaction between science and society
- The general public become the protagonists of the flows of scientific information.
- The interests and needs of the general public guide the trajectories of scientific research.
- Feedback as a powerful means of evaluating the product offered

structured the specific functioning of each. With the so-called PUS (Public Understanding of Science, Box 1), the aim was to increase the scientific and literacy knowledge of the public according to a linear flow model (Deficit Model). This disseminated communication takes place by direct osmosis, from a place where knowledge is most concentrated, to a place where it is strongly diluted, by means of appropriate media devices capable of "democratising" the contents. The creation of various scientific entertainment programmes dates back to this period (one example was Quark, a popular Italian television programme). In 2002, *Science* magazine decreed the end of the PUS period[6] with an editorial titled "From PUS to PEST". Thus, the transition to a new communication vision was sanctioned, that of "Public Engagement with Science and Technology" (Box 2). With the advent and diffusion of the internet, it was considered essential to directly involve the general public by giving them the power of "decision maker" on scientific issues with a major social impact.

In other words, the PEST model no longer aimed to encourage a simple understanding of science by the public but rather to arouse a widespread commitment to research topics through an open and equal discussion between scientists and non-experts. Research and scientific information were thus socialised. The goal was to promote engagement, a two-way integration between social dialogue and scientific development.

It is clear that the prerogative of the PEST model is to involve society so that it is possible to switch from "scientific research" to "scientific enterprise". The bidirectionality of communication flow, and the possibility of interaction through feedback, define social trends capable of affecting the direction of scientific research. In other words, society becomes a part of the "scientific construction". In this sense, scientific research may become a factory of "special products" (scientific information) that can be consumed and marketed. For this reason, disseminating scientific content to the widest possible audience becomes the nodal point and the most important link on the assembly line.

The PEST model was initially conceived as a permanent opportunity to promote the universal responsibility of knowledge and scientific research, but subsequently it had to deal with the increasingly pervasive development of the "communication network", which led to significant distortion of scientific content. With the advent of computer communication, the style of writing has drastically changed. From the written printed text, we have moved on to the virtually written one. Above all, the largest transformation concerned the invention of the "hypertext".[7] It was Theodor H. Nelson who coined the term hypertext in the 1960s, referring to a series of linked text pieces that allow the reader to enjoy them through different paths. In hypertext, the information is connected to a myriad of others. Hypertext communication makes it impossible to isolate the contents, which are therefore dendritically connected to infinity, but at the same time atomised and vaporised. The structure of the text no longer enjoys any conceptual self-sufficiency. Unlike written communication, in electronic communication it is no longer possible to identify a textual nucleus separate from the concentric orbits of comment and individual opinion. Rather, the direction in which the reading goes is centrifugal. In particular, there is a progressive decentralisation, and a possible subsequent recentring takes place according to the interests and subjective curiosities of the reader. In hypertext, it is not the author who guides understanding but the reader himself. In hypertext, the "outside" and "inside" of the content are separated only illusively. As the number of clicks increases, chasing the different and subsequent references, the reader may believe that they are going deeper into the topic but in fact they are going through it from the outside. Each attempt to deepen turns out to be an exercise of "superficialisation". This can be illustrated using the "Klein bottle" or the "Moebius strip" (Figure 1).

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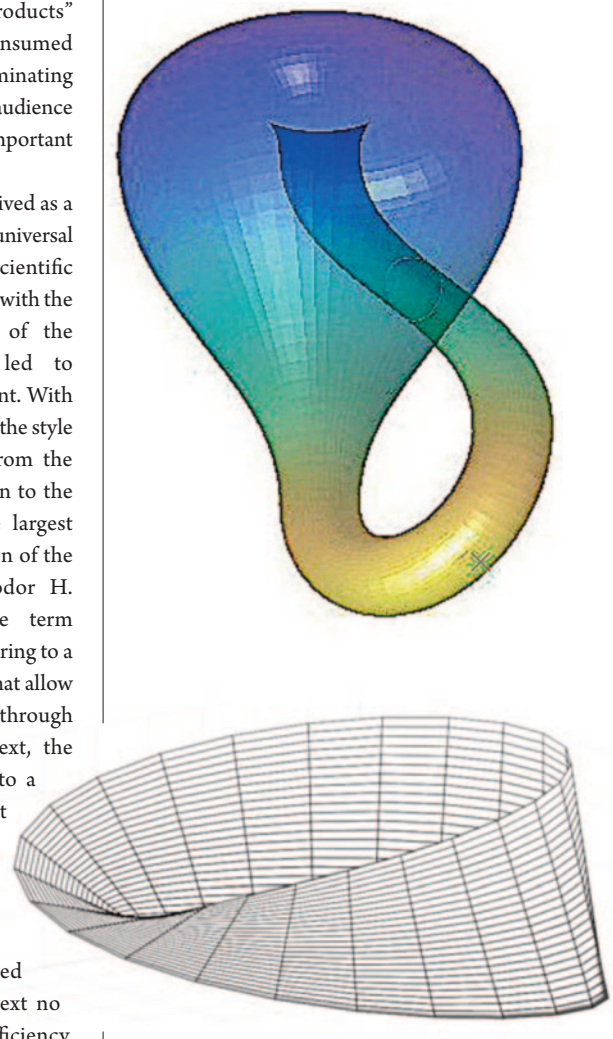

Figure 1. The Klein bottle (top) and Moebius strip (bottom) represent two topologic models of the "unavoidable superficialisation" of hypertext.

Going viral

Ultimately, information via the web becomes "viral".[8] When viral, the transmission of the information follows the law of "maximum diffusion" and moves in the same way as a virus in a pandemic. If one wanted to ironically borrow from the epidemiologic model of the "basic reproduction number" of social diffusion of trivialised scientific content, the value would far exceed the cut-off given to signify a pandemic. In the same way, continuing the virologic analogy, it could be concluded that as the number of replications of the same virus increases, the probability of additions and deletions of nucleotides and larger sequences increases, and the diffusion of the mutated scientific content is wider and the risk of additions and subtractions of words and phrases that could change the authentic meaning of the message is higher. (This may partly explain the genesis of some fake news with a scientific semblance).[9] If we also consider that, as the German philosopher Peter Sloterdjk maintains, the systems of "knowledge" (Sciences, Religions, Narratives) exercise an immune function on people (being deputies to protect the psychic balance of human groups), then we can deduce that communicative virulence attacks the intimate defences of humanity.[10] The "great narratives" of the past and present create an ideological network that allows people to be connected in a kind of mutual interdependence. Humanity recognises itself in common ideas and values that constitute an inclusive dimension, as if it were a sphere, or a kind of "Symbolic Uterus" with a protective and therefore immune function. It could be said that there is no "humanity" without "immunity".

If this concerns some dynamics of the communication of scientific content between the places of knowledge and the general public, it is also worth further investigating intra-epistemic communication (between experts). As discussed, communication is configured as a marketing tool.[11] In 1994, George Loewenstein published an article whose title was "Psychology of Curiosity: A Review and Reinterpretation".[12] Among his conclusions, he referred to the idea that curiosity was "an induced cognitive function that arises from the perception of a knowledge gap". As an induced function, it would behave like all other driver-state functions, needing a certain amount of priming information to be induced and fed. More recently, a study by Kang et al.[13] has established the relationship between curiosity and confidence in the knowledge of an

answer. An average level of confidence in the knowledge of a certain topic corresponds to the maximum level of curiosity. On the other hand, a lack of or "complete" knowledge of a topic only induces a reduced level of curiosity. An adequate "priming", an average level of curiosity, and a moderate knowledge of the proposed topic are the structural elements at the basis of the development of the clickbait technique.[14]

What is meant by "clickbait" is that an article has a bait title – a title capable of triggering a level of curiosity in the reader that leads to clicking on a link to open its contents.[15,16] The clickbait, far from being a widespread technique in a certain type of journalism and online marketing, is also a model applied to the intra and trans-epistemic communication of scientific contents. The construction of "titles" of scientific articles capable of igniting the curiosity of colleagues on the one hand, and that of newspapers and social networks on the other, has become a strongly prevalent trend. It seems that the communication industry is increasingly improving the way it offers its product to the public, precisely to make it increasingly recognisable. Producing a specific title represents an almost additional skill to that needed to produce a scientific communication. A suggestive title is the best advert for the "product", and its importance cannot be overlooked. The preparation of a title thus becomes a real work of communicative engineering. The need to produce scientific titles and articles in compliance with a certain format is the reactive response to the demands of the postmodern communication system.[17]

In recent decades, universities have also undergone a progressive process of corporatisation for socio-political-economic reasons.[18] Academic management, although with significant differences between countries, is now centred on production and development mechanisms of a corporate type. Funding for studies often depends on the studies themselves, on their ability to produce profitable results.[19] Inserted in this context, the issue of clickbait is not marginal at all. In fact, the power to produce curiosity through titles is only one of the many faces of the culture of "spectacularisation".[20] Sometimes the content to which the title refers can only be alluded to, as the title ideally refers to an object to which collective attention is directed, thus taking advantage of its popularity while never dealing with the real question of relevance. The title of this article is an example.

That said, you cannot remain shy about the risks associated with the various issues addressed here. On the one hand, studies that have poorly established data but that are capable of attracting the general attention of social media, newspapers, and therefore easily "saleable",[21-23] are quickly published and disseminated.[24] On the other hand, longer and more difficult communications and with an important amount of supporting data, but lacking in the ability to attract public curiosity, as they are not "saleable", are aborted.[25] Another potentially dangerous phenomenon is the capability of public opinion to drive scientific research through media pressure on a particular topic,[26-28] which can lead to the initiation of new clinical trials without robust basic evidence. An example is the clinical trial of the drug favipinavir (Avigan), which started recently in Italy due to the diffusion of some videos on the supposed efficacy of the drug circulating on the internet.[29]

Furthermore, given the now inveterate cultural prejudice in the face of a proven thesis, there has to be an antithesis capable of denying it, even without supporting evidence. Some works are artfully produced as "faithful negatives" of a truth. It is clear how this other pattern of denied truths is able to attract general curiosity on certain issues. Once curiosity is turned on, diffusion, sale, and a form of profit are guaranteed.[30] This is another of the levers of the "fake news" phenomenon.[31,32] In any case, if the general tendency is to consider between two opposing theses a third halfway between the two, capable of denying and affirming the other two, it will result in a shift from the centre of any scientific truth. We must increase awareness of this so that we can try to study appropriate countermeasures.

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