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Discursive Representations of Controversial Issues
in Medicine and Health

La rappresentazione discorsiva di questioni controverse
in ambito medico e sanitario

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Giuliana Elena Garzone, Maria Cristina Paganoni, Martin Reisigl

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Editorial

Discursive Representations of Controversial Issues in Medicine and Health

*Giuliana Elena Garzone, Maria Cristina Paganoni,
and Martin Reisigl*

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The topic of this *LCM* issue, which comes within the compass of the national research project “Knowledge dissemination across media in English: continuity and change in discourse strategies, ideologies, and epistemologies” (PRIN 2015TJ8ZAS), addresses representations of controversial issues in medicine and health from the perspective of discourse analysis. The focus is on science communication in society, where the production and consumption of scientific information involve, affect and (dis)connect multiple actors, stakeholders and multiple publics, sub-publics as well as counter-publics. It is a picture of remarkable complexity where different values, opinions and beliefs are shaped by a multiplicity of social and cognitive factors (Nisbet and Markowitz 2014). This editorial deals with a few general aspects, providing some background to the more specific studies presented in the chapters included in this volume.

In specialised domains, medicine and health are among those that most directly affect people’s lives, embracing topics about which ordinary people discuss, express opinions, take a stance, and about which they sometimes have to make crucial decisions. Evidence for ordinary people’s familiarity with medical questions can be found in the medical lexicon of ‘popular’ synonyms for many specialised words, easier synonyms that enable laypersons to talk about health issues, conditions and diseases comfortably, without having recourse to ‘difficult’ words and expressions of classical derivation. Medicine is one of the few specialised

domains with a consolidated ‘popular register’. Of course, this popularisation of medical knowledge brings in various challenges, among others that of reducing the complexity of medical facts without distorting them. Thus, someone who learns that she or he has a *tumour* should be made aware that *tumour* is not necessarily synonymous with malignant *cancer*.

Due to its high relevance in everybody’s lives, it comes as no surprise that medical and health issues will and should figure prominently in public debates. Some of the most controversial topics are abortion, medical use of marijuana, euthanasia and assisted suicide, end-of-life care, life support for the terminally ill, gene editing, genomic medicine, donor insemination, surrogacy, to name but a few. In particular, the chapters collected in this thematic issue deal with a selection of representative topics currently polarising public opinion, which are investigated in depth, sometimes with the aid of a case study. They focus on the anti-vaccination movement (Maci), the withdrawal of life support in the case of terminally ill young children (Turnbull), prenatal genome editing (Mattiello), parents’ empowerment as caregivers in paediatric neurological disorders (Cavaliere and Diani), the ‘deterrence vs. education’ debate within the anti-doping community (Heaney), and treatment options of trauma in soldiers (Doerr). The specific texts and discourse fragments analysed are representative of different media: the daily press, websites, social networking sites.

That there is a public debate on these issues, also encouraged by institutions, is a very positive fact. Aware of the far-reaching implications that decisions on biomedical issues may have for different groups and individuals in a context often characterised by scientific uncertainty and conflicting norms and values, through its Committee on Bioethics (DH-BO) the Council of Europe has produced a *Draft Guide on Public Debate* (published on 18 March 2019). The main purpose is to encourage public engagement by discussion and consultation, as provided for in Art. 28 of the Oviedo Convention¹, so that citizens’ opinions on biomedical ‘hot’ topics may be taken into consideration more adequately.

¹ *Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine* opened for signature on 4 April 1997 and entered into force on 1 December 1999. The purpose of the Convention is to set out common general standards for the protection of the dignity of the human person in relation to biomedical sciences. Cf. Andorno 2005.

The *Guide* calls on Member States to “create opportunities for citizens to engage in the governance of biological and medical developments”. It underlines the special nature of biomedical and health issues which differ from other (technological) changes on account of their special implications for human rights, “because they often raise concerns about integrity, dignity, autonomy, privacy, justice, equity and non discrimination among human beings” (*Draft Guide* 2019, III, 8). Indeed, it has been shown that public participation improves the quality and legitimacy of policy decisions, in addition to enhancing trust and understanding among the parties involved (National Research Council 2012, 226).

Of course, genuine constructive, informed and inclusive citizen debates with a real impact on policy decisions are difficult to achieve. However, governments have tended to commit to such engagement only on select crucial issues, and especially before legislative consultations². Usually, these debates take place in a variety of public and private spheres, first and foremost the media, e.g. on radio and television programmes, in daily newspaper columns, on blogs and through social networks (Parker and Thorson 2009; Myers 2015; Pershad *et al.* 2018) and, perhaps even more extensively, in the informal spaces of daily life, the so-called “third places” (Oldenburg 2000).

This picture is made even more complex by the fact that, in general, lay publics have limited science literacy, and in many specific cases hardly any detailed knowledge of the issues at stake. Their main sources of scientific information are the mass media, which tend to offer simplified versions of science that do not do justice to its complexities, and often fail to present notions and facts in an accurate manner. In addition, in all forms of science popularisation, there is ample scope for ideological and political partisanship in a context of growing politicisation in the presentation of scientific facts (Bolsen *et al.* 2013). In some cases, this leads to the deliberate spread of fake news and misinformation, a malpractice which has become ever more frequent thanks to web-mediated affordances, as for instance in the case of the anti-vaccine campaigns commented upon in Stefania Maci’s chapter.

² The *Guide* actually contains references to exemplary cases like the debate in Ireland concerning abortion that resulted in the repeal of the Eighth Amendment to the constitution (2018) and the public debate in France on bioethics (2018), together with examples from other countries, collected in the addendum to the *Draft Guide* [doc DH-BO (2018) 16 REV ADD].

But apart from explicit misinformation or hoaxes, texts dealing with medicine and health are not exempt from slant and bias, all the more so as the outcomes of debates have important social, political and economic implications. Therefore, it is inevitable that whenever relevant issues are represented, discussed, or just referred to, there will be a degree of slant, orienting the reader or listener towards a certain standpoint on the issue in question. To obtain this effect, discursive choices can be more or less deliberately organised to orient readers' perception of scientific issues, for instance by means of strongly evaluative language – as found by Judith Turnbull in her discussion of the Charlie Gard case, a phenomenon that occurs not only in news articles, but also in institutional texts. Similarly, the extensive use of metaphors – as described by Elisa Mattiello in her analysis of gene editing reports – also serves to influence readers' perceptions. Showing how the deployment of linguistic and discursive strategies often responds to the evident desire to present issues in a certain light is one of the main purposes of the chapters collected in this thematic issue.

Overall, the results of the studies presented here confirm that the media have an extremely important role in how people's opinions are formed, or at least influenced, and how public debates develop in different countries. They show that frames embedded in the media activate core beliefs and underlying science-related schemes, and that they contribute to shaping or co-determining public opinions and individual judgments (Nisbet and Markowitz 2014), although also generalised beliefs about science and society have a substantially strong impact on individual judgments, influencing opinions and perceptions of science (Nisbet *et al.* 2002).

Thus, *science literacy* is a very important factor in the formation of opinions on medical issues by various publics. It puts people in a position to produce qualified judgments and to give informed consent about specific aspects of the world. In the context of the present issue, *science literacy* specifically relates to *health literacy*. According to the definition of the National Institutes of Health (NIH)'s *Quick Guide to Health Literacy* (U.S. Department of Health and Human Services 2000), "health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions"³.

³ As indicated in the *Guide* (p. 2.4, n. 1), the definition was originally developed by Ratzan and Parker in a 2000 NIH publication.

Although this notion is more limited in scope than that of *science literacy*, it is no less important. It particularly refers to people's individual knowledge. Additionally, it equips them to handle medical concepts and health issues well beyond their own personal interests and needs.

Since medical and healthcare controversies engage not just scientific, but also social consensus, the news media and social networks play a key role in the discursive unfolding of contentious issues. In the past, public engagement with science tended to be unidirectional, moving from experts to laypeople through mainstream media, with little or no direct interaction between scientists and their multiple publics. This authoritative paradigm clashes with people's current desire to participate as informed and responsible actors and the emergence of "Patient 2.0" (Danholt *et al.* 2013).

The rise of social media has changed, and partly subverted, the notion of expert opinion. The public sharing of information has become more prone to controversy in knowledge landscapes where authority is often replaced by 'near-experts' (Solomon 2015; Fischer *at al.* 2018), including journalists, bloggers and influencers lacking extensive knowledge of the subject and unable to provide high-quality, sustained reporting. What is more, public discourses are increasingly fragmented (Danholt *et al.* 2013), and not just with respect to problematic concepts such as 'public good', 'best interest', 'protection' and 'cost-effectiveness'.

In our digital times, the whole communicative infrastructure for publics, subpublics and counter-publics has tremendously changed, and this has inevitably had an impact on the quality of public and semi-public discourse. We are increasingly faced with various forms of digital *polylogues*, in which many communicate with many and the participants' communicative commitment is often weak. Here, we may think, for instance, of online posters, who contribute a short comment below the line of a digital newspaper article to only disappear into thin air. The participation framework in many polylogues has become less stable. A multiplicity of participants with differing statuses produce, distribute and receive a variety of different utterances or discourse fragments, e.g. with respect to health issues. These participants introduce many different and often contradicting interests, frequently with very compressed production, distribution and reception times. Many discourse contributions cohere at best at a local level, but not at a more general level. The high quantity of heterogeneous contributions hinders participants from taking more comprehensive perspectives; it is impossible to reach an overview from a myriad of online postings. Thus, the perspective of

users becomes selective and fragmented. There has been a shift from predominantly mono-centric communication to multi-focus encounters with sideplays and byplays, various degrees of participation and commitment, multiple groups of arguers and primary, secondary, tertiary and even more addressees. In short, we are faced with complex constellations of multifunctional communication – functions ranging from information, expression of opinion, self-presentation, identity work, and aggressive acting out to entertainment, political participation, and so on.

As a result of these developments in the new media ecosystem, it is the very notion of trust that is endangered (Solomon 2015; Weingart and Guenther 2016). Scientists as primary experts in the field are not the only voices to express their opinion nor necessarily those most trusted by media consumers. Despite the ever-growing demands of addressees, policy-makers and the media, science communication means different things to different scientists. Public-health authorities struggle and often fail to orchestrate general consensus.

Turning now to the role and responsibility of discourse participants in the attempt to bridge the gap between science and society, the question is why medical and health issues generate debate. What are the multi-faceted communication-based origins of the perception that a given health issue is controversial, generating a diversification and often a polarisation of opinions?

A recent report of the U.S. National Academies of Sciences, Engineering and Medicine (2017) considers a number of related factors. First of all, in some cases science-related controversies arise because the science around a topic is perceived to be unclear and people hold mistaken impressions about the degree of certainty within the scientific community. In these instances the controversial character of knowledge is, then, a direct consequence of the fact that science itself is sometimes inconclusive and does not take into consideration long-held common-sense perceptions, or moral, ethical and social values. On the one hand, scientists often fail to adequately communicate to their multiple publics that science as such is inevitably faced with challenges of uncertainty and that uncertainty is a constitutive driving force for the scientific enterprise. On the other hand, scientists sometimes fail to explain that uncertainty can often be reduced and limited to specific areas, and that many fields of scientific research are accessible with a high degree of certainty. It is often difficult for media consumers to acquire a clear idea about what is scientifically certain and what is (still) uncertain. And when people feel that their convictions (including religious beliefs) are

challenged and their values threatened, their attitude towards science can change and turn into one of distrust.

Some authors have also pointed out that even publications announcing a discovery are sometimes subject to 'spin', i.e. "a specific intentional or unintentional reporting that fails to faithfully reflect the nature and range of findings and that could affect the impression the results produce in readers" (Boutron and Ravaud 2018, 2613), mainly because of pressure resulting from the 'publish or perish' academic environment.

With respect to the issues dealt with in the present volume, there are cases where the relevant science is well established and agreed upon by the majority of the scientific community, but where specific medical and health issues have not been fully solved yet because of their complex nature. In such cases, the level of scientific agreement can be misunderstood or misrepresented in public discourses.

Moreover, it is not unusual for public controversy to arise not so much from objective limits of science or from the way it is communicated, but rather from conflicting concerns, differing beliefs and values, be they personal, political, social, or economic interests, or related to the fears and moral and ethical considerations of individuals and organisations (Einsiedel 2013; Dieckmann *et al.* 2017; Fischer *et al.* 2018). "Despite the temptation to see some issues as inherently contentious, particularly if they have ethical dimensions or disruptive societal implications, controversy can often be traced to social and political factors that put the issue in dispute" (Akin 2017, 174), as was the case of the Human Papilloma Virus vaccine controversy in the US.

Part of the picture is also the indisputable fact that in some medicine- and health-related controversial debates where big interests are at stake, there can be interference (for instance, economic) from parties determined to protect their interests, and this is a factor that, in addition to being objectionable in itself, also results in a lack of confidence on the part of many media consumers.

Furthermore, the media also play a role. Sometimes they can emphasise the polarisation of opinions by giving opposing views an equal presentation, what is known as 'false balance reporting' or 'balance as bias' (Boykoff and Boykoff 2004), regardless of the extent to which views are supported by evidence. 'Pro-science' versus 'anti-vax' falls into this category. Anti-vaxxers escalate their arguments by using fake experts. They carry out social media-driven campaigns that spread misinformation, mistrust and fear of vaccines to a transnational network.

Without doubt, the problem of knowledge transfer and its certainty currently affecting the field of science communication and public health is to an extent nurtured by distrust of scientific expertise and governmental policy making. It is a problem that cannot be solved by rules and regulations, but rather through “cooperative communication and engagement” (Akin 2017, 175) that will aim to condense and disseminate accurate scientific information through an ethical use of language in the first place. Quite significantly, the UN *2030 Agenda for Sustainable Development* (UN General Assembly 2015) includes health literacy among its goals.

REFERENCES

- Akin, Heather. 2017. “Science Communication: A Recap”. In *The Oxford Handbook of the Science of Science Communication*, edited by Kathleen Hall Jamieson, Dan Kahan, and Dietram A. Scheufele, 173-176. New York: Oxford University Press.
- Andorno, Roberto. 2005. “The Oviedo Convention: A European Legal Framework at the Intersection of Human Rights and Health Law”. *Journal of International Biotechnology Law* 2 (4): 133-143. <https://doi.org/10.1515/jibl.2005.2.4.133>.
- Bolsen, Toby, James Druckman, and Fay Lomax Cook. 2013. *The Effects of the Politicization of Science on Public Support for Emergent Technologies*. Working Paper WP 13-11. Evanston (IL): Institute for Policy Research Northwestern University. [28/08/2019]. <http://www.ipr.northwestern.edu/publications/docs/workingpapers/2013/IPR-WP-13-11.pdf>.
- Boutron, Isabelle, and Philippe Ravaud. 2018. “Misrepresentation and Distortion of Research in Biomedical Literature”. *PNAS: Proceedings of the National Academy of Sciences of the United States of America* 115 (11): 2613-2619. <https://doi.org/10.1073/pnas.1710755115>.
- Boykoff, Maxwell T., and Jules M. Boykoff. 2004. “Balance as Bias: Global Warming and the US Prestige Press”. *Global Environmental Change* 14 (2): 125-136.
- Council of Europe. *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine*. European Treaty Series – Nr. 164. [28/08/2019]. <https://rm.coe.int/168007cf98>.
- Council of Europe. 2019. *Draft Guide on Public Debate*. [28/08/2019]. <https://rm.coe.int/inf-2018-11-rev-draft-guide-on-public-debate-e/1680948ed3>.
- Danholt, Peter, Enrico Maria Piras, Cristiano Storni, and Alberto Zanutto. 2013. “The Shaping of Patient 2.0: Exploring Agencies, Technologies and Dis-

- courses in New Healthcare Practices”. *Science & Technology Studies* 26 (2): 3-13.
- Dieckmann, Nathan F., Branden B. Johnson, Robin Gregory, Marcus Mayorga, Paul K.J. Han, and Paul Slovic. 2017. “Public Perceptions of Expert Disagreement: Bias and Incompetence or a Complex and Random World?”. *Public Understanding of Science* 26 (3): 325-338. <https://doi.org/10.1177/0963662515603271>.
- Einsiedel, Edna F. 2014. “Publics and Their Participation in Science and Technology: Changing Roles, Blurring Boundaries”. In *The Routledge Handbook of Public Communication of Science and Technology*. 2nd ed., edited by Massimiano Bucchi and Brian Trench, 125-139. Abingdon - New York: Routledge.
- Fischer, Frank, Clark A. Chinn, Katharina Engelmann, and Jonathan Osborne, eds. 2018. *Scientific Reasoning and Argumentation: The Roles of Domain-specific and Domain-general Knowledge*. New York - Abingdon: Routledge.
- Myers, Greg. 2015. “Social Media and the Professional Practice in Medical Twitter”. In *Insights into Medical Communication*, edited by Maurizio Gotti, Stefania M. Maci, and Michele Sala, 51-69. Bern: Peter Lang.
- National Academies of Sciences, Engineering, and Medicine. 2017. *Communicating Science Effectively: A Research Agenda*. Washington (DC): The National Academies Press.
- National Research Council. 2012. *Using Science as Evidence in Public Policy*. Committee on the Use of Social Science Knowledge in Public Policy, Division of Behavioural and Social Sciences and Education. Washington (DC): The National Academies Press.
- Nisbet, Matthew, and Ezra M. Markowitz. 2014. “Understanding Public Opinion in Debates over Biomedical Research: Looking beyond Political Partisanship to Focus on Beliefs about Science and Society”. *PLOS ONE* 9 (2): e88473: 1-12. <https://doi.org/10.1371/journal.pone.0088473>.
- Nisbet, Matthew C., Dietram A. Scheufele, James Shanahan, Patricia Moy, Dominique Brossard, and Bruce V. Lewenstein. 2002. “Knowledge, Reservations, or Promise? A Media Effects Model for Public Perceptions of Science and Technology”. *Communication Research* 29 (5): 584-608. <http://dx.doi.org/10.1177/009365002236196>.
- Oldenburg, Ray. 2000. *Celebrating the Third Place: Inspiring Stories about the “Great Good Places” at the Heart of Our Communities*. New York: Marlowe & Company.
- Parker, Jerry C., and Esther Thorson. 2009. *Health Communication in the New Media Landscape*. New York: Springer.
- Pershad, Yash, Patrick Hangge, Hassan Albadawi, and Rahmi Oklu. 2018. “Social Medicine: Twitter in Healthcare”. *Journal of Clinical Medicine* 7 (121): 1-9. <https://doi.org/10.3390/jcm7060121>.
- Ratzan, Scott C., and Ruth M. Parker. 2000. “Introduction”. In *National Library of Medicine Current Bibliographies in Medicine: Health Literacy*, edited by

- Catherine R. Selden, Marcia Zorn, Scott Ratzan, and Ruth M. Parker, iii-vii. Bethesda (MD): National Institutes of Health, U.S. Department of Health and Human Sciences.
- Solomon, Miriam. 2015. *Making Medical Knowledge*. Oxford: Oxford University Press.
- UN General Assembly. 2015. *Transforming Our World: The 2030 Agenda for Sustainable Development*. Resolution adopted by the General Assembly on 25 September 2015. [28/08/2019]. https://www.un.org/ga/search/view_doc.asp?symbol=A/RES/70/1&Lang=E.
- U.S. Department of Health and Human Services Office of Disease Prevention and Health Promotion. 2000. *Quick Guide to Health Literacy*. [28/08/2019]. <https://health.gov/communication/literacy/quickguide/factsbasic.htm>.
- Weingart, Peter, and Lars Guenther. 2016. "Science Communication and the Issue of Trust". *Journal of Science Communication* 15 (5): 1-11. <https://doi.org/10.22323/2.15050301>.