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Representing, Disseminating, and Debating Controversial Bioethical Issues in Popularised Discourse

Edited by Giuseppe De Riso, Roxanne Barbara Doerr and Giuliana Garzone

Table of Contents

Giuliana Garzone, Roxanne Barbara Doerr, Giuseppe De Riso Introduction	1
Bioethics as a research perspective	
<i>Giuseppe De Riso</i> Ethical Responsibility in <i>Midnight's Children</i> : Clinical Storytelling as a Form of Biological and Cultural Survival	9
Beyond limits: ethical dilemmas	
<i>Giuliana Garzone</i> Exploring the Complexities of Bioethical Discourse: Primate Cloning in the Press	27
Jekaterina Nikitina Representing Gene-Editing in Newspapers: Between Science Dissemination and Fantasy	43
Kim Grego Marketing Life after Death: Cryopreservation in the Hope of Resuscitation	59
Maria Cristina Paganoni Ethical Concerns over Facial Recognition Technology	85
Bioethics and health issues	
Annalisa Zanola 'Informed Consent' (IC) in Health Literacy (HL): State-of-the-art of an Elaborate Legal-lay Communication Process	95
Francesca Santulli The Concepts of Norm and Disease from Scientific to Popularization Discourse	107
<i>Giorgia Riboni</i> Representation of Knowledge about Opioid Addiction between Criminalization and Medicalization	123

Dermot Heaney Taking a Stance on Doping: Online Press Evaluation of a Parliamentary Select Committee's Investigations into Doping in British Cycling	141
Bioethics, health and the market	
Walter Giordano Ethics and Accessibility to Knowledge in Prescription Drug Commercials in the USA	159
<i>Cinzia Giglioni</i> Ethics, Pricing, and the Pharmaceutical Industry: Corporate Communication Faces Drug-Cost Issues	175
Bioethics and the environment	
Emanuele Brambilla Knowledge Dissemination and Cultural Specificity in Greenpeace's Canned Tuna Guides	185
Paola Catenaccio Ethics and Legitimacy in the Discourse of Agri-biotechnology: A Study in Argumentation	203
Bioethics guidelines and instruction	
Roxanne Barbara Doerr Dual Loyalties and Shifting (Bio)ethical Principles: An Analysis of the Defense Health Board's Ethical Guidelines and Practices	227
Karen Dwyer Discourse Analysis for Exploring Bioethics in Biomedical and Medical Sciences Education	243
Reviews	
Maddalena Carfora A Review of Giuseppe De Riso, Affect and the Performative Dimension of Fear in the Indian English Novel: Tumults of the Imagination (Newcastle Upon Tyne: Cambridge Scholars, 2018)	265
Santo Michael Orefice A Review of Roxanne Barbara Doerr, Communicating Professions via Blog: An Applied Linguistics Approach (Munich: Grin Verlag, 2019)	269

Notes on Contributors

273

Popularised Discourse and/on Bioethics: An Introduction

1. Discourses of and on Bioethics

In the last few decades a variety of bioethically-relevant issues have been at the centre of public debate, attracting ample coverage from the media in a context where unprecedentedly fast and pervasive scientific and technological progress has led to new questions on the actual application of advances to real life cases, e.g. in biotechnologies, genetics, medicine, with an impact on human identities, relations and practices, and therefore effect on human rights and fundamental freedoms. This special issue of *Anglistica AION* on *Representing, Disseminating, and Debating Controversial Bioethical Issues in Popularised Discourse* focuses on the discursive representation of such issues in popularising texts. It owes its core idea to the main theme of investigation of the Milan research unit – the representation of bioethical issues – co-ordinated by Giuliana Garzone as part of a National Research Programme on knowledge dissemination.¹ In particular, attention is centred on the linguistic and discursive strategies that are employed in 'translating' and framing specialised bioethical notions, terms and debates within journalistic, online, promotional, corporate and legal texts, and media coverage.

While the literature on the strategies enacted in knowledge dissemination and popularisation in general has grown exponentially over the past few years, the texts and discourses that are deployed in the popularisation of bioethical themes have received much less scholarly attention in linguistic and literary studies, in spite of the prominence and discursive complexity of communication on bioethical themes. This special issue therefore aims at filling this research gap by specifically focusing on the reframing of bioethically sensitive issues by popularising writers and by public and private institutions through determined language, genres and channels on a large scale, and providing an overview on potential manners to influence public opinion and socio-cultural debates. In fact, it is all the more essential for linguistic, literary and cultural studies dealing with bioethical issues to detect all possible linguistic, discursive and rhetorical alterations and imbalances that might lead to inaccuracies, especially when they involve ideological manipulation or slant, and identify the linguistic and discursive transformations that bioethically relevant and sensitive knowledge may be consciously or unconsciously subjected to in the course of the dissemination process by individual writers, institutions, professions, organisations or corporations.²

¹ Research programme "Knowledge dissemination across media in English: continuity and change in discourse strategies, ideologies and epistemologies" financed by the Italian Ministry of Education, University and Research (PRIN 2015TJ8ZAS).

² Among the innumerable studies on popularisation in general, see Greg Myers, "Discourse Studies of Scientific Popularization: Questioning the Boundaries", *Discourse Studies*, 5.2 (2003), 265-279, and all the articles collected in Vol 5.2 of *Discourse*

As a preliminary step to illustrate the broad conceptual and methodological framework underlying the studies collected in this issue, it is useful to refer to Art. 1 of UNESCO's *Declaration on Bioethics and Human Rights* (2005), where bioethics is described as embracing "the ethical issues related to medicine, life sciences and associated technologies as applied to human beings, taking into account their social, legal and environmental dimensions" (Art. 1). This definition, which shapes the themes to be explored in this special issue, sets a rather broad topical range.

In the field of linguistics and discourse analysis, research on so broad a spectrum of themes has been further enriched through a necessary expansion of its inquiry into the fields of literature, cultural studies and higher education, as attested by some of the essays collected in this special issue. This reflects the undeniable fact that bioethical issues are at the centre of political, legal, and cultural debates at a global level,³ especially in the aftermath of unprecedented legal and ethical scenarios opened up by the recent pandemic and of high profile cases resulting in pioneering institutional and legal provisions.

In terms of areas of investigation, the papers in this issue fall within the purview of what Stephen G. Post sees as the two main thematic "lineages" from which modern bioethics developed: "the important moral questions surrounding developments in healthcare, medicine, research, and the professional/patient relationship" on the one hand and, on the other hand, concerns that "emerged from biologists who felt obliged to address the moral meaning of the biosphere, and to reflect on the remarkable implications of their discoveries and technological innovations".⁴

2. The Bioethics Perspective

Most of the articles included in this volume explore one of a diversified range of topics within these two areas, dealing with the representation of issues that are broadly associated with ethics in medicine and ethics in the life sciences. The only exception is Giuseppe De Riso's essay which has an essentially literary focus, taking Salman Rushdie's *Midnight's Children* (1981) as an example of bioethical narrative. It applies the notion of bioethics to the analysis of fiction, seeing narration as a bioethical effort that assumes a clinical epistemology demanding the participation of both storyteller and readers, who become progressively aware of the relativity of the human comprehension of individual and social experience.

Studies, edited by Greg Myers; Giuliana Garzone, Perspectives on ESP and Popularization (Milan: CUEM, 2006); Giancarmine Bongo and Giuditta Caliendo, eds., The Language of Popularization/Die Sprache der Populaiserung (Bern: Peter Lang, 2014); and Giuliana Garzone, Specialized Communication and Popularization in English (Rome: Carocci, 2020).

³ See among others Jerry Menikoff, *Law and Bioethics: An Introduction* (Washington DC: Georgetown U.P., 2001); Marcus Düwell et al., eds., *Bioethics in Cultural Contexts: Reflections on Methods and Finitude* (Dordrecht: Springer, 2006). Among recent books on bioethics in medical practice, cf. Brown Caruso et al., eds., *Bioethics, Public Health, and the Social Sciences for the Medical Professions: An Integrated, Case-Based Approach* (Dordrecht: Springer, 2020); Joris Gielen, ed., *Dealing with Bioethical Issues in a Globalized World: Normativity in Bioethics* (Dordrecht: Springer, 2020).

⁴ Stephen G. Post, "Introduction", in *Encyclopedia of Bioethics*, Third edition, Vol. 1 (Farmington Hills, MI: Thomson Gale, 2003), xi.

What emerges clearly from this paper is that looking at facts and issues through the lens of bioethics means evaluating their legitimacy and merits, and reflecting on the responsibilities pertaining to them. In this process, language and discourse play a very important role: this is the main focus of the other articles in this special issue, which mainly deal with problems having to do with the application of science and technologies. In fact, while scientific and technological research and experimentation work to promote innovation and offer new opportunities, the humanities maintain their role in expounding the outcomes of such research under an ethical perspective for the benefit of institutions and of the general public by considering emotional, psychological, geopolitical and societal factors. They also play a role in productively communicating policies, possibilities and potential issues and hypotheses, and in many cases in framing legal concepts and principles like proportionality and personhood⁵ and the power of agency of the professionals and stakeholders that are involved.

Especially interesting from this viewpoint are the recent and dramatic advances in all fields of the biomedical and life sciences which have offered mankind unprecedented and previously unimaginable abilities to tamper with processes that, until not long ago, were totally beyond our control (e.g. artificial reproduction, end of life care, cloning, etc.). As new cutting edge techniques are made available, the problem arises of whether and how such techniques can and should be used: what are the limits? Can we go beyond them? How is the debate over these issues framed in linguistic and discursive terms? This is dealt with in the first group of papers in this issue which look at the representation of "hot" topics in contemporary public debate: primate cloning and the possibility of cloning humans (Giuliana Garzone), gene editing (Jekaterina Nikitina), cryopreservation as a technology to prolong life with a view to future resuscitation (Kim Grego), and facial recognition, encroaching on people's right to privacy (Maria Cristina Paganoni). Whether directed towards the promotion of new services based on pseudo-science (as in the case of cryonics) or aimed at informing the general public about new procedures for the purpose of disseminating knowledge so that people may form an opinion on innovations, as in the cases of coverage in the periodical press in Garzone's, Nikitina's and Paganoni's articles, what emerges here is that in order to form an opinion and take a stance the layman is inevitably and totally dependent on the popularisation – indeed, vulgarisation – of advanced and innovative technologies and procedures. Popularising genres especially enable practitioners' and participants' ideological stances regarding innovative and controversial decisions and practices to be communicated, and supported or opposed, in an open and accessible arena.

If the orientation of people's perception of far-fetched scientific and technological innovations is a critical issue, what emerges as even more critical is how the general public is informed about practices concerning medical ethics or bioethics, especially in cases where the possibility of relying on accurate information may be crucial in people's or practitioners' decisions.

This is the case, for instance, of texts used to obtain patients' informed consent, as discussed in Zanola's paper, or the categorisation of any given disorder, which is examined in Francesca Santulli's paper focusing on the description of Disorders of Neurodevelopment in the authoritative *Diagnostic*

⁵ Alexander Morgan Capron and Vicki Michel, "Law and Bioethics", *Loyola of Los Angeles Law Review*, 27.25 (1993), 25-40, 32.

and Statistical Manual of Mental Disorders. Also, the discursive framing of health issues in the press may have an impact on the consideration given on a personal, societal and political level to problems such as drug abuse and performance enhancement in sports as a result of their representation and framing in the press, as outlined respectively in Giorgia Riboni's and Dermot Heaney's articles.

While bias in popularisation strategies is often present but not overtly deployed in journalistic and institutional communication, it is rife when popularisation is aimed at the market, as discussed in Walter Giordano's paper on the advertising of pharmaceutical products, and in Cinzia Giglioni's essay on apologetic strategies in press releases issued by a Big Pharma company to justify its drug pricing policy.

If in the first part of the special issue the focus was mostly on bioethical issues in the health and medical sphere, with the following papers the focus shifts to the environment, instantiating what Post sees as the second important line of development of modern bioethics, i.e. the life sciences. The two papers included in this section look at environmental issues from two opposite viewpoints: Paola Catenaccio explores the argumentative strategies relied on by major players in the agro-biotech sector to legitimate their operations and the technologies upon which they are based, while Emanuele Brambilla looks at the discursive conventions of environmental activist cultures. In both cases, discursive strategies are strongly oriented towards influencing public opinion and are therefore highly manipulative.

The issue closes with two papers that look at texts aimed at shaping the medical practitioner's attitude toward bioethical issues, respectively guidelines for doctors (the Defense Health Board's *Ethical Guidelines and Practices for US Military Medical Professionals*) in Roxanne Barbara Doerr's article, and texts used in a series of scientific communication workshops to introduce postgraduate Biomedical and Medical Science education in Karen Dwyer's article.

3. Final Remarks

The picture that emerges from this collection of articles is one of extreme complexity, which reflects on the one hand the great diversity of the issues included under the "bioethics" label, and on the other hand the complex discursive strategies deployed to disseminate knowledge on the most sensitive issues in contemporary society, both due to the difficulty and the complicacy of the notions to be popularised, and the bias that is often conferred upon the relayed information.

Another aspect that emerges from the studies in the present issue is that the original four principles of bioethics introduced by Beauchamp and Childress (1979/2001) and upheld in medical ethics (autonomy, beneficence, non-maleficence and justice) are not monolithic and indisputable but, as they have been constructed, could be deconstructed and reconstructed not only based on cultural but even professional contexts. In fact, highly specialised professionals who are the first to have to respond to emergencies, dilemmas and demands having bioethical implications are often the first to realise that a reframing of procedures and guidelines is in order to face these challenges. On their part, academic scholars observe that linguistic analysis, literary reflection and didactic debate may pave the way

towards non-experts' better understanding of highly complex and life-changing phenomena and knowledge when people fear that the application of new scientific experiments and findings could impinge on human rights and the dignity of – and responsibility for – birth, illness, performance, privacy, personhood and death, as well as the integrity and well-being of the environment and the flora and fauna that populate it and also need to be protected.

4. Contents of the Special Issue

The issue starts with Giuseppe De Riso's analysis of the 'medical epistemology' employed by Salman Rushdie in *Midnight's Children*, his first novel and a masterpiece in postcolonial literature. Rushdie's clinical concerns rely on a metanarrative confusion of invention and reality which cunningly interrogates how cultural and biological knowledge is transmitted in the contemporary world, and expresses the author's artistic preoccupations for the ethical implications of such spreading.

The subsequent essays are divided into five sections. The first one, "Beyond limits: ethical dilemmas", is introduced by Giuliana Garzone, who deals with the ethical implications of cloning, one of the most heated subjects in the public debate on bioethics. More specifically, she looks at the discursive procedures employed in a corpus of worldwide news articles illustrating the implications of the successful cloning of two macaque monkeys in 2018, as well as their attempt at favouring the public's acceptance of such a controversial event in light of rising concerns. This is especially relevant if one considers that the frequent inaccuracies contained in the articles denounce a deontic issue in the way the news was reported by professional journalists. Drawing on the methodological framework of Corpus-Assisted Discourse Analysis, Jekaterina Nikitina looks at the selective, yet careful, representation of gene-editing in British tabloids and broadsheets in 2017 and 2018, both from a linguistic and discursive point of view, through news reports which could influence public opinion. Kim Grego follows suit with an essay considering the dissemination of scientific information about cryonics services, meant to preserve bodies after death and bring them back to life at a later time in the expectation that technology may one day allow so. Grego argues that such technology is ambiguously marketed as if it were not bioethically relevant, and on an often negotiable notion of death which may result in misled choices about life or death by consumers. Maria Cristina Paganoni closes this section with a contribution to the sensitive debate about the impact of facial recognition technology and related software by noting the contrast between the fervent narrative of technological progress adopted by the AI industry, and the more cautious approach of news media on the more questionable aspects of the ethical implications of the man-machine configurations that are involved in facial recognition technology.

Annalisa Zanola opens the second section, "(Bio)ethics and health issues", taking an approach both diachronic and synchronic to informed consent to scrutinise how it is valued by patients in terms of satisfaction and anxiety. In finding a way to assure that informed consent is clearly understood by patients, as it lies at the crossroads of lay, scientific and legal discourses, Zanola suggests that researchers should be aware of the laws which actually enforce the ethical implications of informed consent in any given context. The ideological implications behind the notions of norm and disease is the object of interest of Francesca Santulli who, describing moving in the area of Disorders of

Neurodevelopment, points out the difficulties of adopting a model capable of identifying 'normal' behaviour in light of each person's specificities. Giorgia Riboni presents an analysis of the debate on opioid addiction in the United States and the clear shift in its representation in newspapers from a criminalization to a medicalization framework, with a resulting change in proposed solutions from punitive to medicalized treatment. Dermot Heaney adopts a Computer-Assisted Discourse Studies approach to compare the evaluation strategies present in a corpus of hearings about the doping investigations which occurred during 2016 and 2017, after it was revealed that such practice was indeed very common in British sport, with a corpus of online media coverage. Heaney thus manages to attest the close relationship between politicians and the press and recognises the debt of political committees to media exposure as far as incidence in public life is concerned.

Walter Giordano and Cinzia Giglioni provide the two contributions which make up the third section of the present issue, "Bioethics, health and the market". Giordano focuses on a corpus of over seventy commercials advertising several drugs authorized by the Food and Drug Administration in the USA to analyse discourses influencing the knowledge of diseases, access to information about drugs and the interaction between patient and physician. There emerges a reduction of the physician's responsibility, a part of which is loaded onto the shoulders of patients. As a consequence, they are expected to have a more active role in becoming informed on their condition, the appropriate drug to treat it and its side effects. Instead, Giglioni deals with the press releases that the pharmaceutical company Mylan has issued to counter the strong criticism it had to face in 2016 for hiking the price of one its most sold drugs. In highlighting the link which financially solid companies create with abstract values correlated to bioethical ethics, Giglioni is able to single out bolstering as the main communicative strategy used in their annual reports as an apologetic strategy to improve the public perception of the company.

"Bioethics and the environment" is the title of the fourth section of the issue. In it, Paola Catenaccio explores the concealment of the argumentative, self-legitimising strategies employed by major players in the agro-biotech sector in order to justify their operations and technologies. Such strategies rely not on hiding problems, but on their benefits and advantages for the human environment, thus making it more difficult for critical opponents to raise uncomfortable questions. Dissemination strategies are also central in Emanuela Brambilla's dissertation on three tune guides issued in Australia, Italy and the USA by Greenpeace with the aim of influencing the behaviour of tuna consumers. A close inspection of such guides allows Brambilla to reveal that the necessity to face global bioethical crisis is central in the creation of narratives which, by targeting specific national audiences, manage to raise local action, thus effectively overshadowing the unethical practices of certain tuna brands.

The fifth and concluding section on "Bioethics guidelines and instruction" opens with a study by Roxanne Barbara Doerr, who has recourse to Critical Discourse Analysis (CDA) in order to investigate the vagueness of medical ethics as expressed through the dissemination of information regarding medical professionals belonging to the military community, as well as the bioethical contradictions and struggles lying therein. The special interest towards this category derives from its subjects' ambiguous and unstable positioning on the line between their Hippocratic vocation to take care of others and the oppressive practice of military culture. In addition to CDA, Karen Dwyer also draws on Foucauldian Discourse Analysis to analyse how debates about medical cannabis have influenced drug use and perception, as well as medical cannabis policy. This may reveal a possible way to incorporate Discourse Analysis into Biomedical and Medical Science Education and help students gain a deeper understanding of bioethical issues.