

# Discourse, Narrative, and Voice: The Power of Communicating Bioethics Through the Media

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Résumé de l'article

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TÉMOIGNAGE / PERSPECTIVE

# Discourse, Narrative, and Voice: The Power of Communicating Bioethics Through the Media

Hortense Gallois<sup>a,b</sup>

## Résumé

Cette perspective explore le rôle du bioéthicien dans l'élaboration du discours public par le biais des médias, en tenant compte du pouvoir des récits et de la voix.

## Mots-clés

bioéthique, discours, médias, narration, voix, communication

## Abstract

This perspective explores the role of the bioethicist in shaping public discourse through the media, while accounting for the power of narratives and voice.

## Keywords

bioethics, discourse, media, narrative, voice, communication

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## INTRODUCTION

*“From its beginning, bioethics has gotten people talking. It is public discourse carried on by many people in many settings.”* (1, p.352)

Bioethics holds a unique place in both the scientific community and society at large. Inherently interdisciplinary, bioethics has been described as both a second-order discipline (i.e., a discipline that analyzes other disciplines) and a public discourse (2). Understood as the speech, publications, and other statements made in pursuit of the public good, public discourse plays a central role in policymaking, and as such, in shaping our collective future (3).

This perspective explores the role of bioethics as public discourse, especially in its relationship with the media. Critical platforms for constructing and disseminating bioethical discourse, the media – and especially social media – are powerful vectors of public conversation, but they also have the potential to spread misinformation about science and divide public opinion. The Covid-19 pandemic exacerbated this potential and further reinforced inequalities, while at the same time shedding light on the systemic issues faced by minorities and vulnerable groups. For example, social media played a significant role in the spread of misinformation about the effectiveness and safety of vaccines, leading to vaccine hesitancy in various communities, including among some minority groups already distrustful of medical systems due to historical injustices. Additionally, false claims about home remedies and prevention methods circulated widely, confusing public understanding of effective health measures and disproportionately affecting those without access to reliable healthcare information. In this media space, bioethicists face the crucial task of leveraging media platforms to help shape public discourse in order to foster inclusivity in public discussions and counter the spread of false information.

This contribution explores the role of bioethics as public discourse and considers the power of narratives as communication tools in bioethical discourse. Guided by the principle “nothing about us without us,” bioethics can help amplify community voices, particularly those of minorities and vulnerable groups. (4) My vision for bioethics discourse is a complete cycle: one that not only originates from communities but is also aimed at them, accessible to them, and affirmed by them.

## THE POWER OF VOICE(S)

Besides giving us the ability to be heard, voice holds symbolic value as the representation of a person's or a group's opinions and beliefs. “Finding one's voice” also refers to a state of accomplishment in a person's life. Voice can further represent the imbalance of power in a society, where, for example, a white man's voice is still typically given more weight than a black woman's. This inequality in the ability to be heard and believed affects public discourse, favoring some groups and eclipsing others. As already stated, any truly public discourse should ensure fair representation of all groups in the conversation, especially minorities and groups made vulnerable due to their gender, race/ethnicity, sexual orientation, or disability, and any other group that has historically been excluded from ethics and policy decision-making.

Bioethicists have the responsibility to advocate for individuals who have historically been overlooked and whose voices have gone unheard, and to promote representation of the diversity of our society. Sub-fields of bioethics have emerged as an attempt to be more inclusive. Feminist approaches and global bioethics, among others, have gained increasing popularity in the last decade. These approaches both require the integration of the voice(s) of the community(ies) engaged in bioethical inquiry. Additionally, approaches such as involving communities directly in the research process or employing member checking – a technique where participants review and provide feedback on findings to ensure accuracy – can enhance the credibility and

reliability of findings in bioethics research. These techniques can help ensure that research findings accurately reflect participants' perspectives and experiences, thereby fostering a sense of respect and transparency between researchers and the communities involved.

Activists inside and outside academia have argued that any research with the disability community should be based on the principle of “nothing about us without us” (4). First coined by disability rights activists in the 1990s, this principle conveys the idea that no policy should be reached without full participation of representatives of all stakeholders involved. The principle was later claimed by the intersex community and other marginalized groups: “nothing about us without us” expresses well the idea that, in making public policy, both the end goal and the root of the research should be the community. This also, I argue, applies to bioethical discourse in the media and in academic work.

Ensuring effective inclusion of communities in public discussions involves guaranteeing both their physical and active intellectual participation (4). Physical presence entails inviting people to the table, and intellectual presence means ensuring the debate is tailored for their understanding and participation. By inviting more people into the conversation, a genuine public discourse can emerge, promoting inclusion and empowerment of minorities and vulnerable groups.

## BIOETHICAL DISCOURSE AND THE MEDIA

The scientific literature can be hard to access for the general public, either because of monetary constraints (paywalls) or due to the level of literacy required, making the general media a more efficient way to bring bioethics to the public. According to Simonson, “popular media may make short shrift of complex ideas and moral deliberations, but it can also serve bioethics well. Bioethics should embrace the ritual function of the media in bringing issues to public attention and in reinforcing bioethics as a field.” (5, p.32) A few bioethicists in North America are frequently heard and seen in the media or featured in press articles. Arthur Caplan, for example, has affirmed a long-standing interest in “pushing bioethics into the public arena,” (6) while for Vardit Ravitsky, “because bioethics is all about making a difference, it is always critical that we translate our scholarship to the world outside the proverbial ivory tower.” (7)

However, discussions on bioethical issues are occasionally presented to the public without seeking input from experts or recognizing the extensive research that bioethicists have already conducted on the topic. A recent example was published in the New York Times (8): two journalists conducted a substantial investigation on Non-Invasive Prenatal Screening (NIPS) offered by US companies, resulting in a Sunday front-page article and weeks of backlash from genetic counsellors across North America for qualifying a useful technology as “usually wrong.” The choice of word matters, as the word ‘wrong’ can carry a moral dimension, besides the test results’ accuracy. By focusing mainly on the marketing practices of companies offering NIPS and not addressing the broader ethical questions such as the acceptability of prenatal testing, the purpose behind it, and its societal implications, the article missed an opportunity to enrich public understanding of complex bioethical issues (9). This example underscores the complex relationship between bioethicists, the press, and public discourse. Journalists, through their investigations and the language they use, can significantly influence public perception of bioethical issues. The backlash from genetic counsellors highlights the critical importance of using precise language, as terms loaded with moral implications can skew the understanding of technological efficacy and ethical considerations. This incident points to the responsibility of bioethicists to engage with the media – and vice versa – to ensure that nuanced and informed discussions of bioethical topics are presented to the public.

Aside from traditional mainstream media, social media offer the space for anyone to converse or voice their opinion on any subject, including those of ethical import. The Covid-19 pandemic propelled societies into a new world of very public bioethical dilemmas, both at the individual and population levels: Should I wear a mask? Should I turn down dinner invitations? Is a vaccine pass ethical? These and many other questions were part of both public and private conversations. While bioethicists were attempting to address such dilemmas and guide the drafting of vaccine policies and sanitary measures in many countries, these questions were already polarizing public opinion through social media. The power of social media to create, shape, divide or unite public opinion is arguably unprecedented. For bioethics to act as public discourse, it needs to permeate conversations that are outside academia in order to reach all sections of society (e.g., public, civil society groups, policy makers), and, in turn, integrate voices from the public into academic work and policy development. In shaping such discourse, narratives can be efficient means to clarify complex issues and guide ethical inquiry, but also to spread the results of rigorous scientific research in a way that is both accessible and intelligible.

## USING NARRATIVES TO PROMOTE VOICE(S)

Through the media, narratives can both help spread and counter misinformation. Social media have proven uniquely efficient in spreading (mis)information – working as echo chambers to confirm convictions and leave aside alternative realities, they use narrative or storytelling to reach audiences and spread fake information. The anti-vax movement, for example, has spread stories during the pandemic of children suffering from side effects after getting vaccinated, without providing any scientific proof of causation between the symptoms and the vaccine. In that sense, narratives are effective but also dangerous tools of communication.

However, Caulfield et al (10) suggest that narratives also have the potential to spread scientific truths that serve the public good. A narrative communication style can improve public understanding of science, both in social and traditional media, and

facilitate understanding of complicated topics (10). As part of scientific popularization (*vulgarization* in French), which seeks to bring knowledge within reach of a non-expert audience, the use of storytelling can make scientific information more relatable and accessible. Making science easier to understand for a wider public can foster greater public reflection and discussion, and also provide the public with the necessary critical tools to understand complex bioethical issues. Popularized science (and bioethics) that is based on narratives can effectively bridge existing gaps between academic discourse and the media, thereby promoting richer and more nuanced public discourse.

In the academic context, narratives have also been used not only to bring stories to the public, but to acknowledge the importance of people's individual stories. Narrative ethics as a methodology uses a person's story in a bottom-up approach to resolve a moral question, pushing aside traditional principlist or theoretical approaches (11). Saulnier reminds us that narrative ethics should be used with caution, and not without first examining the biases at play, as "not everyone's words are afforded equal power." (11) In the healthcare context, this is illustrated by societal biases that systematically discredit the voice of minorities, based on race, ethnicity, gender, sexual orientation, disability or socioeconomic background when seeking care (11). In the context of shaping a genuine public discourse, the use of narratives as communication tools implies first hearing and empowering the voice(s) of various groups in society, especially those that are more vulnerable.

## CONCLUSION

Bioethics' role as public discourse is intertwined with its place in the media. Public discourse is powerful in shaping a society's future, as it aims at promoting moral reflection and discussion to guide policymaking (2). For Foucault, discourse can be both an instrument of domination and fuel for resistance: "discourse transmits and produces power; it reinforces it, but also undermines it and exposes it, renders it fragile and makes it possible to thwart it." (12, p.100-1) The power of public discourse implies engaging with all groups of our society, especially the most vulnerable. This, in my view, implies two commitments for bioethicists: to conduct research in an inclusive and empowering way, and to ensure that results are returned to the communities in a language that is accessible to and validated by them.

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