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**Orientalional Knowledge and  
the Ever-Changing Demands of Bioethics**

**Integrative Bioethics and Its Take on Informed Consent**

**Abstract**

*The concept of orientational knowledge, as presented by Jürgen Mittelstraß, is an important resource for defining discursive instabilities and inadequacies in different disciplines. When it comes to bioethics, Mittelstraß's work can also be used in the context of refining contemporary theoretical positions, especially the notion of Informed Consent. Today's problems with the relationship between patients and doctors have been made even more complex by the postmodernist scientific discourse and its new three-pronged articulations: "alternative facts", "fake news", and the "post-truth era". Hidden behind these concepts are ideas of "misrepresentation of facts", "discrediting of facts", and "equivalence between facts and emotions" – in short "counterfactual iterations" of content. These attitudes towards truth are blurring important theoretical requirements that make bioethically (as well as ethically) sound judgement calls for professionals possible. The overlapping of factual and counterfactual statements makes navigating the complex bioethical landscape almost impossible without an integrative and orientational approach. Mittelstraß's understanding of orientational knowledge becomes an indispensable tool for critical analysis of information dissemination and its integration into decision-making in bioethics. Therefore, the aim of this article is to provide us with an analysis of these concepts in integrative bioethics.*

**Keywords**

integrative bioethics, informed consent, fake news, literacy, orientational knowledge, Jürgen Mittelstraß

**I**

Bioethics is a subject, a discipline, in constant and ever-changing flux, consistently influenced by changes on the cultural, and broader, civilizational level. If we think of culture as social behaviours of a particular group of people (cities, provinces, states), we notice that changes in these groups – be it small sudden changes or larger socio-political calamities – can be translated to other cultural groups almost in an instant. These ideas of fast paced progression and dissemination of information were true at the beginning of the 20th century as they are now, mostly due to the improvements we made to infrastructures that enabled us to use data retrieval and data dissemination more efficiently. In this game of outpacing ourselves – or the fact that our technological progress is more prominent than our "moral" development – the real change came about through new social behaviours enabled by practices that circumvent culturally imprinted habits and go even further, removing all possible barriers between individuals.

Aforementioned exchanges between individuals happen through technological advances in retrieval and dissemination of data, especially in the field of communication technologies. The primary protagonist in our research story is

social media and the accompanying contemporary interpretations. One might ask, “What is social media?” If we strip its definition to the basic elements, social media is a combination of technologies and behavioural patterns. In our experience, on the technological level it is a web 2.0 application for sharing content via personal profiles/accounts, but on the behavioural level it is a networking platform for interpersonal exchanges of user generated content between individuals and/or groups. Over the past hundred years, humanity has learned that there is a strong plurality in our thought processes and the conclusions we derive from them, but no other technological advance has made it so easy to share our own thoughts with others as did electronic social media. Forums, chat applications, Facebook, Twitter, Instagram and other platforms became relevant sources of information to the same extent as books, scientific publications and newspapers had been in history. The speculated number of social media users is up to 5.17 billion people worldwide,<sup>1</sup> around 63.7% of humanity, and not all of them concern themselves with the accuracy or thoughtfulness of their statements – of course only some of this percentage is to be ascribed to people with various nefarious intentions.

We could imagine all kinds of scenarios where spreading disinformation could lead, and more importantly has led to actions of unimaginable consequences – the anti-Semitic Propaganda in the twenties and thirties of the 20th century, anti-Semitic science, racist science, the First and the Second Red Scare, Cuban Revolution, Vietnam War, Yugoslav War, the Rohingya situation, COVID-19 disinformation campaigns and many others. Since the topic of this article is the question about decision making in ethics/bioethics, these examples are a good starting point to highlight one of the fundamental principles of ethics, that sound ethical judgement is always based on the information we have on the issue we are dealing with. Sound ethical judgement is always based on facts. But what does this mean? There are three concepts we often use interchangeably without justification, truth, fact and knowledge – after millennia of debates on this issue it won’t be resolved as an introductory remark to the main topic of this article, but it should be stated in simplest terms. Facts are “occurrences” that correspond to the state of affairs in the world/reality – “The world is all that is the case”<sup>2</sup> and “The world is the totality of facts”<sup>3</sup> are the most common references when we are talking about facts, but to put it more simply “a fact is just a true truth-bearer”.<sup>4</sup> Therefore, we could say that truth is the quality of a fact, and knowledge is a justified true belief (Plato).

To understand the unbreakable interdependency between morality and fact, a small introduction into moral reflexion is required – since our notions of moral reflexions are usually taken for granted. The most common understanding of what ethics are is based on the description of this field of study as a philosophical discipline that deals with questions about good and bad, actions based on guidelines for conduct that when followed result in behaviour we define as moral. The deeper level of understanding of ethics states that ethics<sup>5</sup> are a discipline that deals with “moral reflexions”, cognitive processes we go through while deciding what action to take. These processes are usually described through a three-step path: 1) “problem definition”, recognition of a problem that demands our attention; 2) “reflexion”; and 3) “action”. Due to the complexity of our world, which includes human social context and emotional make up, our actions are layered and multi-dimensional, so that the morality of an action is just one of the dimensions of that action. The same

action can be judged in any of its dimensions by different criteria, for instance if it is legal, legitimate, safe or reckless, or the one we are interested in, if it is moral.<sup>6</sup> Therefore what is moral and if our actions are moral is going to be defined through our cognitive processes, how we defined the problem, the reflexions on the problem and in the end by our action – the decision we acted upon. One of the problems we encounter here are the criteria for judging what is moral, and these come in a vast array of cultural contexts, religious and ethical theories.

We can conclude that moral judgments often rely on (factual) information to assess situations accurately. For instance, for an individual to determine whether an action is moral, one must understand the implications and the potential consequences following from an action, the intentions behind it, and the context in which it occurs. But also, we can approach this explanation in the negative, where misinformation or ignorance of facts can lead to flawed moral judgments. The second point we should make is that while facts are crucial for informed moral reasoning, they alone cannot dictate what is morally right. Ethical reasoning, values, and principles are needed to interpret facts within a moral framework. Consequently, we need to be aware that our moral beliefs can change when we learn new facts, as well as that many moral disagreements are rooted in disputes over facts. The COVID-19 debate was often rooted in factual disagreements, which in turn influenced moral stances on responsibility towards others.

The underlying question for ethics and bioethics in the 21st century will be the problem of making informed decisions that lead to moral actions in the age of misinformation and disinformation. One possible answer to this question could be the revitalisation of the concept of orientational knowledge and the theory of integrative bioethics.

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*Global Social Media Statistics* are reports produced by the *Kepios* team; the data has been produced in July of 2024. The full statistics and the slideshow explaining them is available here: <https://datareportal.com/social-media-users> (accessed on 10 August 2024).

2  
Ludwig Wittgenstein, *Tractatus Logico-Philosophicus*, Kegan Paul, Trench Trubner & Co. Ltd., London 1922, p. 25. Available at: *Project Gutenberg*, <https://www.gutenberg.org/files/5740/5740-pdf.pdf> (accessed on 10 August 2024). In the *Tractatus Logico-Philosophicus* Wittgenstein states it as: “1.1. The world is the totality of facts, not of things.”

3  
Ibid.

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Kevin Mulligan, Fabrice Correia, “Facts”, *Stanford Encyclopedia of Philosophy*, 2020. Available at: <https://plato.stanford.edu/entries/facts/> (accessed on 8 August 2024).

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The viewpoints on ethics are taken from the article by Ante Čović published in Croatian as: Ante Čović, “Pojmovna razgraničenja: moral, etika, medicinska etika, bioetika, integrativna bioetika” [Conceptual Demarcations: Morality, Ethics, Medical Ethics, Bioethics, Integrative Bioethics], in: Ante Čović, Marija Radonić (eds.), *Bioetika i dijete. Moralne dileme u pedijatriji* [*Bioethics and the Child. Moral Dilemmas in Paediatrics*], Pergamena – Hrvatsko društvo za preventivnu i socijalnu pedijatriju, Zagreb 2010, pp. 11–24.

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Ethics and ethical reflexions need to be discerned from moral reflexions. Ethical reflexions are what we do as ethicists and by some researchers they are used interchangeably, but moral reflexions are the subject of research in ethics. Therefore, ethical reflexions and moral reflexions are not the same, subsequently the same is true for the difference between ‘ethical’ and ‘moral’.

## II

In the past fifteen years many have made attempts to formulate a theory of bioethics that would help guide our actions in this new technological era. The demand for such a theory is real and continuous, mostly because we do not have the answers on how to deal with the power we produce. Actions of individuals can change the fate of humankind with a single telephone call and with each new technology these problems become more complex and less likely to be solved without guided endeavours – approaches that put emphasis on bioethical sensibility, like integrative bioethics. For many involved in the debate the problem is not only “how”, but “where” to start since it seems that all commonly used platforms (United Nations Framework Convention on Climate Change, World Health Organisation, and many others) are not adequate or produce slow results – whereas on the other hand many countries and various interest groups refuse to participate, often hiding behind bad science and deliberate misinformation and/or disinformation.

The theoretical framework suggested here to deal with the “moral” side of these issues is integrative bioethics. According to its definition, integrative bioethics is “an open field of encounters and dialogue between different sciences and professions, and diverse approaches and worldviews, which gather to articulate, discuss and solve ethical questions concerning life, life as a whole and each of its parts, life in all its forms, shapes, degrees, stages and manifestations”.<sup>7</sup> Formulated in this way, bioethics seems to cover everything and nothing at all. Why should we use it to guide our actions, what would be its strong suit? The answer is provided in the methodology of the discipline itself, so bioethics should be “an integrative orientative science”, or “a pluriperspectival field, in which footholds and measures for orientation in the questions concerning life or the conditions and circumstances of the preservation of life are being created through the interaction of diverse perspectives”.<sup>8</sup> How are we to understand these claims? The idea behind integrative bioethics even though it sounds complex, is a simple one. There is no “problem definition” without collaboration on the interpersonal but also on the scientific level. Integrative bioethics claims to use interdisciplinary, multidisciplinary and transdisciplinary methodology – while the transdisciplinary approach surely is the most significant one in negotiating answers and defining issues in the interaction between science and society.

The advantage of integrative bioethics in dealing with social media lies in its broad scope and perspective integration. Integrative bioethics enables different disciplines and perspectives to build a common methodology and collaborate on complex problems that require a larger number of disciplines that usually do not “meet” due to disciplinary differences. Social media represent a problematic field of research that cannot be adequately reviewed from the position of a single science. Therefore, we need a transdisciplinary (or if the issue is only scientific, interdisciplinary)<sup>9</sup> field of research that allows us to step out of our disciplinary constraints and collaborate with researchers from other areas.

Transdisciplinarity requires a special approach to disciplinary research that is in the process of being established as the norm in certain fields of science. The main goal in transdisciplinary research is to establish a level of scientific enterprise that enables researchers in specific disciplines to ask “questions related to the subject jointly, form the course of research together, transfer methods from one discipline to another, but also add the implementation of

political initiatives, cultural elements and diverse social moments”.<sup>10</sup> The simplest way to understand this is to imagine an interdisciplinary research endeavour with integration of social/political factors into the course of bioethical research. The relevance for bioethics is underlined by Hrvoje Jurić as “the overcoming of [...] mutual differences, or the incorporation of these differences in a unique, bioethical view focused on questions that cannot be fathomed from the perspective of a single science or a single field of knowledge”.<sup>11</sup> Julie Thomas Klein claims that

“... transdisciplinarity transcends disciplinary worldviews through (1) more comprehensive frameworks and/or (2) problem-oriented research that crosses boundaries of academic disciplines and the public and private spheres. Major examples of the first connotation – new synthetic frameworks – include general systems theory, feminist theory, and sustainability, new paradigms for health and wellness, and new principles of unity informed by the worldview of complexity in science. In the second connotation, mutual learning, joint work, and knowledge integration are key to solving ‘real-world’ problems.”<sup>12</sup>

The basic principle of transdisciplinary research is to focus on everyday problems and their formulation as well as seeking resolutions as a joint task for the public agents and the scientific community.

The last aspect to be addressed is the question of orientational knowledge. The idea of knowledge as a factor for orientation in the world and the history (man-made world) is as old as our first definitions of knowledge by the old-Greek philosophers. In this day and age, we refer to the elaborations on the subject by the German philosopher Jürgen Mittelstraß. Mittelstraß observes that the original idea of science has been forgotten, and that science and the universities should not only be institutions that reproduce knowledge, but also that they should be institutions that provide orientation in social life. Moreover, it can be stated that in modern industrial societies, which Mittelstraß calls “technical cultures” (*technische Kulturen*), the orientational form of knowledge has almost completely disappeared. Mittelstraß establishes

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Hrvoje Jurić, “The Footholds of an Integrative Bioethics in the Work of Van Rensselaer Potter”, *Facta Universitatis* 15 (2017) 2, p. 123, <https://doi.org/10.22190/FULP1702127J>.

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Ante Čović, “Bioethik unter den Bedingungen des Postkommunismus – Fallbeispiel Kroatien”, in: Ante Čović, Thomas Sören Hoffmann (eds.), *Bioethik und kulturelle Pluralität. Die südosteuropäische Perspektive*, Academia Verlag, Sankt Augustin 2005, pp. 150–151.

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‘Multidisciplinarity’ refers to a scientific process where those involved in specific scientific disciplines work in parallel on the same subject without extra-disciplinary consultation in order to expand knowledge on the same topic. Interdisciplinarity implies the elaboration of numerous segments of research, jointly undertaken by two or more different disciplines as cooperative research. See Thomas Potthast, “Bioethik als inter- und transdisziplinäre Unternehmung”, in: Cordula Brand, Eve-Marie

Engels, Arianna Ferrari, László Kovács (eds.), *Wie funktioniert Bioethik?*, Mentis Verlag, Paderborn 2008, pp. 255–280. The difference between interdisciplinarity and transdisciplinarity is in the integration of social factors, or non-scientific factors, into the research process.

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Th. Potthast, “Bioethik als inter- und transdisziplinäre Unternehmung”, p. 261.

11

H. Jurić, “The Footholds of an Integrative Bioethics in the Work of Van Rensselaer Potter”, p. 132.

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Julie Thompson Klein, “Communication and Collaboration in Interdisciplinary Research”, in: Michael O’Rourke, Stephen Crowley, Sanford D. Eigenbrode, J. D. Wulfhorst (eds.), *Enhancing Communication and Collaboration in Interdisciplinary Research*, Sage, Los Angeles – London 2014, p. 13.

the conceptual distinction between (partial) “knowledge about mastering nature and society” and (universal) “knowledge of orientation in nature and society”,<sup>13</sup> which is very clearly summarized in the categorical differentiation between *Verfügungswissen* (usable, instrumental or technical knowledge) and *Orientierungswissen* (orientational knowledge).<sup>14</sup> Almost all of the present efforts are based on expanding our knowledge about mastering nature and society, but the knowledge needed to understand our place in the world and the interdependencies between humans (and humans and nature) that shape us, have been lost. But our last resorts and remaining efforts to steer humanity from the path of ecological crisis and global turmoil are being endangered by misinformation.

### III

So far, we have mentioned the presence of misinformation but we have not defined what we are referring to. The most common form of misinformation in the last few years has been “fake news”, and by fake news we mean “articles that are intentionally and verifiably false and could mislead readers”.<sup>15</sup> Fake news is used as a cover term for all kinds of intentionally fabricated news. Melissa Zimdars in her article for *The Washing Post* writes about four different kinds of misinformation: false, misleading, clickbait, and satire.<sup>16</sup> Some of her claims coincide with Don Fallis’ analysis of disinformation – information disseminated or created with the explicit purpose of deceiving people.<sup>17</sup> So far, we have only used the concept of misinformation, but now we are making a distinction between misinformation and disinformation. Misinformation is information that can mislead people, whether deliberately or not, by definition it is informational content that makes decision-making practices vulnerable. On the other hand, disinformation is intentional deception; we could claim its only purpose is to influence the decision-making process in a negative capacity. Fake news can be misinformation and disinformation, although often they start as disinformation shared by a public figure, or a person enabled by his position or platform (number of friends, subscribers, followers and so on) to reach a wider audience. Once the information is out there it can be picked up as misinformation by anyone and shared with others almost like a virus. These kinds of explanations of misinformation dissemination might seem trivial; sadly, they are a fact in the age of social media. The most common ways to spot fake news could be arranged into four points:

1. *Research the source.* Author details, article details and the media outlet info-page can be helpful to determine if your source is a valid news source. Checking if the article references real life dates and recorded events as well as other reference points (links to other pages, persons and places) is always a good starting point to make sure you are not forwarding misinformation.
2. *Critical reading.* Reading the article past the catchy or scandalous headline wasn’t always something that needed to be said to the average news consumer. A study done in 2014 by the Media Insight Project – an initiative of the American Press Institute and the Associated Press-NORC Center for Public Affairs Research – has shown that only 4 in 10 Americans read more than a headline of the article. Therefore, reading through the article with your critical sensibilities might help to dismantle some of the nebulous headline statements.

3. *Intention.* Reviewing the article, you have to read for the sections that are trying to invoke emotional responses and focus your attention on biased points of view signalling the intentions of the author.
4. *Verification.* After reading the article in question you might want to “fact check” or verify the information by consulting other articles on the same topic written by known and respected experts.

Misinformation and disinformation are becoming a big hindrance while dealing with health-related issues, and the matters of informed consent. Professionals are experiencing more and more issues with gathering of informed consent and the subjects concerned with it understand it less and less. One of the main reasons is the presence of easily accessible disinformation.

## IV

Informed consent was conceived after the Second World War<sup>18</sup> and it has its roots in many post-war documents and was refined throughout the decades it is in use – the *Declaration of Geneva*, *Declaration of Helsinki* and other documents expanded on its definitions and complexity. As a legal document it is applicable in various fields of medical practice and research with the goal to protect the rights and dignity of persons.<sup>19</sup> Informed consent is given when the person has been provided with sufficient information in order to understand all the facts, potential implications and consequences of the actions taken concerning the person. The number of crucial concepts needed to be considered to establish informed consent varies from form to form but we could agree on five<sup>20</sup> most important, voluntariness, capacity, disclosure, understanding and

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Jürgen Mittelstraß, *Wissenschaft als Lebensform. Reden über philosophische Orientierungen in Wissenschaft und Universität*, Suhrkamp, Frankfurt a. M. 1982, p. 12.

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See *ibid.*

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Hunt Allcott, Matthew Gentzkow, “Social Media and Fake News in the 2016 Election”, *Journal of Economic Perspectives* 31 (2017) 2, p. 213.

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Melissa Zimdars, “My ‘fake news list’ went viral. But made-up stories are only part of the problem”, *The Washington Post*, 2016. Available at: <https://www.washingtonpost.com/posteverything/wp/2016/11/18/my-fake-news-list-went-viral-but-made-up-stories-are-only-part-of-the-problem/> (accessed on 9 August 2024).

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Don Fallis, “What Is Disinformation?”, *Library Trends* 63 (2015) 3, p. 402, <https://doi.org/10.1353/lib.2015.0014>.

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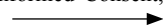
The legal term “informed consent” was coined by Paul G. Gebhard for use in a medical malpractice case in 1957. See Eric Pace, “P. G. Gebhard, 69, Developer of the Term ‘Informed Consent’”, *The New York Times*, 26 August 1997. Available at: <https://www.nytimes.com/1997/08/26/us/p-g-gebhard-69-developer-of-the-term-informed-consent.html> (accessed on 9 August 2024).

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See Ahmed Elsayyad, “Informed Consent for Comparative Effectiveness Trials”, *New England Journal of Medicine* 370, (2014) 20, pp. 1958–1959, <https://doi.org/10.1056/NEJMc1403310#SA3>.

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Other authors propose different definitions: “An informed consent resides on its three critical and essential elements including voluntarism, information disclosure, and decision-making capacity. For an ethically valid and real informed consent, these critical elements are required to be essentially employed and adequately present while informed consent is expressly sought from a research subject.” (Ruth R. Faden, Tom L. Beauchamp, Nancy E. Kass, “Informed Consent,



decision.<sup>21</sup> These concepts refer to predispositions that need to be met before the medical research in question can start.<sup>22</sup>

“Voluntariness means that an individual’s decision to participate is made without coercion or persuasion. Capacity relates to an individual’s ability to make decisions that stems from his or her ability to understand the information provided. Disclosure involves giving research participants all relevant information about the research, including its nature, purpose, risks and potential benefits as well as the alternatives available. Understanding implies that research participants are able to comprehend the information provided and appreciate its relevance to their personal situations. Decision is that made to participate, or not.”<sup>23</sup>

The study on informed consent that we are interested in was conducted in 2014 and it was the first of its kind. Until that point no meta-analysis of patients’ understanding of informed consent had been done – knowing that the literature on informed consent has been accumulating since the 1980s it is strange that no meta-analysis on this topic had been done sooner.<sup>24</sup> The study in question included an analysis of 103 studies, but in the end 135 data sets were used, because some studies evaluated more than one population.

“The sample size ranged from 8 to 1789 participants and the response rate to interview questions ranged from 9.3% to 100%. Participants were adults in 95 data sets, parents or guardians in 34, adult and child patients in three, child patients in two and adult patients or parents in one. Overall, 79% (106) of data sets were conducted in middle- or high-income countries – as classified by the World Bank – and 67% (90) did not report the phase of the clinical trial. The medical specialty was cancer in 33% (44) of data sets, infectious disease in 14% (19), vaccines in 10%, (13) cardiovascular disease in 7% (9), neurology in 6% (8) and other in 31% (42). Moreover, 98% (132) were published in English and only 1% each in Japanese (1) and French (2).”<sup>25</sup>

The analysis yielded different results for different parts of informed consent forms, but none of the results showed a 100% level of understanding by the study participants.

“The highest proportions were 75.8% (95% CI:<sup>26</sup> 70.6–80.3) for freedom to withdraw from the study at any time, 74.7% (95% CI: 68.8–79.8) for the nature of study, 74.7% (95% CI: 67.9–80.5) for the voluntary nature of participation and 74.0% (95% CI: 65.0–81.3) for potential benefits.” (ibid.) “Lower proportions were 69.6% (95% CI: 63.5–75.1) for the purpose of the study, 67.0% (95% CI: 57.4–75.4) for potential risks and side-effects, 66.2% (95% CI: 55.3–75.7) for confidentiality, 64.1% (95% CI: 53.7–73.4) for the availability of alternative treatment if withdrawn and 62.9% (95% CI: 45.5–77.5) for knowing that treatments were being compared. In addition, 62.4% (95% CI: 50.1–73.2) had no therapeutic misconceptions. The lowest proportions were 54.9% (95% CI: 43.3–65.0) for naming at least one risk, followed by 53.3% (95% CI: 38.4–67.6) for understanding of placebo and 52.1% (95% CI: 41.3–62.7) for understanding of randomization.”<sup>27</sup>

These figures reveal a problematic aspect of informed consent; furthermore, they are problematic on many levels. We know that generalizations based on one meta-analytical study cannot be considered a definitive proof, but the study is indicative especially considering the volume of the data set (135 studies) used. The 2014 study provides a comprehensive analysis of patient understanding of informed consent, revealing substantial deficiencies in comprehension across many various elements. Despite informed consent being a cornerstone of ethical research, the study shows that many participants struggle with grasping critical aspects such as risks, placebo use, and randomization. These findings highlight the persistent challenge of effectively communicating complex medical information to patients and underscore the need for more effective strategies to ensure that consent is truly informed. The study serves as a call to action for researchers and clinicians to improve the clarity and accessibility of consent materials.

The question that remains unanswered is why the figures are so low, why participants do not understand informed consent. While doing research into this problematic a study done by Erin E. Donovan and her colleagues at the University of Texas Austin has shed some light on the topic. The answer to “why are the patients signing consent forms they don’t understand” is given as a twofold problem: reading and literacy. In her study done on 278 patients in various doctors’ offices and waiting rooms they quizzed the patients about what specific words in the informed consent form mean, on the level of everyday language and on the level of health literacy. When they quizzed them about the content of the forms only 4% understood and could explain all of the legal and medical terms used in the form.<sup>28</sup> Donovan’s conclusion was that the language of the forms for informed consent documents in the United States are on the “college level” – no matter what country we analyse the issue of language will remain, for the simplest of reasons, informed consent is (almost) always communicated between a professional and a layman. The other part of the problem is a broader issue, health literacy. Fake news as the predominant expression of disinformation is threatening our health literacy – as witnessed by the COVID-19 crisis. The secondary issue concerns how poorly scientific knowledge has been communicated in the public sphere. The issue has two aspects: 1) Scientific knowledge the science community that has been communicated to media outlets; and, 2) How media outlets communicate the scientific knowledge to the public.

The claim that the influence of disinformation on health decisions is progressively worsening has been recently addressed by the World Health Organization:

“Disinformation in public health is a distinct type of information risk which, unlike misinformation, is created with malicious intent to sow discord, disharmony and mistrust in targets such as government agencies, scientific experts, public health agencies, private sector and law

Comparative Effectiveness, and Learning Health Care”, *New England Journal of Medicine* 370, (2014) 8, pp. 766–768, <https://doi.org/10.1056/NEJMhle1313674>.

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See Tom Beauchamp, James F. Childress, *Principles of Biomedical Ethics*, Oxford University Press, New York 1979. See also: Marcela G. Del Carmen, Steven Joffe, “Informed Consent for Medical Treatment and Research. A Review”, *Oncologist* 10 (2005) 8, pp. 636–641, <https://doi.org/10.1634/theoncologist.10-8-636>.

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See Nguyen Thanh Tam, Nguyen Tien Huy, Le Thi Bich Thoa, Nguyen Phuoc Long, Nguyen Thi Huyen Trang, Kenji Hirayama, Juntra Karbwang, “Participants’ Understanding of Informed Consent in Clinical Trials over Three Decades: Systematic Review and Meta-Analysis”, *Bulletin of the World Health Organization* 93 (2015), pp. 186–198, <http://dx.doi.org/10.2471/BLT.14.141390>.

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Ibid.

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See *ibid.*

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Further data on the study is available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4371493/> (accessed on 9 August 2024).

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‘CI’ means *confidence interval*. The confidence interval shows the range of values you expect the true estimate to fall between if you redo the study.

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Ibid.

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Erin E. Donovan, Brittani Crook, Laura E. Brown, Angie E. Pastorek, Camille A. Hall, Michael S. Mackert, Keri K. Stephens, “An Experimental Test of Medical Disclosure and Consent Documentation: Assessing Patient Comprehension, Self-Efficacy, and Uncertainty”, *Communication Monographs* 81 (2014) 2, pp. 239–260, <https://doi.org/10.1080/003637751.2013.876059>.

enforcement, among others. The potential impacts of disinformation can be understood through examples during the COVID-19 pandemic. The COVID-19 pandemic had two key elements that created the perfect storm for disinformation to proliferate and spread. First, it swiftly caused global fear, uncertainty and doubt. Second, it occurred at a point in history where we can easily access, create and share information (as well as misinformation and disinformation) widely over the internet, mobile telecommunications, media and social media platforms. As the pandemic took hold, many posts appeared on social media and spread through instant messaging communications, stoking uncertainty about the treatment, the safety and effectiveness of vaccines, the usefulness of social distancing, and more. This caused social protest, turmoil, delayed vaccine uptake and led to higher death rates in some instances.”<sup>29</sup>

The statement also indicated the direct link between social media and health decision-making.

## V

The disinformation dissemination phenomena are crippling decision-making processes in various fields. Bioethics and biomedicine are just examples of discourses being influenced. The implementation of transdisciplinary approaches and orientational knowledge should focus on emancipatory learning for the public agents involved in it and introspective learning for scientists involved in the processes of gathering and in the application of the data – these processes cannot be approached without auto-reflection on both sides. The main goal is to engage in an emancipatory process of becoming critically aware of how and why psycho-cultural assumptions form the way we construct and apply scientific knowledge. By reconstructing the analysis of the structure of the dialogue, we allow a more inclusive and selective integration of experiences and actions based on new understanding. Understanding of medical facts by the layman most often experienced in the role of patient, and the understanding of the medical expert for the “situation” of the patients – as well as the general lack of competence to make informed decisions without proper knowledge in the field all need to be addressed.

We propose engaging in research that would aim to develop a subject (be it the expert or the layman) that is critically reflective, not rigidly formed but open, and that breaks the expectations that the techno-scientific discourse has of scientists and how the mediated information effects the patients. We are talking about the ability to overcome monoperspectivism and move towards a subject that is seeking more than usable knowledge – a subject that will find orientational knowledge for decision making in their everyday life, and in the narrow context of this article, for their medical issues.

We perceive bioethics as “an integrative orientative science”, i.e. as “a pluriperspectival field, in which footholds and measures for orientation in the questions concerning life or the conditions and circumstances of the preservation of life are being created through the interaction of diverse perspectives”.<sup>30</sup> If we apply this theoretical framework to our example, after establishing the conceptual distinction between (partial) “knowledge about mastering nature and society” and (universal) “knowledge of orientation in nature and society”, we conclude that being literate in the contemporary sense of the word means to engage orientation knowledge.

Definitions of literacy are contextual, and all information and data-related practices of humans happen in particular contexts. Rigid structures are bound to stay static and uncritical. This represents the move from the functional notion of literacy to the critical and creative notions of literacy. Informed by the

information literacy discourse and the critical outlook on health literacy we have proposed those practices that will equip patients and healthy individuals for informed decision making.

In conclusion, this new literacy proposal based on orientational knowledge should be considered in terms of a wider educational policy expressed as learning “what is necessary is to bring the youth in the position to start the lifelong dedication and self-cultivation of a personal critical attitude towards their practices with information and data, as well as an critical attitude towards the characteristics of information resources they receive”.<sup>31</sup>

## VI

The landscape of bioethics is evolving rapidly, and the issues arising are deeply intertwined with the cultural shifts and technological advancements of our time. As we navigate this complex terrain, the crucial interplay between morality and factual knowledge becomes increasingly evident, in some endeavours more than other. The proliferation of misinformation and disinformation, especially through social media (and other media outlets), poses significant challenges to informed decision-making in bioethical contexts.

In response to these challenges, the concept of orientational knowledge and the theory of integrative bioethics offer promising avenues for addressing the complex ethical dilemmas of the 21st century. Integrative bioethics, as an interdisciplinary and transdisciplinary endeavour, emphasizes collaboration across diverse perspectives and fields of knowledge. It seeks to provide footholds for navigating ethical questions in a rapidly changing world, where traditional frameworks may fall short. The main benefits of these theories consist in their openness towards the public and the possibility to communicate scientific knowledge to the public, but also to gather feedback on potentially less understandable or incomprehensible information.<sup>32</sup>

However, the dissemination of misinformation undermines the foundation of these practices, especially on informed consent, a cornerstone of ethical practice in medicine and research. Studies have revealed deeply concerning levels of misunderstanding among patients regarding the nature and implications of medical procedures, highlighting the urgent need for improved communication and literacy in healthcare contexts.

To address these challenges, a paradigm shift in education and literacy is necessary. We propose a new literacy framework grounded in orientational

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Statement made by the World Health Organisation in February 2024, in the “Questions and Answers” section. World Health Organisation, „How does information manipulation affect public health?”, in: *Disinformation and Public Health*, 6 February 2024. Available at: <https://www.who.int/news-room/questions-and-answers/item/disinformation-and-public-health> (accessed on 6 August 2024).

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A. Čović, “Bioethik unter den Bedingungen des Postkommunismus – Fallbeispiel Kroatien”, pp. 150–151.

31

Denis Kos, Hrvoje Jurić, Marko Kos, “Integrative Bioethics and Knowledge Landscapes”, in: Anna Lydia Svalastog, Srećko Gajović, Andrew Webster (eds.), *Navigating Digital Health Landscapes. A Multidisciplinary Analysis*, Palgrave MacMillan, Singapore 2021, pp. 67–87, doi: [https://doi.org/10.1007/978-981-15-8206-6\\_4](https://doi.org/10.1007/978-981-15-8206-6_4).

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See *ibid.*

knowledge, which empowers individuals to critically engage with information and make informed decisions. This approach transcends mere functional literacy, fostering a deeper understanding of the complexities of contemporary issues and equipping individuals with the skills to navigate them.<sup>33</sup>

In essence, the future of bioethics hinges on our ability to integrate diverse perspectives, confront misinformation, and cultivate a critical and informed citizenry. By embracing the principles of integrative bioethics and orientational knowledge, we can navigate the ethical complexities of our time and work towards a more just and equitable future for all.<sup>34</sup>

Marko Kos

### Orijentacijsko znanje i promjenjivi zahtjevi bioetike

#### Integrativna bioetika i njezin pogled na informirani pristanak

##### **Sažetak**

*Koncept orijentacijskog znanja, kako ga je predstavio Jürgen Mittelstraß, važan je izvor za definiranje diskurzivnih nestabilnosti i neadekvatnosti u različitim disciplinama. Kada je u pitanju bioetika, Mittelstraßov rad može poslužiti i u kontekstu pročišćavanja suvremenih teorijskih pozicija, posebice pojma informiranog pristanka. Današnji problemi u odnosu između pacijenata i liječnika postali su još složeniji s postmodernističkim znanstvenim diskursom i njegovim novim trokrakim artikulacijama: »alternativne činjenice«, »lažne vijesti« i »era post-istine«. Iza ovih koncepata skrivene su ideje o »pogrešnom predstavljanju činjenica«, »diskreditiranju činjenica« i »ekvivalenciji između činjenica i emocija« – jednom riječju, »protučinjenične iteracije« sadržaja. Ovi stavovi prema istini zamagljuju važne teorijske zahtjeve koji omogućuju bioetički (kao i etički) zdrave pozive na prosudbu stručnjaka. Preklapanje činjeničnih i protučinjeničnih izjava čini kretanje složenim bioetičkim krajolikom gotovo nemogućim bez integrativnog i orijentacijskog pristupa. Mittelstraßovo shvaćanje orijentacijskog znanja postaje nezamjenjiv alat za kritičku analizu širenja informacija i njihovu integraciju u odlučivanje u bioetici. Stoga je cilj ovog članka ponuditi analizu tih pojmova u integrativnoj bioetici.*

##### **Ključne riječi**

integrativna bioetika, informirani pristanak, lažne vijesti, pismenost, orijentacijsko znanje, Jürgen Mittelstraß

Marko Kos

### Orientierungswissen und die sich ständig ändernden Anforderungen der Bioethik

#### Integrative Bioethik und ihre Auseinandersetzung mit informierter Einwilligung

##### **Zusammenfassung**

*Das von Jürgen Mittelstraß vorgestellte Konzept des Orientierungswissens ist eine wichtige Ressource zur Definition diskursiver Instabilitäten und Unzulänglichkeiten in verschiedenen Disziplinen. Wenn es um Bioethik geht, kann Mittelstraß' Arbeit auch im Kontext der Weiterentwicklung zeitgenössischer theoretischer Positionen, insbesondere des Konzepts der informierten Einwilligung, genutzt werden. Die heutigen Probleme mit der Beziehung zwischen*

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See *ibid.*

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See *ibid.*

*Patienten und Ärzten sind durch den postmodernen wissenschaftlichen Diskurs und seine neuen dreigleisigen Artikulationen noch komplexer geworden: „alternative Fakten“, „Fake News“ und die „Post-Truth-Ära“. Hinter diesen Konzepten verbergen sich Ideen der „falschen Darstellung von Fakten“, der „Diskreditierung von Fakten“ und der „Äquivalenz zwischen Fakten und Emotionen“ – mit einem Wort „kontrafaktische Iterationen“ von Inhalten. Diese Einstellungen zur Wahrheit verwischen wichtige theoretische Anforderungen, die bioethisch (wie auch ethisch) fundierte Urteilsforderungen für Fachleute ermöglichen. Die Überschneidung von sachlichen und kontrafaktischen Aussagen macht es nahezu unmöglich, sich in der komplexen bioethischen Landschaft ohne einen integrativen und orientierenden Ansatz zurechtzufinden. Mittelstraß' Verständnis von Orientierungswissen wird zu einem unverzichtbaren Werkzeug für die kritische Analyse der Informationsverbreitung und ihrer Integration in die Entscheidungsfindung in der Bioethik. Ziel dieses Artikels ist es daher, uns eine Analyse dieser Konzepte in der integrativen Bioethik zu liefern.*

**Schlüsselwörter**

Integrative Bioethik, informierte Einwilligung, *Fake News*, *Literacy*, Orientierungswissen, Jürgen Mittelstraß

**Marko Kos**

**Connaissance orientante et exigences changeantes de la bioéthique**

**La bioéthique intégrative et sa vision du consentement éclairé**

**Résumé**

*Le concept de connaissance orientante, tel qu'il a été présenté par Jürgen Mittelstraß, constitue une ressource importante pour définir les instabilités discursives et les inadéquations au sein de différentes disciplines. Lorsqu'il est question de bioéthique, le travail de Mittelstraß peut également être utile pour clarifier les positions théoriques contemporaines, en particulier en ce qui concerne le concept de consentement éclairé. Les problèmes actuels dans la relation entre patients et médecins se sont encore complexifiés avec le discours scientifique postmoderne et ses nouvelles articulations triples : « faits alternatifs », « fausses informations » et « ère de la post-vérité ». Derrière ces concepts se cachent les idées de « mauvaise représentation des faits », de « disqualification des faits » et d'« équivalence entre faits et émotions » – en un mot, les « itérations anti-factuelles » du contenu. Ces attitudes envers la vérité brouillent les exigences théoriques fondamentales qui permettent des appels bioéthiques (et éthiques) sains au jugement des experts. Le chevauchement entre déclarations factuelles et anti-factuelles rend presque impossible de naviguer dans le paysage bioéthique complexe sans une approche intégrative et guidée. La compréhension de la connaissance d'orientation par Mittelstraß devient un outil indispensable pour l'analyse critique de la diffusion de l'information et de son intégration dans la prise de décision en bioéthique. L'objectif de cet article est donc de proposer une analyse de ces concepts dans le cadre de la bioéthique intégrative.*

**Mots-clés**

bioéthique intégrative, consentement éclairé, *Fake News*, *Literacy*, connaissance orientante, Jürgen Mittelstraß