

Text Analysis of the *Universal Declaration on Bioethics and Human Rights*

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Abstract

The *Universal Declaration on Bioethics and Human Rights* published in 2005 and signed by 191 countries, is a milestone in bioethics for expanding its scope beyond biomedical issues, emphasising social justice. It is important that the Declaration be broadly disseminated to the general public, including children and teenagers, as it has been done with other international documents. With this in mind, a classic content analysis of the Declaration was carried out, which allowed for the regrouping of the phrasal topics. Three nuclei of content were found: a self-referential nucleus, a nucleus of biomedical issues and a nucleus of ethical values and principles of social justice. It is hoped that this analysis will help the dissemination and greater understanding of the document, making the document better known by a wider public.

Keywords: Bioethics. Human rights. Education.

Resumo

Análise textual da *Declaração Universal sobre Bioética e Direitos Humanos*

A *Declaração Universal sobre Bioética e Direitos Humanos* da Unesco, publicada em 2005 e assinada por 191 países, é considerada marco por expandir a abrangência da bioética para além das questões biomédicas e enfatizar a justiça social. Sua ampla divulgação para o público em geral é importante, inclusive para o público infanto-juvenil, como tem sido feito com outros documentos internacionais. Pensando neste propósito, foi realizada análise textual clássica a fim de reagrupar os tópicos frasais da *Declaração*. Foram encontrados três núcleos de conteúdo: um autorreferente, outro sobre questões biomédicas e um terceiro sobre valores éticos e princípios de justiça social. Espera-se que esta análise colabore com a divulgação e compreensão do documento, facilitando sua circulação entre um público mais abrangente.

Palavras-chave: Bioética. Direitos humanos. Educação.

Resumen

Análisis textual de la *Declaración Universal sobre Bioética y Derechos Humanos*

La *Declaración Universal sobre Bioética y Derechos Humanos*, promulgada en 2005 y firmada por 191 países, constituye un hito en la bioética por ampliar su alcance más allá de las cuestiones biomédicas, haciendo énfasis en la justicia social. Es importante que haya una amplia difusión de la *Declaración* al público en general, inclusive para el público infanto-juvenil, tal como se ha hecho con otros documentos internacionales. Pensando en este propósito, se realizó un análisis textual clásico de la *Declaración*, que permitió reagrupar los tópicos discursivos. Se encontraron tres núcleos de contenido: un núcleo autorreferencial, uno sobre cuestiones biomédicas y un núcleo sobre los valores éticos y los principios de justicia social. Se espera que este análisis pueda colaborar con la difusión y con una mayor comprensión del documento, facilitando que sea conocido por un público más amplio.

Palabras clave: Bioética. Derechos humanos. Educación.

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As an international benchmark in bioethics and public health, the *Universal Declaration on Bioethics and Human Rights* (UDBHR)¹ needs to be more widely disseminated and known. One of the strategies to stimulate its mass communication is to investigate effective linguistic and aesthetic criteria to transform the normative text into reflective text, as it has been done with the *Universal Declaration of Human Rights*², which has already been adapted for illustrations, infographics etc., reaching even the children's audience.

Contextualization

According to Garrafa and Porto³, bioethics has expanded its field of study and action, including, among the issues related to the quality of human life, topics that had been only touched on until now : human rights and citizenship, allocation of human resources and scarce resources, preservation of biodiversity, finiteness of natural resources, ecosystem balance, genetically modified food, racism and other forms of discrimination, etc.

In other words, bioethics addresses both emerging issues and persistent issues³. The first concerns ethical conflicts arising from the advancement of science, especially in regard to new treatments and public health in general. Persistent issues derive from the chronic inequality and social injustice in the world.

Bioethics, therefore, sought to deepen its conceptual bases, since there was a need to adapt its references to the reality of the poorest populations and inhabitants of nations with high rates of social exclusion. In this sense, it became essential to work with new focus, approaches and categories that would give more adequate answers to the problems identified³.

Saada⁴ states that the epistemological status of bioethics goes beyond the four universal principles of Beauchamp and Childress⁵ (autonomy, beneficence, non-maleficence and justice). Recent structural changes in the concepts of the field, with the *Universal Declaration on Bioethics and Human Rights* (UDBHR)¹ adopted by Unesco in 2005, have opened space for critical approaches that include social, sanitary and environmental areas.

The UDBHR proposes ethical reflection as a tool for governments to establish appropriate laws and regulations in the bioethical field, consolidating and guiding health protection policies. Its content consolidates the concrete advance of a new epistemological framework and thematic agenda for the 21st century: a bioethics that is closer to the persistent conflicts that afflict most countries.

Dissemination of the UDBHR for the appropriation of bioethical thought

Despite the relationship between level of schooling and conceptual grasping of the UDBHR or the values reinforced in it, the difficulty of understanding this document does not stem from ignorance or unawareness of people regarding the situations contemplated in the document, but rather from the non comprehension of vocabulary or concepts of the principles elucidated therein⁶:

*Since 2005 [year of the UDBHR's adoption], "steps have been taken to make this content public, but there is still the need to advance so that its dissemination becomes a practical reality applied to the lives of people, communities and countries. The lack of knowledge and understanding of the UDBHR contributes to the maintenance of an uneven status quo and creates a situation where populations do not take advantage from the various nuances of social justice. This is because the unawareness, coupled with factors such as low level of schooling and lack of debate on issues which are crucial to people's lives, reinforces ignorance, apathy and lack of mobilisation to pressure public and private powers to adopt solutions that aim at social and economic development for all"*⁷.

Although the UDBHR arouses debates and reflections around the world, there is still a lack of awareness of its content - by the civil society, communication professionals, public and political managers and researchers in general, which maintains a large part of the world population excluded from participation and important political decision-making⁸. However, this situation is not exclusive to less educated populations: recently, in a landmark decision on embryonic stem cells, ministers of the Brazilian Federal Supreme Court did not even mention the UDBHR as a basis for the judgment⁹.

According to Caetano and Garrafa⁷, in order to become an up-to-date, dynamic instrument capable of provoking reflections and practical transformations, the UDBHR itself presents two articles (22 and 23) that deal with the need for its diffusion and dissemination. In other words, *the dissemination of the main concepts of the UDBHR has to be seen as a global political act, (...) assumed directly by the 191 nations that signed the document. And this interventionist act depends, among other points, on a structured plan of communicative action to achieve the goal of transforming the social reality*¹⁰.

Considering the above, the purpose of this work was to interpret the UDBHR's articles through

semiotics and analysis of the text, identifying thematic-conceptual nuclei that could support the dissemination of this fundamental document, especially among children and adolescents.

Method

The official Portuguese version of the UDBHR was analysed in order to separate phrasal topics (main and secondary ideas) of each section of the text: the preamble and the articles. The classic textual analysis method was used, as described by Barros¹¹, with the heading of each article being considered the main idea, and the other parts (paragraphs and itens), secondary and complementary ideas.

After the phrasal topics were defined, the articles were regrouped by semantic and conceptual similarity, allowing reinterpretation of the document. The analysis was guided by semiotic theory with the objective of reorganising the structure of the text, reaching results that could be used in the adaptation of the UDBHR to different media tools.

Such a choice is justified by the fact that semiotics focuses on what the text says and how it does it, through the meaning defined by procedures and mechanisms that structure the text. Thus, unlike linguistics or semantics, semiotics provides the mobility of the same textual record in different artistic or cultural manifestations, with minimal loss of the original structures of meaning.

It should be noted that this methodological choice is adequate to the objective of this work: to look at the internal structures of the text. Although the semantic parallelism method is useful in interpretative matters, as in the comparative study of normative bioethical documents¹², the focus here is on the internal textual regrouping of the UDBHR.

Thus, in order to proceed to the semiotic analysis of the document under study, we used the concepts of

“fundamental level” for the content of the text, and of “elementary statements” for the narrative aspect of the text, according to the theory of Barros¹¹. The first refers to the meaning of the text as identification of the minimum elements that allow to understand the roles in the discourse. The second concept corresponds to the different interactions (of conformity or lack of conformity) between these fundamental elements. Such interactions allow the reader to effectively decode the intentions of the discourse.

Following this identification process, the statements of the UDBHR articles were analysed in order to define the relations between the subjects and objects of the discourse and to group the convergent articles into similar groups for later reorganisation of the document analysed.

Results

In its preamble, the UDBHR values the freedom of science and research and the welfare of individuals, families, groups or communities and human kind as a whole. The text is based on the recognition of human dignity and observance of human rights and fundamental freedoms. In it, there is a strong call for the protection of the most vulnerable and respect for the autonomy of individuals.

The need for documents with adequate clarifications to obtain the consent of individuals undergoing biomedical research is emphasised. The text still rejects double standards in research and reaffirms the social responsibility of the state in relation to health, declaring the principle of benefit sharing and broadening the view of respect and protection for the future of humanity and the planet.

Except for some differentiations between the action subject and the concrete object generated, the semiotic analysis of each article found a preponderance of disconnected relations between subjects of the statement (Table 1).

Table 1. Semiotic elements of the Portuguese text of Unesco’s Universal Declaration on Bioethics and Human Rights.

| Article UDBHR | Subject of the Action | Subject of the state | Concrete object | Reflective object |
|---|-----------------------|----------------------|---|-------------------------------|
| 1º Scope | Norm | States | Normative guidance | – |
| 2º Aims | Norm | States | Normative guidance | – |
| 3º Human dignity and human rights | Norm | Bioethics’ agents | welfare of the individual and interest of science | – |
| 4º Benefit and Harm | Norm | Bioethics’ agents | Effects of advances in science | – |
| 5º Autonomy and individual responsibility | World community | World community | – | Conceptualisation of autonomy |

continue...

Table 1. Continuation

| Article UDBHR | Subject of the Action | Subject of the state | Concrete object | Reflective object |
|---|-----------------------|----------------------|--|--|
| 6 ^o Consent | Norm | Bioethics' agents | Clinical treatment and research | – |
| 7 ^o Persons without the capacity to consent | Norm | Bioethics' agents | Incapacity to express consent | – |
| 8 ^o Respect for human vulnerability and personal integrity | Norm | Bioethics' agents | Respect for human vulnerability and personal integrity | – |
| 9 ^o Privacy and confidentiality | Norm | Bioethics' agents | Confidentiality | – |
| 10 ^o Equality, justice and equity | World community | World community | – | Conceptualisation of equality, justice and equity |
| 11 ^o Non-discrimination and non-stigmatisation | World community | World community | – | Conceptualisation of non-discrimination and non-stigmatisation |
| 12 ^o Respect for cultural diversity and pluralism | World community | World community | – | Conceptualisation of diversity and pluralism |
| 13 ^o Solidarity and cooperation | Norm | States | Encouragement for international cooperation | – |
| 14 ^o Social responsibility and health | Norm | Bioethics' agents | Social responsibility | – |
| 15 ^o Sharing of benefits | Norm | Bioethics' agents | Sharing of benefits resulting from scientific research | – |
| 16 ^o Protecting future generations | Norm | Bioethics' agents | Impact on genetics | – |
| 17 ^o Protection of the environment, the biosphere and biodiversity | World community | World community | – | Conceptualisation of the protection of biodiversity |
| 18 ^o Decision-making and addressing bioethical issues | Norm | Bioethics' agents | addressing bioethical issues | – |
| 19 ^o Ethics committees | Norm | Bioethics' agents | Establishment of ethics committees | – |
| 20 ^o Risk assessment and management | Norm | Bioethics' agents | Promotion of risk management | – |
| 21 ^o Transnational practices | Norm | Bioethics' agents | Promotion of transnational practices | – |
| 22 ^o Role of States | Norm | States | Application of norms | – |
| 23 ^o Bioethics education, training and information | Norm | States | Dissemination and normative fostering | – |
| 24 ^o International cooperation | Norm | States | Integration of the bioethics community | – |
| 25 ^o Follow-up action by UNESCO | Norm | States | Participation of Unesco | – |
| 26 ^o Interrelation and complementarity of the principles | Norm | States | Interpretation guidance | – |
| 27 ^o Limitations on the application of the principles | Norm | States | Application of the norms | – |
| 28 ^o Denial of acts contrary to human rights, fundamental freedoms and human dignity | Norm | States | Restriction of the norms | – |

The analysis allows dividing the UDBHR into three large nuclei of statements. The first one is referential, that is, it is formed by articles related to the declaration itself, defining, formalising and objectifying its specificity, application and validity. In these articles (1st, 2nd, 22nd to 28th), the subject of the action is the norm and the agents are the states/countries, which generate concrete objects in the form of normative guidance.

The second nucleus is specific and depicts exclusively clinical, legal, or academic issues. In the articles that materialise it (3^o, 4^o, 6^o to 9^o, 14^o to 16^o, 18^o to 21^o), the subject of action is the norm and the subject of state are the bioethical agents that generate object of concrete signification in the form of orientation in bioethical practice.

The third nucleus is reflexive and presents concepts related to moral values. Although it is difficult to define the subjects of the statements, it is concluded that in the articles of this nucleus (5^o, 10^o to 12^o, 17^o), the subject of action and the subject of state are the world community, which generate object of reflective meaning in the form of moral or ethical conceptualisation.

Discussion

The semiotic analysis of a normative text must follow two methodological steps. In the first place, one must identify the fundamental elements and determine the types of interaction between them, in the simplest, elementary and most concise way possible. Take, for example, an excerpt from Article 6 of the UDBHR, which states that: *any preventive, diagnostic and therapeutic medical intervention is only to be carried out with the prior, free and informed consent of the person concerned, based on adequate information*¹.

Following the established method of analysis, we first identify the minimum elements of the text: a) preventive, diagnostic or therapeutic medical intervention; b) the subject that modifies or promotes the action (consent term); c) the subject of the state of the text, that is, the element that is subjected to the actions of the discourse (doctor and patient) and, finally, d) the intended product (clinical treatment or qualitative research).

In normative texts, the concepts of subject of action and object of action do not necessarily presuppose an animate being. In the example analysed, the subject of action is a document (the consent term), while the object (information) is

also an inanimate entity. It is also observed that the subjects of the state of action are patient and physician, which, in an elementary way, can be categorised as “bioethics agents» (Table 1).

In the second methodological step, the relationship between subject, action and object of the text are identified. A single aspect must be observed in this step of analysis: whether the subject of the action and that of the state are represented in the text by the same or different elements. This is what determines the types of meaning relationships generated in a discourse. Thus, if the subject of the action is the same that suffers its consequences, the product of this text is reflexive; if the subject of the action and that of the state are represented by distinct elements, the meaning of the statement is concrete.

In general, normative texts, especially legal ones, present a self-referential core that exposes its internal organisation, the validity of the text and its comprehensiveness, as well as future mechanisms of updating and correction^{7,13}. As an international text, with format and legal scope, the UDBHR presents in its preamble this type of consideration, which, despite consolidating and validating the text, tends not to arouse interest in the non-specialised public¹³.

Usually, the dissemination of Unesco's documents tends to make them understandable even to children. Thus, before approaching the UDBHR levels of adaptation to the non-specialised audience (including children), it is important to emphasise that recreational, didactic forms that integrate text and image are the best for broadening the reach of publications^{13,14}.

Given the difficulty of controlling the interpretation of a specific text, when adapting dense language documents, one must consider fundamental levels of communication and adjust the language^{14,15}. This task is made even more difficult by the worldwide levels of illiteracy, whether absolute or functional, that characterise Brazilian social inequality¹⁶.

The Universal Declaration on Bioethics and Human Rights (UDBHR) can be reorganised from its three large nuclei of semiotic statements, which would facilitate the elaboration of documents that convey the main idea in a more concise way, respecting the reading maturity of the target audience and its relation with the subject addressed. In the initiative of Silva¹⁷, aimed at high school students, a higher than average textual comprehension is already expected, although not at the same level of university students.

Generally, adaptations to the non-specialised public have a clear pedagogical function - that is, they hold certain information to be captured by the reader as a formation of values, usually associated with some level of entertainment.

This model is very evident in the adaptation of the *Universal Declaration of Human Rights*² produced by Stam¹⁵: in this case, not all articles were translated for the children public, only those whose abstract concepts were closer to children's imagination. In addition, the communication was based on infographics that illustrated the mentioned topic, having images as the central element.

The option of organising the text in three large nuclei also favours the production of material on various media platforms for different audiences, not necessarily the children. With the definition of subjects of action and state, of the expected product of this interaction and of reflexive or concrete objects, practical actions can be elaborated more effectively.

Among these actions, the following stand out: the production of videos for streaming platforms, directed to subjects of the state of a specific group, with the intention of guiding scientific research in bioethics; the creation of applications of consultation to the legislation, directed to the reference group, disseminating the UDBHR and extending its use as reference in documents produced by bioethics agents; and, finally, the adoption of educational practices on the UDBHR directed to the adult public, considering the formation of the health professional, focusing on a group of specific articles.

Final considerations

Analyses of UDBHR have been done in order to generate meanings and readings external to the text,

interpreting it for the purpose of guiding bioethics actions and reflections¹⁷⁻²⁰. On the other hand, this work tries to identify elements inherent in the text, that is, while the research cited¹⁷⁻²⁰ examines the UDBHR by looking "outwards", the method used here aims to look "inward" at the text, seeking its points of convergence and divergence.

This "inward" analysis allows a clearer understanding of the normative text, since it works with its minimal, elementary structures, as if there were a content compression. When this type of analysis is carried out, it is possible to start from the essence of the text, defining which nucleus of the UDBHR will be analysed: the internal normative nucleus, the essential bioethical values or the norms relevant to bioethics.

In addition, when articles from the UDBHR are regrouped to reach a wider audience, it is perceived that the nucleus of the text organisation and its self-referencing tends to arouse less interest from the non-specialist audience. The nucleus of biomedical research is one of the most important of the Declaration and one of most difficult to adapt because of its use of technical language and its content, which deals with clinical, laboratory and academic situations that are distant from the general population. Nevertheless, it is possible to disseminate the various situations that refer to this nucleus for those who experience them or not, facilitating the empathy of the population^{18,19}.

Finally, because it does not depend on the reader's academic, clinical or juridical knowledge, the reflective nucleus, which deals with ethical / bioethical values, would be easier to adapt to the general public. To do so, it would be necessary to adjust the vocabulary of the text and translate its content into a nonverbal format, facilitating the understanding of bioethics concepts.

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Referências

1. Organização das Nações Unidas para a Educação, a Ciência e a Cultura. Declaração universal sobre bioética e direitos humanos [Internet]. Lisboa: Unesco; 2005 [acesso 10 nov 2016]. Disponível: <https://bit.ly/1TRJFa9>
2. Organização das Nações Unidas. Declaração universal dos direitos humanos [Internet]. Rio de Janeiro: ONU; 2009 [acesso 10 nov 2016]. Disponível: <https://bit.ly/1CVqinH>
3. Garrafa V, Porto D. Intervention bioethics: a proposal for peripheral countries in a context of power and injustice. *Bioethics* [Internet]. 2003 [acesso 10 nov 2016];17(5-6):399-416. Disponível: <https://doi.org/10.1111/1467-8519.00356>
4. Saada A. La declaración universal sobre bioética y derechos humanos: ampliación democrática para una sociedad mas justa. *Rev Bras Bioética* [Internet]. 2006 [acesso 10 nov 2016];2(4):413-22. Disponível: <https://bit.ly/2yW5I3N>

5. Beauchamp TL, Childress JF. *Princípios de ética biomédica*. São Paulo: Loyola; 2002.
6. Batista MB, Soares MTAM, Soares SP, Porto D. Conhecimento e percepções sobre bioética em uma amostra da população de Brasília. *Rev Bras Bioética* [Internet]. 2009 [acesso 10 nov 2016];5(1-4):106-25. Disponível: <http://periodicos.unb.br/ojs311/index.php/rbb/article/view/7864>
7. Caetano R, Garrafa V. Comunicação como ferramenta para divulgar e promover a Declaração Universal sobre Bioética e Direitos Humanos. *Rev. bioét (Impr.)* [Internet]. 2014 [acesso 9 nov 2018];22(1):34-44. p. 35. Disponível: <https://bit.ly/2z1quJT>
8. Caetano R, Garrafa V. Op. cit. p. 42.
9. Brasil. Supremo Tribunal Federal. Ação Direta de Inconstitucionalidade 3.510-0 [Internet]. [s.d.] [acesso 10 nov 2016]. Disponível: <https://bit.ly/2MrkGgG>
10. Caetano R, Garrafa V. Op. cit. p. 37.
11. Barros DLP. *Teoria semiótica do texto*. São Paulo: Ática; 1999.
12. Rippel JA, Medeiros CA, Maluf F. Declaração Universal sobre Bioética e Direitos Humanos e Resolução CNS 466/2012: análise comparativa. *Rev. bioét (Impr.)* [Internet]. 2016 [acesso 10 nov 2016];24(3):603-12. Disponível: <https://bit.ly/2wr9kGy>
13. Pietroforte AV. *Semiótica visual: os percursos do olhar*. São Paulo: Contexto; 2004.
14. Massarani L. *Ciência e criança: a divulgação científica para o público infanto-juvenil*. Rio de Janeiro: Fiocruz; 2008.
15. Stam R. Teoria e prática da adaptação: da fidelidade à intertextualidade. *Ilha do Desterro* [Internet]. 2006 [acesso 10 nov 2016];(51):19-53. Disponível: <https://bit.ly/2Feij2t>
16. Lorenzo C. O consentimento livre e esclarecido e a realidade do analfabetismo funcional no Brasil: uma abordagem para a norma e para além da norma. *Rev. Bioética* [Internet]. 2007 [acesso 10 nov 2016];15(2):268-82. Disponível: <https://bit.ly/2DvZW02>
17. Silva PF. Ensino de bioética no ensino médio: reflexões e desafios para a formação de professores de ciências e biologia. *Rev Bras Bioética* [Internet]. 2010 [acesso 10 nov 2016];6(1-4):98-114. Disponível: <https://bit.ly/2AUXIRN>
18. Barbosa SN. A participação brasileira na construção da Declaração Universal sobre Bioética e Direitos Humanos da Unesco. *Rev Bras Bioética* [Internet]. 2006 [acesso 10 nov 2016];2(4):423-36. Disponível: <https://bit.ly/2T14tDw>
19. Tealdi JC. Para una Declaración Universal de Bioética y Derechos Humanos: una visión de América Latina. *Rev Bras Bioética* [Internet]. 2005 [acesso 10 nov 2016];1(1):7-17. Disponível: <https://bit.ly/2SZ75ld>
20. Santos IL, Garrafa V. Análise da Declaração Universal sobre Bioética e Direitos Humanos da Unesco à luz da ética de Paulo Freire. *Rev Redbioética/Unesco* [Internet]. 2011 [acesso 10 nov 2016];2(3):130-5. Disponível: <https://bit.ly/2Fb9Exu>

Participation of the Authors

Thais Salvador and Hebert Sampaio carried out the textual analyses and wrote the manuscript. Dario Palhares collaborated in the writing and reviewing of the work.

