



Editorial

Managing a difficult ethical and legal equilibrium in healthcare: Assuring access to the basics while keeping up with innovation



A gestão de um difícil equilíbrio ético-legal em saúde: assegurar o acesso aos cuidados básicos mantendo a inovação

There is a new and challenging paradigm in healthcare which is pervading the sector and contains an apparent internal conflict. On one side, the fundamental human right of access to basic healthcare, (see article 25 of the Universal Declaration of Human Rights – UDHR¹ and article 12 of the International Covenant on Economic, Social and Cultural Rights – ICESCR²) seems to become more and more difficult to attain in most parts of the world, including the so-called Western developed countries where a financial crisis, which started in 2008, is

yet to be completely resolved. On the other side, the most advanced and expensive biomedical technologies applied to prevention, diagnosis and treatment continue to expand in very sophisticated ways and the right to enjoy the benefits of such scientific progress is also coined as a fundamental human right (see article 27 of the UDHR³ and article 15 of the ICESCR⁴). This tension between investing in granting immediate access to basic healthcare when resources are lacking and developing novel solutions that can only benefit a few in the short-term but promise to offer widespread progress later, requires rational and reflexive analysis in order

¹ Article 25 of the UDHR

1. Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

2. Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

² Article 12 of the ICESCR

1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:

- (a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;
- (b) The improvement of all aspects of environmental and industrial hygiene;
- (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;
- (d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.

³ Article 27 of the UDHR

1. Everyone has the right to freely participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.

2. Everyone has the right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.

⁴ Article 15 of the ICESCR

1. The States Parties to the present Covenant recognize the right of everyone:

- (a) To take part in cultural life;
 - (b) To enjoy the benefits of scientific progress and its applications;
 - (c) To benefit from the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.
2. Shall take the steps necessary for the conservation, the development and the diffusion of science and culture.
3. Undertake to respect the freedom indispensable for scientific research and creative activity.
4. Recognize the benefits to be derived from the encouragement and development of international contacts and co-operation in the scientific and cultural fields.

to strike the right balance and prioritization. Innovation is indeed fundamental and therefore the funding and the creation of incentives to public and private research cannot be neglected, otherwise the novelty in healthcare can stagnate and with it the endless possibilities to continue to efficiently minimize human suffering. That outcome is undesirable even to those who are most critical of the way healthcare research and innovation are currently designed, financed and executed, particularly concerning well documented unethical practices.

In reality, the investment in innovative leading edge healthcare technology can also contribute to the realization of the right to access healthcare by improving the accuracy and as such also the efficiency of healthcare measures. This investment should proceed in tandem with the application of current know-how to bring healthcare to the regions of the world where it is currently inaccessible and where human suffering demands urgent amelioration. Therefore, a rational system must understand that investing in the future, for example in the form of genomic technologies aimed at achieving effective personalized medicine, does not have to collide or fall under the immediate premise that every human life deserves the highest attainable state of health at the present time. Nevertheless, the required trade-offs to perfect such system are necessarily difficult to find and require permanent scrutiny and multidisciplinary evaluation, which includes necessary inputs from economics, medicine, science, law and ethics.

This issue of the Portuguese Review of Public Health presents original articles that look at these two conflicting realities, i.e. the difficulty of rationing healthcare and the necessity of maintaining a steady pace of innovation, through the lens of human rights, ethics and health law. The result may be a somewhat “bipolar” picture, where we simultaneously strive to search for solutions to the lack of essential healthcare – for example by providing the best legal and ethical answers to tackle inequity in health systems – and on the other side, continue to meet the legal and ethical challenges brought by

the advances of biomedical science, such as the breach of the rights to privacy and medical confidentiality.

The same philosophy encompasses the ongoing societal efforts to implement measures that can expand access to healthcare in more affordable ways (v.g. generics) and also to promote measures and interventions to help the most vulnerable (v.g. the elderly) to better manage and improve their health.

The analysis provided by the articles included in this RPSP issue will certainly contribute to the discussion introduced above. However, it will not offer any decisive or final solutions to such a complex range of topics. Nonetheless, one idea that sounds more like an impasse than a conclusion becomes clear: basic healthcare is a priority but the continuity of the investment in patient safety, health promotion and innovation in health cannot be jeopardized under the economic pressure. This equilibrium is indeed difficult and almost impossible to manage, but no part of it should completely overshadow the other. To our assurance, while trying to deal with the most intricate issues that confront our societies, the best practices often result from the tension between different and sometimes conflicting perspectives and their respective convictions. Hopefully, that will also be the case with the realization of the fundamental human rights discussed above: the right to access timely, acceptable, and affordable health care of appropriate quality and the right to enjoy the benefits of scientific progress and its applications.

Paula Lobato Faria*, João V. Cordeiro
*Grupo de Disciplinas/Departamento de Ciências Sociais em Saúde,
Escola Nacional de Saúde Pública, Universidade Nova de Lisboa,
Lisboa, Portugal*

* Corresponding author.

E-mail address: pa.lobfaria@ensp.unl.pt (P.L. Faria).
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