

Debate

Human rights in the biotechnology era I

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Abstract

Background: The concept of Human Rights has become the modern civilising standard to which all should aspire and indeed attain.

Discussion: In an era characterised by widening disparities in health and human rights across the world and spectacular advances in biotechnology it is necessary to reflect on the extent to which human rights considerations are selectively applied for the benefit of the most privileged people. Attention is drawn particularly to sub-Saharan Africa as a marginalised region at risk of further marginalisation if the power associated with the new biotechnology is not used more wisely than power has been used in the past. To rectify such deficiencies it is proposed that the moral agenda should be broadened and at the very least the concept of rights should be more closely integrated with duties

Summary: New forms of power being unleashed by biotechnology will have to be harnessed and used with greater wisdom than power has been used in the past. Widening disparities in the world are unlikely to be diminished merely by appealing to human rights. We recommend that a deeper understanding is required of the underlying causes of such disparities and that the moral discourse should be extended beyond human rights language.

Background

In an era characterised by both major advances in biotechnology and a high profile for the idea of human rights, it is necessary to ask whether, when we speak about human rights, we are concerned about the rights of the 1 billion people who live so well and who have so much to look forward to from the benefits of further scientific progress or the rights of the 4 billion people who live under miserable conditions?

It is necessary to ask this question for many reasons. Firstly, because the disparities between the lives of people who fall into these two categories have been constantly widening over the past 30 years and there is little evidence that this pattern will be reversed. Secondly, because the abuse

of power has been a significant force in contributing to wide disparities in human lives and to gross violations of human rights. Thirdly, because there is little to suggest that the new power that will be available in the biotechnology era will be used more wisely than other forms of power have been used in the past. Global economic processes have extracted material and human resources from many poor countries, eroded the value of their currencies and placed their economies at the mercy of such unaccountable organisations as the International Monetary Fund and the World Bank. [2–4] Massive deprivation of citizens of poor nations has also been promoted through the sale of arms to corrupt leaders, enabling them to accumulate vast wealth and to wage wars of ethnic conflict, with devastating social effects. [5]

What will happen in the era of biotechnology to improve the lives of the poor? Will advances in plant, animal or human genetic engineering enable major pharmaceutical and agrochemical companies to produce cheaper drugs and food and will the sentiments expressed in the Universal Declaration of the Human Genome be respected – as optimistically suggested by some? [6] Alternatively will the insistence on intellectual property rights and reduction in the biological diversity of agricultural products disrupt the economies of poor nations and ensure that food prices continue to rise and malnutrition aggravated? Is it possible that genetic data from some groups of people will be exploited for economic benefit, or even more horrifyingly, to develop weapons for genocidal purposes? If drugs for malaria, tuberculosis, many tropical diseases and HIV/AIDS have not been made available to billions in poor countries is it likely that the poor will benefit from advances in biotechnology?

Understanding that science is not value free provides some insights. "Scientific knowledge emerges from a process that is intensely human, a process indelibly shaped by human virtues, values and limitations and by social contexts... Science is a social enterprise...and takes place within a broad social and historical context, which gives substance, direction, and ultimately meaning to the work of individual scientists... Individual knowledge only becomes general knowledge after discussion, collaboration, peer review, judgement and incorporation into already accepted knowledge – an ongoing process of review and revision that minimises individual subjectivity." [7]

Several facts illustrate the assertion that science is not value free. Sixty six percent of the USA Government's expenditure on research and development is on military research [5]. Ninety percent of global expenditure on medical research is on diseases causing 10% of global burden of disease, [8] and of 1233 new drugs developed between 1975–1997 only 13 were for the tropical diseases. These observations suggest that the questions pursued by scientists are determined less by the need for knowledge and how to apply knowledge than by the economic forces that drive and support the research endeavour. Indeed there is a need to understand the global economic context in which market forces rather than human needs drive the research endeavour. The emphasis on military research and the neglect of diseases that afflict billions of people living in abject misery reflects a value system that marginalises and devalues the lives of more than half the world's population.

Discussion

While the Universal Declaration on the Human Genome, the first universal instrument in the field of biology, sets out to safeguard human rights, fundamental freedoms

and the freedom of research, [9] it is clear that there are many obstacles to achieving the high ideals expressed in this document. For example despite the statement in Article 4 that "the human genome in its natural state shall not give rise to financial gains," and in Article 6 that "no one shall be subjected to discrimination based on genetic characteristics," "there is already evidence to suggest that these requirements will be ignored." Considerations of "who will offer what to whom and at whose expense in health care in the USA" have been explored in detail and concern expressed that genetic information will be used adversely to influence access to health care in a nation with "a long and disturbing history of drawing sharp distinctions among (its) citizens on the basis of race and ethnicity" as well as "a long tradition of belief in biological determinism." [10]

The implications of genetic testing for medical practice and for the rights of privacy of individuals are many, varied and problematic. Shifting the frontier of medicine from curing diseases and caring for individual persons, towards the public health goals of preventing suffering in future generations, and even to the possibility of enhancing physical and mental capacities, poses major challenges to the concept of human rights. The ability to improve public health through mandatory vaccinations, at the cost of potential suffering of some adverse reactions to vaccines is widely accepted. While such acceptance of social benefit over individual rights does not apply now to predictive and carrier testing for genetic abnormalities or to correcting genetic abnormalities – and indeed the analogy drawn here is not exact – in due course public health considerations may also achieve over-riding importance. A new balance may need to be established regarding the rights of individuals and the rights of groups in order to improve public health, although great caution will be needed to avoid undue coercion.

Also problematic is the generation of massive amounts of genomics data that drives megamergers by companies seeking patents. The USA patent and trademark office has received thousands of requests for patents on nucleic acid sequences, and major biotechnology, chemical, pharmaceutical and agribusiness companies are investing in molecular technologies. Techniques paving the way to controlling farming and world food production by giant agrochemical companies may threaten subsistence farmers in poor countries. Reduction of the genetic diversity of agricultural products or excessive protection of intellectual property rights, locking farmers into corporate control of production, could have profoundly adverse effects on the economies of developing countries and the lives of their citizens. [11] Alternatively, more optimistic attitudes [6] need to be vigorously promoted in order to alter existing patterns of behaviour.

At least three key risks are associated with the new life science industry: (i) the excessively high valuation of some life science conglomerates could substantially influence the international stock market, (ii) genetically engineered products may be widely used before they have been rigorously tested, and (iii) developments in biotechnology are outstripping public understanding – and hence eroding both the trust and confidence of the public [11,12].

In 1991 when the Human Genome Diversity Project was proposed, critics of the project argued that minority populations struggling for survival needed economic support and not the preservation of their genes or "immortalisation" in laboratories. Plans to put the health records of every Icelandic citizen into a huge data base with private company rights to analyse and market the data, and to exploit the genetic composition of Icelanders are other examples of practices that cause great concern [13].

How will individual human rights be protected under these circumstances? More declarations will not be sufficient. Against the background of power abuse in this century, it can be justifiably concluded that human rights declarations, despite their best intentions, have not achieved as much as desired to guarantee widespread access to even the most basic requirements for a decent human existence. It therefore becomes necessary to question whether in the era of biotechnology the language of rights alone can enable achievement of the respect we desire for all individuals, or whether the moral goods to which we aspire require a richer moral language and greater emphasis on social justice?

In defence of the Human Rights approach, as the single most powerful means of promoting human well-being, it can be argued that failure to achieve human rights more widely is not the result of an inadequate concept of human rights, but rather that the full potential of the human rights approach has not been achieved because of simplistic or insincere use of the term, and a lack of commitment by powerful nations to what a more wholesome concept of human rights means and implies for them as well as for others. Civil and political rights are required components of political citizenship of any nation. However, recognition of political citizenship is not sufficient for human flourishing. Recognition of social, economic and cultural rights are also necessary. The claimed universality and indivisibility of human rights reflects the need for both sets of rights in order to achieve respect for the dignity of individuals. Rights and responsibilities are inextricably related and must be reintegrated to enhance the power of human rights language, as proposed by Chapman [14] and in the Universal Declaration of Human Duties that has recently offered as a supplement to the UDHR [15].

As powerful as exhortation and pleas for human rights may be, the power of wealthy countries in setting a moral example is potentially more influential. This point is illustrated by fact that a powerful nation that has failed to ratify social and economic rights and that propagates the concept solely for civil and political rights is, in the wake of the September 11 attack on the World Trade Center and the Pentagon, legislating to curtail even these rights. The implications of such action for global propagation of the human rights concept are of great concern [16]. The US backed complaint by pharmaceutical companies against South Africa's intention to import generic drugs to deal with the human tragedy of HIV/AIDS, while taking such action themselves to over-ride Trade Related Intellectual Property Rights (TRIPS) to import drugs for a potential public health anthrax threat makes a mockery of claims of concern for universal rights and security [17]. The shortcomings of a narrow approach to human solidarity and morality reflect the need for a more coherent approach to moral behaviour with full consideration of the co-relative duties that form part of the conceptual logic of rights language and its moral grip [18–20].

Some considerations from Africa

The African continent has long been central to the aspirations of the West. Initially presenting great challenges to circumnavigation, it became a continent inviting exploration resulting in a clash of civilisations, enslavement of its people, colonisation and extraction of its resources. Since the release of Africa to independence, the collusion of powerful nations with despotic leaders and their co-option into neo-liberal economic policies, enslavement has continued covertly. The tragedy of the continent is now aggravated by its elimination from the foreign policy agendas of powerful countries because of crises conveniently perceived to be of its own making [19]. Endeavours to restore Africa to a position of strategic and moral importance to the US are to be admired [21].

The problems of Africa are so enormous that the debate on genetic engineering has had a minimal profile on the continent. The use of biotechnology to mass produce drugs such as insulin and vaccines, to develop more resilient crops, to increase the efficiency of food production, or in other ways that improve the lives of individuals, would be uniformly welcomed, especially if such techniques offer to reduce the cost and increase access for all to drugs, vaccines and food. However, as in the past it is likely that such developments will be denied to the poor, or may only trickle down sporadically. Genetically engineered production of insulin, for example, creates a product more expensive than animal insulin and the poor now have less access to insulin than in the past. Pleas for donations of insulin (less than 0.5% of global use) to type 1 diabetics in the developing world have not been heeded

[22]. In addition techniques that are now paving the way to controlling farming and world food production by giant agrochemical companies are seen as threats to farmers.

Attempts to patent products developed with information derived from the practices of indigenous healers, and eagerness to patent components of the human genome for exclusive economic gain are viewed as new forms of exploitation that exclude considerations of the humanity of those living in economic misery [23]. The way in which power has been used in the past thus gives rise to valid concerns that the power of genetic engineering may also be used for the exclusive good of some, or to harm others.

Contributions from biotechnology to the development of biological weapons are adding new dimensions of military horror to future conflicts. [24] During the Truth and Reconciliation Commission's investigations into biological warfare in South Africa it was revealed that there had been programs designed to investigate methods of interfering with the ability of Africans to reproduce. [25]. This gives some credibility to more widespread fear among the marginalised and oppressed of the world that knowledge gained from the Human Genome Project and the Human Genome Diversity Project may be used for genocidal purposes

Secular western attitudes to the concept of the self as highly individualistic, and unconnected to the wider community or spiritual world further undermines the confidence of Africans who view people as both uniquely individual and as spiritually connected by relationships to others in the present, past and future.

Summary

Clearly the new forms of power being unleashed by biotechnology will have to be harnessed and used with greater wisdom than power has been used in the past. Like nuclear power, biotechnology has the capacity for great harm and this must be avoided. The resources and energy being devoted to ethical aspects of biotechnology reflect our awareness and concern for potential abuse. [6] Can we be successful? I should like to be cautiously optimistic that we can – but only if the nascent intellectual forces moving the world towards new ways of thinking and acting [26] can be transformed into more widespread attitudes among citizens, governments and multinational organisations.

An encouraging practical sign is the recent report from the US Council of Foreign Relations and the Milbank Memorial Fund, outlining the importance of health to US foreign policy. By acknowledging the relationships between health, social capital, political stability, the economy and

war a deeper commitment could be developed by the USA and other nations to the moral and strategic importance of improving global health [27]. In addition the work of the Commission on Macroeconomics for Health, [28] the inauguration of a Global Health Fund, [29] and the recent announcement by President George Bush that the USA will increase its annual development aid from \$10 billion to \$15 billion [30] reveal both a deeper understanding of the importance of global health and an acknowledgement of the responsibility of developed nations to address this constructively. Further progress will be driven by insights into how a global awareness and a global community could be promoted [31].

Competing interests

None declared

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