COMMENTARY:
JUSTICE AND MEDICAL RESEARCH: A GLOBAL PERSPECTIVE

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ABSTRACT

Economic globalization has profound implications for health. The scale of injustice at a global level, reflected in inexorably widening disparities in wealth and health, also has critical implications for health related research – in particular when the opportunities for exploiting research subjects are carefully considered. The challenge of developing universal guidelines for international clinical research is addressed against the background of a polarizing, yet interdependent, world in which all are ultimately threatened by lack of social justice. It is proposed that in such a world there is a need for new ways of thinking about research and its relevance to health at a global level. Responsibility to use knowledge and power wisely requires more radical changes to guidelines for research ethics than are currently under consideration.

INTRODUCTION

When Harold Macmillan (then Prime Minister of Britain) visited Africa in 1960, he referred to the ‘wind of change’ that he perceived blowing through Africa – in the wake of decades of colonialism and oppression. The history of sub-Saharan Africa since then has been stormy. Initial encouraging advances made by many countries in the early years of their independence have

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1 Based on the opening address given by the author at the Fogarty International Global Research Ethics Forum Bethesda, Maryland. USA, November 1999.

2 H. Macmillan. ‘The wind of change is blowing through the continent. Whether we like it or not, this growth of national consciousness is a fact.’ Speech in the South African Parliament, Cape Town, February 3, 1960.
been followed by subsequent retrogression due to both external and internal influences. External factors include the adverse effects of neo-liberal economics on trade and the incurring of debts, the subsequent structural adjustment programs imposed by the IMF and World Bank, and the impact of arms trading and ‘Cold War’ interference in Africa. Internal factors include corruption, political patronage, power struggles and poor governance. Adverse environmental conditions and the HIV/AIDS pandemic have posed additional massive burdens to progress.³ The ‘wind of change’ associated with emancipation from oppression in apartheid South Africa has culminated in a much admired peaceful transition in that country.⁴ How this transition will play out in the face of the HIV/AIDS pandemic and in the context of a globalising world is of great importance.⁵

THE WORLD AT THE BEGINNING OF THE 21ST CENTURY

It is necessary to appreciate that the ‘wind of change’ is now being felt throughout the world, as globalising forces create ever widening disparities in wealth, with important implications for health and well being.⁶ Despite great progress in science, technology and communication during the 20th century, the world at the beginning of the new millennium is characterized by chaos and despair at many levels.⁷ Escalating economic disparities, especially during the past 30 years, illustrate the impact of the ‘visible hand’ of the market place and the ’squeezed up’ effect that is, the funneling of resources upwards resulting in wider disparities in wealth and health between rich and poor than ever before – rather than the so much spoken about and praised ‘invisible hand’ and ‘trickle down effect.’ Indeed more than half the world’s population lives in poverty – 25% in abject poverty.

The shift in the accumulation of capital from the nation state to multinational corporations, and the creation of unpayable third world debt, have impoverished third world countries and reduced annual per capita health care expenditures to less than $10 in most poor countries – where less than 50% of the population have access to even essential drugs. Health care services are rudimentary for many in a world in which 87% of annual global expenditure on health is directed to 16% of the world’s population, who only bear 7% of the global burden of disease, and in which increasingly unethical, market driven research neglects many diseases.\textsuperscript{8} Of all US $56 billion spent annually on medical research 90% is spent on those diseases causing only 10% of the global burden of disease.\textsuperscript{9}

Meanwhile vast expenditure continues on the military. Many small wars, fuelled by trade in weapons, have resulted in unprecedented numbers of civilian deaths and displacement of millions of people from their social roots, with profound disruption of their lives. In addition there is a world-wide movement of people, within and across national borders through urbanization, migration, tourism and illicit trading in drugs and people\textsuperscript{10} – all favoring the rapid spread of infectious diseases. Growth of the world’s population and massive increases in energy consumption (five and 30 fold increases respectively over the past 150 years) further threaten our ecology.\textsuperscript{11}

New ecological niches created by these destructive social and environmental changes favor the emergence of many new infectious diseases, the worst being HIV/AIDS, and the recrudescence of old diseases such as tuberculosis and malaria that cause immense suffering and millions of premature deaths.\textsuperscript{12} These and other infectious diseases that may emerge in the future challenge thinkers to better understand the world and how it could be improved.

HOW CAN THE WORLD BE EXPLAINED?

On the one hand the world can be considered as an unfortunate place in which most suffer disproportionately and unavoidably. On this account it is presumed that the manner and direction in which money flows, power is expressed, and social values develop are shaped by forces beyond the control of individuals or nations.

On the other hand an unjust world can be considered as one created by human activities, and one which can, and should be, changed. On this account the flow of money can be explained on the basis of national/international political forces and economic trends, and on such other aspects of globalization as advances in science and technology that have profoundly altered the nature of the global economy, as well as by exploitation at many levels (both overt – trade practices protecting the rich, and covert – debt trade and the arms trade as forms of enslavement). Some have used the term ‘global apartheid’ for the processes that have promoted (and continue to aggravate) vast disparities between rich and poor across the world. Others have described third world debt, an integral component of globalization, as analogous to slavery in its impact, and have called for reflection on the magnificent achievements of the 20th century, and on how the human condition and health could be improved globally.

CHALLENGES FOR INTERNATIONAL RESEARCH ETHICS

This brief review of the adverse effects of progress serves to locate the context in which the controversy about research ethics has arisen and the backdrop against which the goals of change need to be considered: how to construct universally valid guidelines for collaborative international medical research with the view to enhancing sensitivity to issues of justice and our common humanity. In brief, the rationale for embarking on this endeavor now more than ever before includes:

- The scale of injustice at a global level.


Knowledge of the history of abuse of humans in medical research and the need to protect (vulnerable) research subjects.

The need for research on diseases that know no boundaries and potentially threaten all – e.g. HIV/AIDS, and the diseases to which antimicrobial drug resistance is developing.

Significant growth of research to promote the use of therapeutic drugs in a lucrative market.

The attractiveness of doing research in developing countries: easy access to patients, reduced costs, and less stringent regulations – the ‘research sweat shop’ equivalent.

Understanding that researchers do not go to developing countries mainly for altruistic reasons.

A perception by the vulnerable that they are being exploited.

The need to balance the notion that solutions to disease and illness lie entirely in the realm of biomedicine with recognition that global forces promote emergence and resurgence of infectious diseases, and have many adverse effects on health.

The goal of fostering empowerment through co-operation that may enhance human flourishing by making subjects essential partners in the research process.

The challenge to be faced in international research ethics is the development of universal rules for research world wide, at a time when health care is being delivered within very different health care systems (even within any single country) and in a multicultural world in which people live under radically different conditions – ranging from immense luxury to abject poverty. Variable trajectories of emancipation of individuals from communities have also given rise to a wide spectrum of how people view themselves, what it means to be ill and how health care systems should be structured.16 With recognition of the role of social conditions in shaping the world, and how privileged people view the world and themselves, comes the realization that research cannot be considered in isolation. Medical research, health care, conditions of life around the world and how humans flourish may seem separate, but they are all interdependent. Taking such a comprehensive global perspective adds complexity to the task of crafting universal research ethics guidelines.

SOME SOLUTIONS TO THE CONTROVERSY ON RESEARCH ETHICS

Against this background of the context in which the controversy regarding alterations to the Helsinki Declaration and other guidelines for research ethics has arisen\(^\text{17}\) a choice which can be made from several options. First, the status quo could be upheld in the hope that the progress of science and of economic growth will continue uninterrupted with beneficial effects for all even if disparities persist or grow. This would be the easiest choice as it presupposes no responsibility for global injustice. However, it would also be immoral as current injustices will be perpetuated and aggravated.

The second choice would be to make piecemeal changes at the margins – for example in international research by tinkering with the Helsinki Declaration and making some minor modifications. This course is also appealing to those who wish to make research easier and less accountable, but there is powerful and justified resistance to diluting protection for vulnerable research subjects and any progress made would in all probability be insufficient and temporary.\(^\text{18}\)

Third, there could be acknowledgment of the need for a paradigm shift in thinking and action – towards reciprocal relationships between individuals, society, and the notion of rational self-interest and long term interdependence.\(^\text{19}\) This is a more difficult decision and one that may have higher costs in the short term. It would, however, reflect recognition of the adverse impact of globalization and allow use of such desirable universal values as human rights to build a more widely achievable universalism. Such a decision could advance human relationships to the high moral ground, with the consequent best hope for long-term results. South Africa’s peaceful transition through a negotiated revolution is an example. It is suggested that privileged people need to hold up a mirror to their lives, and try to see themselves from the perspective of the


\(^{18}\) The Helsinki Declaration was modified at the 52nd World Medical Association (WMA) General Assembly in October 2000, Edinburgh, Scotland.


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marginalised and weak in the world today and as historians in the future may see them in retrospect – as decadent and selfish.

Given the responsibility to use power and knowledge wisely, it is suggested that the deliberations at this meeting should include the possibility of introducing several new components into the Declaration of Helsinki and other international research guidelines – to extend and honor the concepts of justice and of integrity in the research endeavor:

- Vulnerable groups should be provided with increasing accessibility to research, and this should apply to the vulnerable within all countries.
- Exploitation of subjects, or their use as mere means to the ends of others, should be explicitly excluded by ensuring that the research is of relevance to the individuals participating in the research as well as their communities.
- The potential benefits of research should considerably outweigh potential risks or harms to vulnerable individuals and communities.
- Research subjects should be encouraged to participate in planning and conducting studies.
- Research in developing countries should be linked with capacity building in health care, and with economic and educational empowerment that has beneficial effects on the delivery of health care and on progress generally in the host country.

The first Global Forum on International Research, which opened discussion of all the topics listed on this agenda, was an enlightened first step forward. The second step would be to promote the addition of the newly proposed clauses to the Helsinki and other declarations. Third, there should be consideration of an expanded role for Institutional Review Boards (Research Ethics Committees) – taking them beyond mere review bodies to include duties of audit and education. Fourth, there is the need to influence mind sets – for example through societal marketing processes, rewards for compliance, wider publicity for and marginalisation of those doing unethical research, and by bringing bioethics and human rights programs closer to each other. Such actions could act as bridges, levers, and moral examples for the process of narrowing disparities. Education, the acquisition of self-knowledge coupled to activism, and moral example are all necessary for the promotion of a ‘global new deal.’

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In summary support is provided here for the suggestion that to help the world’s poorest, and indeed to foster the interests of all, the dialogue between rich and poor should be enhanced, the power of science and technology should be mobilized to address the problems of poor countries, new institutional alliances should be constructed, the concept of intellectual property rights should be re-evaluated to avoid ‘ripping off the poor,’ and long term financing should be planned for the international good necessary for human flourishing. Herein lie the challenges to which the international research ethics endeavor could contribute.

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