

Human Rights and Bioethics

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The Nuremberg Trials, and, for our purposes, in particular the case of *US v Brandt*,¹ focused the world's attention on the atrocities committed by physicians and scientists in the name of National Socialism, and in some cases in the purported interests of medical and scientific progress. Not only did they participate in the 'final solution', but they also conducted non-consensual experiments, commonly with inmates of concentration camps. Among the experiments conducted were those to:

....ascertain how long individuals immersed in freezing water could survive, how well they functioned at pressure levels existing at high altitudes, the viability of various sterilization techniques, the development of vaccines for a variety of diseases, including jaundice, malaria, diphtheria and typhus, which involved directly injecting subjects with infectious agents, and experimentation with novel surgical techniques.²

Among those charged with these atrocities were senior members of the medical community, such as Lt. General Siegfried Handloser (Chief of Medical Services of the Wehrmacht), Karl Gebhardt (Chief Surgeon of the SS and President of the German Red Cross) and Paul Rostock (Chief of the Office for Medical Science and Research and Dean of the Medical Faculty of the University of Berlin).³

The promulgation of the Nuremberg Declaration in 1947 saw the beginning of the modern era of human rights. Katz says that:

The Nuremberg Code is a remarkable document. Never before in the history of human experimentation, and never since, has any code or any regulation of research declared in such relentless and uncompromising a fashion that the psychological integrity of research subjects must be protected absolutely.⁴

Of course, the Code was specific to human research and experimentation, areas of medicine which, it has been said, were '....born in scandal and reared

¹ available at http://nuremberg.law.harvard.edu/php/pflip.php?caseid=HLSL_NMT01&docnum=2&numpages=78&startpage=1&title=Closing+argument+for+the+United+States+of+America.&color_set ting=C (accessed on 10/10/2008)

² *loc cit*

³ *id*

⁴ J. Katz,, 'The Consent Principle of the Nuremberg Code: its Significance The and Now', in Annas, G.J. and Grodin, M.A. (eds), *The Nazi Doctors and the Nuremberg Code*, OUP, 1992, 227-239, at p. 227

in protectionism.', and was therefore of limited applicability.⁵ It can, however, plausibly be described as the 'grandmother' of modern bioethics. One year after the Nuremberg Code was promulgated the most significant event in human rights in the modern era occurred – the adoption of the Universal Declaration of Human Rights by the United Nations. Baker asserts that this document was in part informed by the revelations that led to the adoption of the Nuremberg Code. Indeed, he claims that '.....the details revealed daily at Nuremberg gave content to the rights recognized by Articles 4 through 20 of the Declaration.'⁶ The most important impact of the UN Declaration was, he claims, to rectify the problem that until then "[t]he nature of "human rights" was left unspecified....'⁷ In the 1948 Declaration, on the other hand, the world was given both 'an agenda and a philosophy.'⁸ The numerous international declarations that have proliferated since 1948 have striven to follow that agenda.

Medical Ethics

Between Nuremberg and modern times, came the development of what is generally referred to as 'medical ethics'. Unlike the human rights agenda, the focus of medical ethics is relatively narrow; concerning itself predominantly with the relationship between doctor and patient. Guided by influential commentators, and professional organisations, medical ethics seeks to provide a set of principles designed to inform the way in which doctors relate to their patients. Irrespective of the ethical model used, however, medical ethics arguably hinges on the duties of physicians to their patients, and has a correspondingly limited – albeit not negligible - emphasis on human rights.

While many examples exist in routine clinical practice, given my initial mention of the Nuremberg Code, the question of human experimentation/research can usefully be returned to as a template of the relationship between medical ethics and human rights, by addressing the World Medical Association's Declaration of Helsinki.⁹ This Declaration was

⁵ C. Levine, 'Has AIDS changed the ethics of human subjects research?', *Law, Medicine and Health Care*, 1988;12:167-173, at p. 167

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⁷ Baker, R., 'Bioethics and Human Rights: A Historical Perspective', *Cambridge Quarterly of Healthcare Ethics* (2001), **10**, 241-252, at p. 242

⁸ Annas, G.J., 'American bioethics and Human Rights: The End of All Our Exploring', *Journal of Law, Medicine & Ethics*, Winter 2004, 658-663, at p. 660

⁹ Adopted by the 18th WMA General Assembly, Helsinki, Finland, June 1964, and amended by the 29th WMA General Assembly, Tokyo, Japan, October 1975; 35th WMA General Assembly, Venice, Italy, October 1983; 41st WMA General Assembly, Hong Kong, September 1989; 48th WMA General Assembly, Somerset West, Republic of South Africa, October 1996; and the 52nd WMA General Assembly, Edinburgh, Scotland, October 2000; Note of Clarification on Paragraph 29 added by the WMA General Assembly, Washington 2002; Note of Clarification on Paragraph 30 added by the WMA General Assembly, Tokyo 2004

first promulgated in 1964 and has been revised several times. Its aim is to provide an ethical framework for human experimentation and research (just as was the Nuremberg Code). However, the Declaration of Helsinki, rather than fully endorsing the human rights focused approach of the Nuremberg Code, in fact moves away from its first, and most fundamental, principle; namely, that research is only permissible with the free and informed consent of the individual subject. Now, it might be said that the absolute nature of article 1 of the Nuremberg Code was an inevitable and necessary response to the specific circumstances it addressed and was, therefore, time specific. Thus, it could be argued that loosening the requirements of article 1 was both desirable and inevitable. The Helsinki Declaration's concession that research can be conducted on non-competent individuals could be said to be a response to changing political and social regimes; no longer are states (or physicians) engaged in wholesale abuse of citizens, and therefore a new political and social environment permits – even requires - less stringent requirements.

Childress describes the Declaration's two major deviations from the Nuremberg Code, namely that:

....it offers a less stringent requirement of the research subject's own voluntary, informed consent: it allows some incompetent subjects to be enrolled in some research protocols on the basis of a legal guardian's consent or permission.¹⁰

While this no doubt assists in the development and progress of medicine and healthcare, it also shows what I will call 'bioethical drift'. Of course, this 'drift' may also be politically generated or responsive. Baker, for example, suggests that '[t]he Nuremberg Code and the Universal Declaration of Human Rights are artefacts of the short-lived era of post-war idealism, which was an early casualty of the Cold War.'¹¹ While we might reasonably welcome the advances in medicine that research on the incompetent may bring, in fact this rests on two assumptions, neither of which is uncontroversial. First, it assumes that it is legitimate to use people as a 'means to an end', often for the greater good of the rest of us; second, it assumes that medical research has actually made a difference so great that it can override any concerns we might have. While there is no doubt that research/experimentation has moved medicine forward, for some that progress should be recognised as less dramatic than is generally believed (at least in certain areas) raising concerns about the balance between human rights and medical progress. On the one hand, while '[a] medical profession which did not seek improved means to conquer disease would be condemned for dereliction of its duty.'¹² on the

¹⁰ J.F. Childress, 'Nuremberg's Legacy: Some Ethical Reflections', *Perspectives in Biology and Medicine*, 43,3, Spring 2000, 347-61 at p. 351

¹¹ Baker, R., Bioethics and Human Rights: A Historical Perspective', *Cambridge Quarterly of Healthcare Ethics* (2001), **10**, 241-252, at pp. 244-245

¹² B.M. Dickens, 'Human Rights in Medical Experimentation', *Israeli Yearbook on Human Rights*, Volume 9, 1979, 23, at p. 23

other '[m]ost of the progress in recent years in the treatment of the chronic diseases has been really to limit our error and limit the harm we do whilst waiting for the small breakthroughs which will ultimately reduce the total sum of human suffering.'¹³ I mention this not to decry the progress made by medicine, but rather to highlight the extent to which principles of human rights – once apparently regarded as sacred in a war ravaged world – have been modified for reasons, good or bad, which reflect on the perceived social and political differences between then and now.

Bioethics

Only a few short decades ago, medical ethics was complemented, if not supplemented, by what is now known as bioethics. While some doubt whether or not it truly is a discipline, it is certainly a presence in people's minds. It is fruitless to enter in any depth into this particular debate at this time, although it is interesting to note that some of those who accept it as a discipline have been somewhat cynical about what it is actually for. Cameron, for example, argues that '...the function of bioethics in the past thirty years has been to commend new technologies to a suspicious public, and aid their adoption.'¹⁴ Further, asking whether bioethicists are truly professionals, Churchill says - albeit from an American perspective - that:

Bioethical disputes – as measured by the debates in journals and conferences in the United States – often seem to be remote from the values of ordinary people and largely irrelevant to the decisions they encounter in health care. In this sense, philosophical theorizing might be considered harmless entertainment, which if taken too seriously would look ridiculous, as several Monty Python skits have successfully demonstrated.¹⁵

Other, less sceptical, views recognise the extent to which bioethics can aspire to playing a valuable role by making 'connections between the introduction of new technologies and the moral concerns of citizens...'.¹⁶ Salter and Jones add that 'bioethics presents itself as both expert and as having a hotline to the needs of civil society through its impartial consideration of moral concerns.'¹⁷

¹³ Baum, M., 'The Ethics of Clinical Research', in Byrne, P. (ed), *Ethics and Law in Health Care and Research*, Chichester, John Wiley & Sons, 1990, 1-8, at p. 3

¹⁴ De S. Cameron, N. M., 'Biotechnology and the Future of Humanity', *Journal of Contemporary Health Law and Policy*, Vol. XXII, Spring 2006, 413-423, at p. 417

¹⁵ Churchill, L.R., 'Are We Professionals? A Critical Look at the Social Role of Bioethicists', *Daedalus* 128 (1999): 253-274, at p. 255

¹⁶ Salter, B., Jones, M., 'Regulating human genetics: the changing politics of biotechnology governance in the European Union', *Health, Risk & Society*, Vol. 4, No. 3, 2002, 325-340, at p. 330

¹⁷ *loc cit*, at p. 338

Human Rights and Bioethics

The link between bioethics (however conceptualised) and human rights was historically strong, not least because of the intimate relationship between the Nuremberg Code and the Universal Declaration of Human Rights, and *ex hypothesi*, those human rights declarations that have followed them. For example, commenting on the Universal Declaration on the Human Genome and Human Rights, Salter and Jones say that behind it 'lies the rise of bioethics as a political and, to the extent that it advocates a coherent system of values, ideological phenomenon capable of acting in opposition to the economic regulatory dynamic.'¹⁸ For Annas, '[t]he disciplines of bioethics, health law, and human rights are....all members of the broad human rights community....'¹⁹ Gostin agrees, but laments that '[b]ioethics scholars are only beginning to go beyond individual interests to explore the fundamental importance of a population's health and well-being.'²⁰

The interconnectedness of human right and bioethics should not, however, be taken for granted. Although both seem to seek similar, if not the same, outcomes, some deviations or differences can be identified which could arguably be a matter of concern. It must be remembered that much of bioethics has concerned itself not with human rights in general, but rather has focused on medicine and healthcare. While it is more philosophically based than medical ethics, it is nonetheless driven – in large part - by the same, or similar, concerns. Further, it is arguable that the technological 'revolution' that resulted, amongst other things, in the birth of Dolly, hijacked bioethics, and pointed it towards a more narrow focus than a human rights agenda might seem to require. As has been said, '....it is in the nature of fast-moving scientific research that its progress can outstrip the ability of its lines of social, ethical and regulatory support to keep up.'²¹ Bioethics seeks to fill that lacuna. It is also true that the interests of a particular and powerful social enterprise, like medicine, can drive the agenda to which its partner discipline – in this case bioethics – subscribes.

Baker says that '[o]riginally, the principles of bioethics were a means for protecting human rights, but through a historical accident bioethical principles came to be considered as fundamental.'²² He identifies the 'accidental

¹⁸ Salter, B., Jones, M., 'Regulating human genetics: the changing politics of biotechnology governance in the European Union', *Health, Risk & Society*, Vol. 4, No. 3, 2002, 325-340, at p. 328

¹⁹ Annas, G.J., 'American bioethics and Human Rights: The End of All Our Exploring', *Journal of Law, Medicine & Ethics*, Winter 2004, 658-663, at p. 658

²⁰ Gostin, L. O., 'Public Health, Ethics, and Human Rights: A Tribute to the Late Jonathan Mann', *Journal of Law, Medicine & Ethics*, 29 (2001):121-130

²¹ Salter, B., Jones, M., 'Regulating human genetics: the changing politics of biotechnology governance in the European Union', *Health, Risk & Society*, Vol. 4, No. 3, 2002, 325-340, at p. 327

²² *loc cit*, at p. 24

divorce of bioethics and human rights',²³ while Pope pleads for 'bioethics and human rights to be 'be reunited and harmonized.'²⁴ For Knowles:

Adopting the language of human rights means moving toward a more expansive understanding of the relationships between human health, medicine and the environment, socioeconomic and civil and political rights, and public health initiatives and human rights.²⁵

The distinguished commentator, David Thomasma, further believes that there is a lesson that bioethics can learn from human rights, saying that, '[h]uman rights are grounded in the community and in nature itself. They cannot be isolated from economic and social rights. This is what bioethicists will have to explore internationally and interculturallly.'²⁶

If so, then the agenda and scope of bioethics needs to be expanded into arenas beyond the medical, and into environment, poverty and other important social questions. This is a position which, of course, now garners growing support. Baker,²⁷ for example, has criticised US bioethical debate which, it is argued, has been overly dependent on the principlism derived from the influential work of Beauchamp and Childress,²⁸ rendering it incapable of forming the basis for universal norms such as those contained in human rights language. Further, since science and medicine and the goals pursued by them, are not value-free enterprises, bioethics can be tempted by an agenda set by an individual 'society's priorities and interests.'²⁹ Moreover, since '....bioethics has been to a large extent a phenomenon of industrialized nations....',³⁰ according to Farmer and Gastineau Campos, this has meant that 'the great majority of the world's ethical dilemmas – and, in our opinion, the most serious ones – are not discussed at all by the very discipline claiming expertise in such matters.'³¹ While conceding that '[b]ioethics has, for too long, focused on a too-narrow range of high-technology issues affecting few people....',³² Pope argues that bioethics and human right can usefully learn

²³ *id*

²⁴ Pope, T.M., 'Reuniting Human Rights and Bioethics to Address Medical Futlity and End-of-Life Treatment', available at http://www.thaddeuspope.com/images/Pope_abstract_for_NYC_AALS.pdf (accessed on 09/10/2008), Transcript, p. 1

²⁵ Knowles, L.P., 'The Lingua Franca of Human Rights and the Rise of a Global Bioethic', Cambridge Quarterly of Healthcare Ethics (2001), **10**, 253-263, at p. 260

²⁶ Thomasma, D.C., 'Bioethics and International Human Rights', Journal of Law, Medicine & Ethics, 25 (1997): 295-306, at p. 303

²⁷ *loc cit*

²⁸ Beauchamp, T.L., Childress, J.F., *Principles of Biomedical Ethics*, (6th Ed), Oxford UP, 2009

²⁹ Farmer, P., Gastineau Campos, N., 'New Malaise: Bioethics and Human Rights in the Global Era', Journal of Law, Medicine & Ethics, 32 (2004):243-251, at p. 245

³⁰ Farmer, P., Gastineau Campos, N., 'New Malaise: Bioethics and Human Rights in the Global Era', Journal of Law, Medicine & Ethics, 32 (2004):243-251, at p. 245

³¹ *id*

³² Pope, T.M., 'Reuniting Human Rights and Bioethics to Address Medical Futlity and End-of-Life Treatment', available at

from each other. For example, he argues that '[h]uman rights' focus on globalization and public health can be used to beneficially reorient bioethics to address broader issues.³³ In addition, since human rights commentators, he argues, lack experience in health related issues, 'human rights law can gain a rich vocabulary and conceptual toolkit from bioethics.'³⁴

Of course, like all human rights endeavours, bioethics confronts the accusation that it is culturally relativistic; in other words, that – as some of the commentators already referred to have suggested – some bioethical (and human rights) norms which are aspirational for the western or rich world, may be ill suited to other countries and their interests. The importance of respect for cultural diversity is, of course, specifically referred to in article 12 of UNESCO's Declaration on Bioethics and Human Rights, which mandates that '[t]he importance of cultural diversity and pluralism should be given due regard.'³⁵ However, and importantly, this same article goes on to insist that nonetheless, 'such considerations are not to be invoked to infringe upon human dignity, human rights and fundamental freedoms, nor upon the principles set out in this Declaration, nor to limit their scope.' This is a clear echo of the fundamental principles of the Universal Declaration.

Veatch argues that it is necessary to identify principles which are 'sufficiently abstract to identify general norms and the norms apply to conduct, not the character of the actor who engages in the conduct.'³⁶ He urges what he calls 'universalism' on bioethics, and claims that 'for ethical judgments (as opposed to matters of taste or preference) this universalism makes sense.'³⁷ This, of course, is not to ignore cultural diversity, but rather, as Thomasma puts it, the 'relativistic challenges' faced by both human rights and bioethics require that 'attention is paid to those features of human existence and culture that unite human beings without overruling the very real differences.'³⁸

Conclusion

The importance of a marriage between bioethics and human rights was expressly recognised by UNESCO's International Bioethics Committee itself, in 2003, when it said that 'modern bioethics is indisputably founded on the

http://www.thaddeuspope.com/images/Pope_abstract_for_NYC_AALS.pdf (accessed on 09/10/2008), transcript, at p. 1

³³ *id*

³⁴ *id*

³⁵ *Universal Declaration on Bioethics and Human Rights*, 19 October 2005

³⁶ Veatch, R.M., 'The Foundations of Bioethics', *Bioethics* Volume 13 Number 3/4, 1999, 206-217, at p. 216

³⁷ at p. 208

³⁸ Thomasma, D.C., 'Proposing a New Agenda: Bioethics and International Human Rights', *Cambridge Quarterly of Healthcare Ethics* (2001), **10**,299-310, at p. 307

pedestal of the values enshrined in the Universal Declaration of Human Rights.³⁹ One important consequence of this close relationship is that:

A global bioethics that envisions principles as mechanisms for protecting human rights will....inherit an internationally accepted ethical discourse, rights discourse is the best means available for achieving the shared goal of both bioethics and human rights theory....⁴⁰

Baker continues that 'an international bioethics based on respect for human rights will also be free from the feckless dispute over whose principles are preferable.⁴¹ Thus, '[t]he transcultural scope of human rights discourse can....dissipate problems of moral parochialism.⁴² The value and symbolic authority of human rights discourse has already been referred to. It 'lies in the association of some very fundamental moral values: rationality, free will and dignity, with the moral appeal of basic human interests, such as life, bodily integrity and freedom from suffering.⁴³ However, Benatar proposes that we need more than simply this language, arguing that '[u]sing only the language of rights to grapple with every moral issue is analogous to treating every sickness with the same medication (or class of medication) or it is like trying to speak by using only nouns. It is crude and ineffective.⁴⁴ Supplementing the language of human rights with a revision of the place of bioethics in the global arena will add force to both bioethics and human rights. Most importantly, it requires bioethics to be an **activity** as well as an academic discipline. As Knowles argues:

The globalization of bioethics demands that we respond with coherent coordinated international policy and action. This action should be guided by a global bioethic. The human rights framework has much to offer as a guide to developing that ethic....The strength of the human rights framework lies in the moral force of its language, its practical and aspirational vision, the connection with international law, and its inclusion of communities and responsibilities.⁴⁵

Despite some criticism that UNESCO has no place in drafting bioethics conventions, it seems to me that the Universal Declaration on Bioethics and Human rights has both practical and symbolic value. At a practical level, it has taken seriously the need to re-harmonise bioethics and human rights, and should assist in reorienting bioethical discourse away from specific, national

³⁹ UNESCO IBC Report of the IBC on the Possibility of Elaborating a Universal Instrument on Bioethics, UNESCO, Paris, June 13, 2003, at p. 1

⁴⁰ Baker, R., 'Bioethics and Human Rights: A Historical Perspective', Cambridge Quarterly of Healthcare Ethics (2001), **10**, 241-252, at p. 250

⁴¹ *id*

⁴² *id*

⁴³ Barilan and Brusa, *loc cit*, at p. 383

⁴⁴ He says that Benatar, D., 'Bioethics and health and human rights: a critical view', Med. Ethics 2006;32;17-20, at p. 19

⁴⁵ Knowles, L.P., 'The Lingua Franca of Human Rights and the Rise of a Global Bioethic', Cambridge Quarterly of Healthcare Ethics (2001), **10**, 253-263, at p. 262

agendas, and towards a broader base. Symbolically, it reminds commentators and governments that the mere rhetoric of rights is insufficient to protect those who are most vulnerable in the world, yet who are the rightful primary focus of human rights. Basing the Declaration in respect for persons – whoever and wherever they may be – leaves no scope for the potential hazards of cultural relativism nor, indeed, of cultural hegemony, and may assist bioethics in its major tasks for the future – not least, the continued effort to develop an inclusive global bioethic rooted firmly in human rights. It has also opened new agendas, and taken on the complex task of refining new bioethical standards and principles.

However difficult these tasks may be, the Declaration supercedes the narrow focus of medical ethics and loosens the handcuffs that tied bioethics and technology. In these senses, it too is a truly 'universal' Declaration, firmly grounded in respect for human rights, and committed to a broad human rights agenda that will facilitate bioethics' aspirations to play a powerful and authoritative role in tackling some of the world's most intransigent problems.