ENT•UK Undergraduate Essay Prize 2010

"Modern Medicine Benefits the Individual but not Humanity"

by

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The National Health Service pledges to give free healthcare at the point of need to all and in doing so aims to ameliorate the health of the entire nation.[1] Although undeniably noble, is such a commitment to care for all until the point of death, often with the most expensive medicine money can buy, the best way to benefit society? Would a policy which focuses on prolonging the lives of only the most productive in society not be more beneficial to humanity? This utilitarian ideal of national health care has long been criticised as eugenic theorising which could never be condoned by medical ethics. However at a time in which the NHS plunges ever deeper into debt, modern medicine in the UK may well be forced to give up its impressive commitment to help all in favour of helping only those who can best benefit from expensive healthcare. If the current financial pressures do eventually force the move from caring for humanity to the individual, there will be great repercussions for medical ethics which has, since the time of Hippocrates, encouraged doctors to care for all until the point of death.

Reverend Thomas Malthus, in his 1798 *Essay on the Principle of Population*, wrote that the human population will always grow exponentially until it is checked by disease, war or famine, at which point the population will again be reduced to the level of subsistence.[2] He predicted that this was the only way in which the population could be checked to avoid the inevitable extinction brought about by the lack of resources available to support exponential population growth.[3] However Malthus' apocalyptic predictions were invalidated by the advent of technology which kept food production increasing ahead of population growth.[4] [5] In the same way the new medical technologies of the 20th and 21st centuries have allowed the sick population of the UK to grow exponentially by enabling those who would have previously died to live with sickness.

Although such life prolonging medical technology has undeniably been a great success of medical innovation, it has also increased the percentage of sick people in society and therefore the financial burden on the NHS. Aggressive attempts to prolong life, even in the face of chronic or terminal illness, goes fundamentally against Darwin's theory of evolution in which only those who are the fittest in society are permitted to survive long enough to be able to reproduce.[6] The concept of 'fittest', now undeniably tainted by connotations of Nazi eugenics, is one that is now often excluded from discussions of the human population.[7] However in a time in which rationing must be introduced in healthcare it is a question that must be addressed. Medical technologies which enable people with diseases, especially those with a hereditary component, to survive and reproduce are contributing significantly to the proportion of the sick in our society. A good example being the neonatal screening programme for phenylketonuria, introduced in the 1950s. The early identification and treatment of the genetic disease with a low phenylalanine diet has allowed children who would have otherwise become mentally retarded to survive with full intellectual

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[1] Douglas R, Richardson R, Robson S. A Better Way. *Commission on the Reform of Public Services*. April 2003

[2] Stokstad, E. Will Malthus Continue to be Wrong? *Science.* 2005;309:102

[3] Cleland, J and Sindling, S. What would Malthus say about AIDS in Africa? *The Lancet* 2005;366:1899-1901

[4] Sachs, JD. The Specter of Malthus Returns. *Scientific American* 2008;Sept:38

[5] Trewavas, A. Malthus Foiled Again and Again. *Nature* 2002;418:668 - 670

[6] Darwin, C. *The Origin of the Species by means of Natural Selection.* London: Penguin Classics, Reprint 1985 p114-129

[7] Garver, KL and Garver BG. Eugenics: Past, Present and Future. *American Journal of Human Genetics* 1991;49:1109-1118

capacity into adulthood and reproduce, thus increasing the rate of the phenylketonuria in the general population.[8]

The idea of choosing only those individuals who are the healthiest to be supported and leaving those who are inherently weak to succumb to their weaknesses is one inseparable from the negative connotations of eugenics. However eugenics did, and still does, rest on a simple principle: encourage the fittest in society to breed and discourage the least fit from it. The aim is to increase the number of 'fit' in the society. 'Fit' has meant different things to different societies at different times; however in all to be fit is to be healthy. It was in Darwin's most famous work, *'The Origin of the Species by Means of Natural Selection'* (1859) that this concept was introduced to explain how the formation of new species and the extinction of others was a result of natural selection.[9] However it was in his later work, *'The Descent of Man and Selection in Relation to Sex'* (1871), that the concept was used explain the present condition of the human population. He claimed natural selection no longer occurred in human society as in the animal kingdom due to the interference of medical care, '*Our medical men exert their utmost still to save the life of everyone to the last moment…Thus the weak members of civilized societies propagate their kind. No one who has attended to the breeding of domestic animals will doubt that this must be highly injurious to the race of man.'*[10]

Health care for all, including the weakest in society, has long been a subject of debate. Critics argue, as Darwin did, that such state support serves to undermine the basic principle that one must work, i.e. be productive, in order to be able to live. Such a utilitarian argument measures the utility of a population based on the total utility of its members. Therefore it is morally acceptable, even good, to allow to population to increase so long as total happiness in the world increases proportionally. The aim is to avoid what Parfit has called the 'repugnant conclusion' that the population is allowed to increase un-checked and happiness of each citizen decreases.[11] However is the repugnant conclusion far off in modern medicine? The sick population has increased exponentially and as a consequence financial constraints are preventing each patient being given the best care available for their condition. Surely this large and ever growing patient population is less happy? Medical technology can only allow the sick population to continue to increase exponentially if funding for such technology allows it.

As already mentioned, the focus on 'humanity' or 'society' is difficult for the doctor in practice. However with growing financial constraints surely patients will come to understand that they are just one of a huge population and that many must share the same medical resources? This is one of the greatest weaknesses of the utilitarian theory, as Singer has explained; it rests on the acceptance that we ought to have the same concern for all human beings.[12] However humans do not, especially in times of extreme stress, such as illness, accept equal concern for all human beings. Patients want to secure expensive drugs for themselves and their loved ones. Exactly because such acts of altruism are rare, the government must step in and choose which of its citizens is most deserving of the available resources. This is an inherent weakness of the NHS, or any system of state funded healthcare, the government must decide and the clinicians must explain that decision to the patient, whether they agree with it or not.

The alternative is a system is like the one which has been in place in the United States for many years (although currently undergoing reform) in which all patients must invest in private insurance to cover the cost of their care. The more money is paid for a policy the more comprehensive the healthcare that can be redeemed. Rationing is therefore explicit and understood by all. Patients

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[8] Lindee, S. Babies' Blood: Phenylketonuira and the Rise of Public Health Genetics. In Lindee, S. *Moments of Truth in Genetic Medicine.* Baltimore: John Hopkins University Press, 2005, p34-35

[9] Darwin, C. *The Origin of the Species by means of Natural Selection.* London: Penguin Classics, Reprint 1985

[10] Darwin, C. *The Descent of Man and Selection in Relation to Sex*. Chicago Rand McNally, 1874, p130

[11] Parfit, D. Future Generations: Further Problems. *Philosophy and Public Affairs.* 1982;11:113-172

[12] Singer, P. *The Expanding Circle: Ethics and Sociobiology*. 1981 New York: Farrar, Straus & Giroux

receive the care that they have paid for. This system has been the target of much international criticism from nations with state funded healthcare systems open to all. Martin Luther King famously said that: '*of all the forms of inequality, injustice in health care is the most shocking and inhumane.'* [13] However is a system in which health care is delivered in direct proportion to the monetary investment of the patient not a modern day survival of the fittest? One must work and earn money to be able to prolong ones life in the event of illness.

Ayres pointed out that the United States is the '*only country in the developed world, except for South Africa, that does not provide health care for all of its citizens.'*[14] The U.S. healthcare system has been so criticised because it implies that the rich are more worthy of care than the poor. However from another angle it simply states that those who choose to pay for health care receive it and those who do not pay do not receive it. This is a capitalist policy. Such a good business plan has kept U.S. healthcare in the black while the NHS plunges into ever greater debt. The aim is to aid the individual not society as a whole. Yet paradoxically it can also be argued that this individualistic approach actually aids society more by focusing resources towards those who, in Darwinian terms, are most 'fit'. However such an approach does not sit well with the ethics of the medical profession. In the 2000 World Health Organisation (WHO) Report comparing the health systems of its 191 member countries, it stated that for a health system to be both good and fair it must have '*a fair distribution of financing health care – where the burden of health costs is fairly distributed on ability to pay, so that everyone is equally protected from the financial risks of illness.'*[15] Therefore, as Ayres has alluded to, the American healthcare system is not fair.

Although the American health care system was deemed 'unfair' by the WHO, it was transparent in its choice of individual above society. In the UK where the NHS mission statement argues to help all but in practice funds are not available to do so to the best ability of modern medical science, the individual versus society compromise is much less transparent for patients. Despite the fact that the National Institute for Clinical Excellence (NICE) has, since 1999, attempted to make rationing decisions explicit for patients and their families in practice several recent studies have shown that rationing within the NHS remains largely implicit. The doctor wields much power in the rationing situation as it falls to the clinician as to whether to tell the patient that they are not being offered the best known treatment and why. Doctors can also instruct patients as to how best to fight the NHS trust's decision not to provide the best treatment available or refer the patient to private practice.

Medical ethics favours patient autonomy and choice. Owen-Smith et al. have found that in line with this the majority patients feel that doctors must be explicit about rationing decisions so they can look into private care or over-turning the decision. A significant proportion of the patients questioned felt that to be honest about rationing was a moral responsibility of doctors and implicit rationing could be detrimental to the patient trust essential for the doctor-patient relationship. The clinical consultants questioned, despite all being in favour of explicit rationing in principle, found that being open about rationing decisions was actually very difficult in practice. Their decisions as to whether to reveal the existence of another treatment, which would not be paid for by the NHS, did depend heavily on the doctor's personal evaluation of how likely the patient would be able to access private care or overturn the trust's decision. Several doctors were also more likely to be explicit if their patients seemed well informed about the treatments available for their condition: '*Wrongly or*

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[13] Bureau of Labour Education. *The U.S. Health Care System: Best in the World, or Just the Most Expensive?* Orono: University of Maine, 2001.

[14] Ayres, SM. *Health Care in the United States: The Facts and the Choices.* Chicago and London: American Library Association, 1996, p xii

[15] World Health Organisation. *The World Health Report 2000 – Health Systems: Improving Performance*. Geneva: World Health Organisation, 2000, p35

rightly, my position has always been if I haven't been asked, and there is a treatment, and the patients doesn't know about it, and hasn't asked about it, then I don't volunteer it.' [16]

This attitude has been criticised by Gubb who claims that the patients who receive the best care in the UK are '*the rich and the articulate, who can afford to pay for the entire course of treatment themselves or have the knowhow to fight for what they want on the NHS.'*[17] However although in theory a more open approach would fit much better with the notions of patient autonomy and choice, the fact remains that a more explicit approach will place more stress on both doctors who have to explain the trust rationing decision, often against their clinical judgement, and the NHS in dealing with an increased volume of appeals.[18] The NHS does not have the funds to give each patient the treatment that they want. Bloor has taken up this argument, stating that patients should be made to understand that their need for a treatment is proportional to their capacity to benefit from it. Therefore those treatments which may offer benefits to individual patients, but offer only a small benefit or low probability of benefit, should not be considered 'necessary' treatments. Bloor believes '*the fact that treatments sometimes have to be rationed is the price paid for the comprehensiveness and humanity of the NHS.'*[19]

The situation of clinicians in the NHS is difficult as the mission statement emphasises benefits to British society as a whole but in practice the individual is increasingly becoming the focus. Despite criticisms of the American system, it is a transparent system in which patients are aware of the care that they are entitled to receive and why not all citizens are entitled to the same standard of care. Douglas et al. have proposed reform of the NHS mission statement to better represent the new situation that the NHS finds itself in: '*The mission statement of the NHS is to improve the health of the nation as a whole. The result was that choice and individual patient entitlement or rights were simply designed out of the system.'* The report recommends a change in the NHS mission statement '*from being about the collectivised provision of healthcare, it should change to being driven by individual patient need.'*[20]

Such a change in the aim of the NHS will reduce the burden on clinicians and help to realign patient expectations with what the NHS is capable of providing. At the minute doctors are being forced to decide whether to comply rigidly with the medical ethics of patient autonomy and choice or to be implicit about rationing decisions and thus decrease the possible stress on patients deemed unable to access the best available treatment.[21] Several patients in the study by Owen-Smith et al. were aware of this stress falling on clinicians: '*I felt sorry for the doctors, they were telling me in one breath that that I needed it [herceptin], and that I really had to have it, but in the next breath they were having to tell me that I couldn't have it.'*[22] The rationing debate clearly illustrates the individual versus society problem in the NHS in which the ethical principles of medicine and the day-to-day problems of running a modern health-care service are difficult to reconcile. If the international

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[16] Owen-Smith A, Coast J, Donovan J. The desirability of being open about health care rationing decisions: findings from a qualitative study of patients and clinical professionals. *Journal of Health Services Research & Policy.* 2010;15:14-20

[17] Gubb, J. Should patients be able to pay top-up fees to receive the treatment they want? Yes. *BMJ.* 2008;336:1104

[18] Owen-Smith A, Coast J, Donovan J. The desirability of being open about health care rationing decisions: findings from a qualitative study of patients and clinical professionals. *Journal of Health Services Research & Policy.* 2010;15:14-20

[19] Bloor, K. Should patients be able to pay top-up fees to receive the treatment they want? No. *BMJ.* 2008;336:1105

[20] Douglas R, Richardson R, Robson S. A Better Way. *Commission on the Reform of Public Services*. April 2003

[21] Carlsen B, Norheim OF. 'Saying no is no easy matter' a qualitative study of competing concerns in rationing decisions in general practice. *BMC Health Services Research.* 2005;5:70

[22] Owen-Smith A, Coast J, Donovan J. The desirability of being open about health care rationing decisions: findings from a qualitative study of patients and clinical professionals. *Journal of Health Services Research & Policy.* 2010;15:14-20

movement towards the explicit healthcare rationing, which both patients and clinicians want in theory, is to be successful in practice patients' expectations of treatment choice must be brought into line with the funding available.[23] [24]

The issue of the individual versus humanity in modern medicine is a complex one. Although utilitarianism is sensible in theory, a civilised society cannot and should not be willing to leave the weakest in society to suffer ill-health unnecessarily. However for the NHS to move forward there must be a realisation that when the NHS vows to treat all at the point of need, that need must be evaluated on an individual basis not on a vague nationwide guideline. The decision on what an individual patient 'needs' must be based on both clinical judgement and cost-benefit. Patients must be educated to realise that the treatment they what and the care that can be provided, may be very different. Doctors will continue to be the face of rationing decisions, however with greater appreciation by patients of the need and methodology of rationing decisions, the negative impact of such decisions on the doctor-patient relationship, itself dependant on the patient being treated as an individual, might be minimised.

[23] Jones IR, Berney L, Kelly M. Is patient involvement possible when decisions involve scarce resources? A qualitative study of decision making in primary care. *Social Science and Medicine* 2004;59:93-102

[24] Owen-Smith A, Coast J, Donovan J. 'I can see where they're coming from, but when you're on the end of it…you just want to get the money and the drug.': Explaining reactions to explicit healthcare rationing. *Social Science and Medicine* 2009;69:1935-1942

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World Health Organisation. *The World Health Report 2000 – Health Systems: Improving Performance*. Geneva: World Health Organisation, 2000, p35