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find. As my legal friends would put it, “details that could reasonably have been expected to appear in evidential text were absent.”

Watson: So, heart disease remains an enigma—though the striking rise and fall over the past 50 years is strongly suggestive of a biological cause. No doubt those who smoke or take insufficient exercise or whose cholesterol concentrations are greatly raised may be at “increased risk,” but none can be determinant (in the way the putative biological cause clearly must be), which is why the pattern of the disease has changed so dramatically quite independently of them. I can hardly wait to smell once again the aroma of a cooked breakfast with an easy conscience.

Holmes: Watson, your wish will be granted, and I will instruct Mrs Hudson accordingly. Meanwhile, given everything we have learnt today—and how fascinating it has been—we should perhaps usefully turn our attention to investigating why your fellow doctors have been persuaded to prescribe cholesterol lowering drugs on so massive a scale.^{21 22} But that is for another day.

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- 1 Doyle AC. Silver Blaze. In: *The Penguin complete Sherlock Holmes*. London: Penguin, 1981.
- 2 Shepherd E. “Non barking dogs and other odd species”: Identifying anomaly in witness testimony. *Med Sci Law* 1999;39:138-45.
- 3 Department of Health. *The health of the nation: a strategy for health in England*. London: HMSO, 1992.
- 4 Ebrahim S, Smith GD. Systematic review of randomised control trials of multiple risk factor interventions for preventing coronary heart disease. *BMJ* 1997;314:1666-74.
- 5 Brull D, Humphries S, Montgomery H. Infection, inflammation and coronary artery disease: more than just an association? *Br J Cardiol* 2000;7:681-9.
- 6 National Advisory Committee on Nutrition Education. *Proposals for nutritional guidelines for health education in Britain*. London: Health Education Council, 1983.
- 7 Kuulasmaa K, Tunstall-Pedoe H, Dobson A, Fortmann S, Sans S, Tolonen H, et al. Estimation of contribution of changes in classic risk factors to trends in coronary-event rates across the WHO MONICA project populations. *Lancet* 2000;355:675-87.
- 8 World Health Organization. *World health statistics annuals*. Geneva: WHO, 1951-1996.
- 9 Barker DJP, Osmond C. Diet and CHD in England and Wales during and after the second world war. *J Epidemiol Community Health* 1986;40:37-44.
- 10 Grove RD, Hetzel AM. *Statistics rates in the United States 1940-1960*. Washington DC: National Center for Health Statistics DHEW, 1968.
- 11 Sigfusson N, Sigvaldason H, Steingrimsdottir L, Gudmundsdottir II, Stefansdottir I, Thorsteinsson T, et al. Decline in ischaemic heart disease in Iceland and changes in risk factor levels. *BMJ* 1991;302:1371-5.
- 12 Vartiainen E, Puska P, Pekkanen J, Tuomilehto J, Jousilahti P. Changes in risk factors explain changes in mortality from ischaemic heart disease in Finland. *BMJ* 1994;309:23-27.
- 13 Keys A, ed. *Seven countries: a multivariate analysis of death and coronary heart disease*. Cambridge, MA: Harvard University Press, 1980.
- 14 Marmot MG, Syme SL, Kagan A. Epidemiological studies of coronary heart disease and stroke in Japanese living in Japan, Hawaii and California. *Am J Epidemiol* 1975;102:514-25.
- 15 Brisson G. *Lipids in human nutrition*. Lancaster: MTP Press, 1982:98.
- 16 Armstrong B, Doll R. Environmental factors in cancer incidence and mortality in different countries, with special reference to dietary practices. *Int J Cancer* 1975;15:617-31.
- 17 Peese DH. *Tobacco consumption in various countries*. London: Tobacco Research Council, 1972. (Tobacco research paper No 6.)
- 18 World Health Organization. *Health statistics annual*. Geneva: WHO, 1977.
- 19 US Public Health Services. *Health consequences of smoking*. Rockville, MD: USPHS, 1976. (USPHS publication No 1696.)
- 20 Cornfeld J, Mitchell S. Selected risk factors in coronary disease. *Arch Environ Health* 1969;19:382-94.
- 21 Davey-Smith G, Pekkanen J. Should there be a moratorium on the use of cholesterol-lowering drugs? *BMJ* 1992;304:431-4.
- 22 Le Fanu J. *The rise and fall of modern medicine*. London: Abacus, 2000.

Are ethical principles relative to time and place? A *Star Wars* perspective on the Alder Hey affair

Kim D Arcus, Anthony S Kessel

The problems at Alder Hey Hospital around how, when, and why parents’ consent should be sought for research on their dead children’s tissues has raised some old philosophical questions. In particular, to what degree can practices be morally defended on the grounds of context? To help shed light on this, Kim D Arcus and Anthony S Kessel went to a different time and place and requested help from a galaxy far, far away—from Dr Luke Skywalker and his mentor, Obi-Wan Kenobi

Dr Luke Skywalker: Obi, I need some advice.

Obi-Wan Kenobi: Ahhh, you only see old Obi when you need advice these days, huh?

Dr Luke: Obi, you know the Force is a delicate balance. Now, let me explain my scenario. Occasionally organs and tissues from babies and fetuses are retained after postmortem examination for research and education. Current practice is to obtain informed consent to retain them, but 10 to 20 years ago this wasn’t commonplace. Recently in England some of these organs were kept at some pathology laboratories with-

out consent—such as at Alder Hey Hospital.^{1 2} Parents feel they were misled into thinking that they were burying their deceased children intact, whereas in fact some organs and tissues were missing. From the pathologists’ point of view, this old paternalistic approach was warranted in the interest of avoiding parental distress and generating benefit to society through research and training. The way I see it, this is a matter of context, and politicians and the media have exaggerated the issue of consent out of proportion. Paternalistic actions of yesteryear are being judged by today’s ethical standards. Surely

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ethical principles change and are relative to time and place?

■ *“An awareness of moral relativism, utilitarianism, Kantian ethics, and biomedical ethics will help.”*

Obi: Mmmm. You can look at this difficult problem from several perspectives; the parents’ and pathologists’ are just two. However, a look through the lenses of moral philosophy and medical ethics may help to untangle this conundrum. These disciplines are concerned with, in the words of Socrates, “how we ought to live, and why”—in other words, how we should treat people and how we decide what is right or wrong. For your scenario, I think an awareness of moral relativism, utilitarianism, Kantian ethics, and biomedical ethics will help.

Dr Luke: OK, I’ll tell Princess Leia I’ll be late for dinner—again!

Obi: So, let’s start with moral relativism which relates to your argument about changes over time and place. Moral relativism is about the nature of ethics and says that ethical standards are contingent on history, context, and culture.³ The famous Roman physician Galen, for example, did most of his anatomy research on pigs and dogs as it was regarded as immoral to dissect humans at that time.⁴ But attitudes changed, and by the 19th century the demand for human cadavers was such that grave robbing became prevalent to supply medical schools in the United Kingdom with necessary teaching resources.⁴

Dr Luke: So there you go—you’ve proved my point that it all changes over time. Hence, you can’t use the consent practices of today to judge actions 20 years ago. Have we finished?

Obi: Well not quite. If we accept this relativism idea wholly then it doesn’t easily allow criticism of people’s actions that you and others may see as immoral.³ For example, if we use a strong relativism framework, Nazi experiments on humans during the second world war could be interpreted as merely an

expression of a set of values and ethics from a different time and place.

Dr Luke: But we all know those experiments were wrong.

Obi: So, there’s the contradiction. Why are the Nazi experiments deemed not relative to time and place and yet the retention of organs without consent are deemed relative?

■ *“There must be some principles that are more consistent over time.”*

Dr Luke: OK, so there must be some principles that are more consistent over time and, well, some that are not.

Obi: Well, philosophers have created many moral theories that are more consistent over time and place. For the purposes of this conundrum we’ll look at utilitarianism, a theory based on consequences, and Kantianism, a theory based on duty or deontology.

Dr Luke: Consequences? Deontology?

Obi: Yes, such as weighing up the expected pleasure and enlightenment you gain from talking to me against the pleasure and enlightenment you gain from time with Princess Leia—that’s utilitarianism. Compare that to an intrinsic duty to, say, be on time for dinner, regardless of the consequences—that’s Kantianism. Let me explain further. Utilitarians, in the tradition of Jeremy Bentham and John Stuart Mill,⁵ believe that actions are morally good if, on balance, they bring the most happiness—commonly referred to as the greatest good for the greater number.⁶ Physicians may claim, on utilitarian grounds, that benefits from research that has helped to reduce mortality and increase scientific understanding are greater than the negative impacts, such as parents’ anguish at having to consider giving consent at such a difficult time.² Some have even questioned why those refusing to take part in such research should gain from those who have.⁷

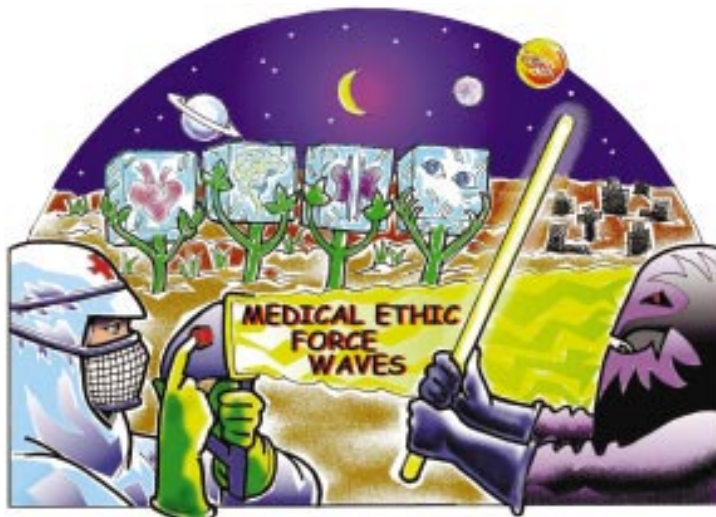
Dr Luke: But forcing everyone to take part in research would bring substantial pain and distress for some people. Body states after death, for example, are very important to some Hindus and Buddhists owing to their possible impact on reincarnation.⁸

■ *“Utilitarianism can defend acts that most people take to be unjust.”*

Obi: Exactly, and those are some of the criticisms of utilitarianism—firstly, that it’s difficult to measure accurately happiness or pain, and, secondly, that it can defend acts that most people take to be unjust, such as forced participation in research or even genocide.

Dr Luke: But ... Kantian ethics?

Obi: Kant’s philosophy is based on duty rather than consequences—such as always telling Princess Leia the truth rather than weighing up the impacts of being honest or lying to her—as a means to determining what to do. Kant argued there was a categorical imperative to “treat people as ends in themselves, never merely as means to an end.”⁹ In not being asked for consent,



SUFE SHARPLES

Let the ethics be with you

parents could argue that their children were effectively being used as a means to research and not as ends in themselves.

Dr Luke: But, under Kant, as long as the intentions of my actions are within my duties then it doesn't matter what the consequences are. So, wasn't retaining those organs part of the clinicians' moral duty to society to further science and reduce mortality? Surely their actions were morally justified—it's just that some of the consequences weren't so good.

Obi: Yes, and that's a criticism of Kantian theories. A lack of consideration for the consequences of actions.

Dr Luke: OK, let me get this straight. Strong relativism, in an extreme individualistic form, can almost lead to a sense of anarchy. So we looked for some universality in utilitarianism and Kantianism. But I've still got parents on one side and clinicians on the other and no universality—at least over time.

■ *“Four principles ... respect for autonomy, non-maleficence, beneficence, and justice.”*

Obi: OK, I didn't say this was going to be easy. Let's see what medical ethics thinks of all this. Beauchamp and Childress identified four principles that were designed to cut across some of the problems posed by relativism while paying heed to the importance of context.¹⁰

Dr Luke: So what are these four principles?

Obi: Respect for autonomy, non-maleficence, beneficence, and justice. In a way these four principles derive both from deontological theories, such as Kantian ethics, and from consequentialist theories, such as utilitarianism. Non-maleficence and beneficence have utilitarian overtones. Recall your Hippocratic Oath to “do no harm.” Some pathologists thought they might cause undue harm (maleficence) by requesting consent especially after a tragic young death. But by retaining the organs they would do social good (beneficence).

Dr Luke: But now comes the Kantian bit, right?

Obi: Yes, in Kantian terms, respect for autonomy is closely related to the categorical imperative of treating people as ends and not means.¹¹ Without respecting informed consent, people's ability to make their own decisions (to “self determine”) is taken away.

■ *“These principles of medical ethics are not without their critics.”*

Dr Luke: So if we are to be utilitarian and Kantian at the same time, surely conflicts must arise?

Obi: Quite right, and therein lies the difficulty. As Lindblom says, we need to incrementally “muddle through” in our decisions.¹² We need to be aware of these underlying principles and continually monitor how they are being exhibited in practice. Guidance is available from the Royal College of Pathologists and the Nuffield Council, as well as from international mandates such as the Nuremberg Code and the Declaration of Helsinki.¹³⁻¹⁶ They all emphasise the importance of respect for people's autonomy. The

Declaration of Helsinki, for example, states that “considerations related to the well-being of the human subject should always take precedence over the interests of science and society.”¹⁶

Dr Luke: So if this maxim of respecting someone's autonomy is universal then we should have been asking for consent then?

Obi: If you subscribe to the principles of biomedical ethics then yes, as the principle of autonomy was not sufficiently addressed. However, these principles of medical ethics are not without their critics.¹⁷ But look around you, Luke. With the rise in human rights, respect for autonomy is a principle being applied more explicitly.¹⁸ The key is to continue to be aware of the history and context in which debates arise and their relation to the ethical norms of the day. And watch out for exaggerations based on personal or political interests—what the pathologists did cannot be compared with the atrocities that Darth Vader is inflicting on our fellows! Engage in debate with your colleagues, and regularly review codes of conduct and guidelines, especially as you fast approach more abstract issues relating to DNA and genomics.¹⁹ Remember, Luke, when I say “let the Force be with you,” I'm talking about the bond and energy between you and your patients. Use the Force, Dr Luke. Together, patient and clinician, you can help improve the health of our galaxy.

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- 1 Bristol Royal Infirmary Inquiry. The inquiry into the management of care of children receiving complex heart surgery at the Bristol Royal Infirmary—interim report: Removal and retention of human material. 2000. www.bristol-inquiry.org.uk/interim_report/pdf/report.pdf (accessed 25 Nov 2002).
- 2 Redfern M, Keeling JW, Powell E. The Royal Liverpool Children's inquiry: summary and recommendations. January 2001. www.rlcinqury.org.uk/download/sum.pdf (accessed 25 Nov 2002).
- 3 Wong D. Relativism. In: Singer P, ed. *A companion to ethics*. Oxford: Blackwell, 1991:442-50.
- 4 Hutchens MP. Grave robbing and ethics in the 19th century. *JAMA* 1997;278:1115.
- 5 Russell B. *History of western philosophy*. London: Routledge, 1991.
- 6 Smart JJC, Williams B. *Utilitarianism: for and against*. Cambridge: Cambridge University Press, 1991.
- 7 Evans HM. What's wrong with “retained organs”? Some personal reflections in the afterglow of “Alder Hey”. *J Clin Path* 2001;54:824-6.
- 8 Veatch RM, ed. *Cross-cultural perspectives in medical ethics*. 2nd ed. Sudbury, MA: Jones and Bartlett, 2000.
- 9 Warburton N. *Philosophy, the basics*. 3rd ed. London: Routledge, 1999:45.
- 10 Beauchamp TL, Childress JF. *Principles of biomedical ethics*. 5th ed. New York: Oxford University Press, 2001.
- 11 Gillon R. Medical ethics: four principles plus attention to scope. *BMJ* 1994;309:184-8.
- 12 Lindblom CE. The science of muddling through. *Public Adm Rev* 1959;19:79-88.
- 13 Royal College of Pathologists (UK). *Guidelines for the retention of tissues and organs at post-mortem examination*. London: RCP, 2000. www.rcpath.org/news/tissue_retention.pdf (accessed 25 Nov 2002).
- 14 Nuffield Council on Bioethics. *Human tissue: ethical and legal issues*. London: NCB, 1995. www.nuffieldbioethics.org/filelibrary/pdf/human_tissue.pdf (accessed 25 Nov 2002).
- 15 Annas GJ, Grodin MA. *The Nazi doctors and the Nuremberg Code: human rights in human experimentation*. New York: Oxford University Press, 1992.
- 16 World Medical Association. The World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. 2000. www.wma.net/e/policy/17c.pdf (accessed 25 Nov 2002).
- 17 Davis R. The principlism debate: a critical overview. *J Med Phil* 1995;20:85-105.
- 18 Hewson B. Why the human rights act matters to doctors. *BMJ* 2000;321:780-1.
- 19 Andrews L, Nelkin D. Whose body is it anyway? Disputes over body tissue in a biotechnology age. *Lancet* 1998;351:53-7.