PAPER

The patient/client/consumer/service user and medical ethics 40 years on

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ABSTRACT
This essay, written from my non-doctor's 'lay' perspective, sketches a gradually improving approach to medical ethics over the 40-year period since this journal was founded. A central feature of this improvement has been the increasing focus of medical ethics on the interests and perspectives of the patients/clients/consumers/service users, whose interests doctors and other healthcare workers serve. Events such as misuse of the end of life 'Liverpool Care Pathway' and the shockingly poor care revealed in National Health Service hospitals in Mid-Staffordshire show that these improvements are by no means universal. Nonetheless, there has been a steady improvement in general terms towards putting patients first and it is not flattery to say that in its consistent support for this concern and in its promotion of non-medical involvement in medical ethics education the *Journal of Medical Ethics* has itself made a significant contribution to 'doing good medical ethics'.

After the shock of some medical research and other scandals from the 1940s and 1950s, it is clear that disciplined thinking about medical ethics has transformed the way doctors and other healthcare professionals practise. From Tuskegee and its 40-year history,[1] finishing only in 1972, a mere 3 years before this journal's birth, to Nazi doctors' experiments on concentration camp inmates,[2 3] to Medical Research Council (MRC) sponsored research in 1950s and 1960s which showed that researchers and doctors lied to parents about their children's bodies and refused to allow bereaved mothers to hold their dead infants in their arms,[4] to the work of Maurice Pappworth, frequently reviled in his lifetime, on how human beings were being used in research,[5] to Henry Beecher who argued much of what Pappworth was saying,[6 7] but did not name and shame, the history was not a happy one. The research concerned ranged from the truly well intentioned (much of it) to the frankly indefensible on any grounds (most Nazi experimentation), but it all suffered from one huge defect—lack of either information or indeed informed consent on the part of the participants or their close relatives, as well as the arguable damage or lack of benefit to the research subjects, not to mention pain, trauma and a sense that the research was for the researchers' benefit, or occasionally the nation's benefit, not for the subjects or others in their cohort.

It took until 1997 for there to be a formal apology by President Bill Clinton to the Tuskegee study participants: 'What was done cannot be undone. But we can end the silence. We can stop turning our heads away. We can look at you in the eye and finally say on behalf of the American people, what the United States government did was shameful, and I am sorry...To our African American citizens, I am sorry that your federal government orchestrated a study so clearly racist.'[8]

As a result of the Tuskegee scandal, and the work done by Henry Beecher and others, in 1974, the year before this journal's birth, the US Congress passed the National Research Act and created a commission to study and write regulations governing studies involving human participants. In the UK, the Royal College of Physicians started serious work on the ethics of experimentation on human subjects in the 1960s, though guidelines were not published till 1987, even though it was that same college which had delayed awarding Maurice Pappworth his fellowship of that college, despite his teaching generations of young doctors to pass the Membership of the Royal Colleges of Physicians (MRCP) examination, until 1993, 57 years after he qualified and passed the MRCP (and only because the leadership of the college had changed considerably by then). Towards the end of his life, Pappworth wrote an article in the *British Medical Journal* that included his view that 'those who dirty the linen and not those who wash it should be criticised. Some do not wash linen in public or in private and the dirt is merely left to accumulate until it stinks'.[9]

I met Maurice Pappworth at his London home in 1990, when I was working on a study of UK research ethics committees,[10] many of which had come into being indirectly—or, in some cases, directly—as a result of his work 'Human Guinea Pigs.' What was remarkable about him, and he was not an easy man, was his emphasis on the welfare of patients and his passionate belief that doctors and healthcare professionals cannot, and should not, do anything to patients that is not either in their direct interest or is done on the basis that it might be of direct benefit to them (eg, they might be the recipients of a new and effective drug for their condition, if they were allocated to that arm of a randomised study that gave them that drug) in part of a study to which they had given their full and informed consent. Pappworth's passion for the welfare of patients, and his anger at parts of the medical establishment, remained undimmed in 1990. He was strongly influenced by the evidence from the Nazi experiments on concentration camp inmates, and by the Nuremberg code, originally submitted to the Counsel for the war crimes trial of the Nazi doctors by Dr Alexander[11] who, long

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before Beecher, had pointed out that American doctors were not wholly exempt from the Hegelian principle of 'what is useful is right' and had better look to their practices, while praising the Dutch physicians for holding out against the Nazis. He also made it clear that the German medical profession could have done what the Dutch did and singled them out for great opprobrium. He then tried to define what legitimate medical research might look like in 1947.

Why the sudden change and what has 40 years of the *JME* done to speed up that transformation in thinking? First, the passion of some of those who campaigned just before the establishment of the journal made a huge difference in putting the issues at the forefront of public, and medical professional, consciousness. But it was not only that. The 1960s and 1970s saw a societal change in the West. Consumerism was making waves. The very beginning had been in the 1950s, with the Consumers' Association, now known as Which?, being formed by Michael Young and others in 1957. In 1962, the British Edition of the American Medical Letter, the forerunner to the Drug and Therapeutics Bulletin, launched and took interest in issues relating to drugs, research and consumers. (By the 1990s, with Professor Joe Collier as its editor, consumer concerns and the rights of patients were at the forefront of its thinking, partly as a result of the huge dissemination of ethical principles surrounding autonomy and informed consent promulgated among others by the *JME*.)

The mood had changed. Patients were beginning to ask questions. The subservient, 'doctor knows best', attitude of the 1940s and early 1950s was fading, and increasing levels of education, and a less deferential society, meant that doctors and researchers could not assume that the public would always regard them as acting beneficently. Into this changing climate, the journal launched in 1975, the same year that sex discrimination and race discrimination legislation came into force in the UK. This was the time of huge medical and research advances, combined with insufficient codes or medical ethics teaching to guide doctors. Beauchamp and Childress came up with their four principles in 1979, which became a common framework for thinking about medical ethics.[12] These were respect for autonomy—the patient has the right to refuse or agree to their treatment: beneficence—a practitioner should act in the best interest of the patient; non-maleficence—'first, do no harm'; and justice—which concerns the distribution of scarce health resources, and the decision of who gets what treatment (fairness and equality). Other values soon included were respect for persons—the patient (and the person treating the patient) have the right to be treated with dignity, truthfulness and honesty—the concept of informed consent, which had increased in importance after the terrifying revelations of the doctors' trial at the Nuremberg trials and the Tuskegee syphilis experiment.[13]

Add to that the first test-tube babies, after Louise Brown was born as a result of natural cycle in vitro fertilization where no stimulation was made, in the pioneering work by Robert (Bob) Edwards in 1978, and a plethora of ethical questions began to arise about the nature of fertility, who the 'real' parents were, what the rights of donors might be, whether 'donors' could or should be 'paid' in cash or services, and, later, questions where there were genuinely three biological parents of a child. The timing was impeccable. While national governments struggled to keep up, Britain took the lead with its Voluntary and then Interim Licensing Authorities, after the Warnock Report was published in July 1984 and highlighted the 'special status' of the embryo. All this was followed by the Human Fertilisation and Embryology Authority being established in 1991.[14] All through these years, the journal focused on the rights of mothers and children (do children have the right to know their biological parents?), on questions of financial gain through the sale of gametes, and encouraged deep thinking about these complex issues, always with the interests of the child at heart and recognising the status of the embryo as 'special'.[15–18]

But, at the same time, concern was growing about what was happening in both research and treatment more generally. First: Was informed consent truly informed? Did patients understand what they were being told, and did it always matter that they should?[19 20] In research, the issues grew greater. Not all research was properly governed by Research Ethics Committees (RECs). Not all RECs had patient/user/lay representation, despite Royal College of Physicians' guidelines, published in 1987. Research on children was a mess, neither with any conception of what it meant to ask for consent of adult parents/guardians or to inform and ask opinions of children, nor with adequate Research Ethics Committees in place, as discussed by the Institute of Medical Ethics in the 1980s.[21–23] Parents became seriously concerned. Increasingly, patients' organisations were demanding more of a voice, encouraged by the journal. The General Medical Council (GMC) began to take a serious interest and published guidance about consent to treatment from an ethical point of view in 1998.[24] 'Tomorrow's Doctors', published by the GMC in 1993, had already made much of thinking ethically and knowing how to do so.[25] The journal had focused on what happens if patients have mental health or learning disability issues.[26–28] Meanwhile issues about breast cancer screening were being raised more widely, and there was a feminist critique, later partly borne out by evidence on utility, that screening might do more harm than good.[29] However, no-one at that time took up what was clearly discriminatory in the age limits imposed for standard breast cancer screening, with automatic recall ceasing just as incidence of breast cancer started to rise with age.

The journal tackled how medical ethics and law should be taught in medical schools and always emphasised patient/user involvement.[30 31] It also rose to the AIDS challenge, where remarkably articulate patient groups refused to go along with testing and indeed randomisation of drugs.[32] All this is merely a sample. Over the last 40 years, the journal has, along with others, been at the forefront of promoting a lay and/or patient view on a huge range of medical and healthcare issues. Its championing of the need for patient involvement has led to a totally different view of how experts should come to their decisions, these days largely—though not always—explained to lay members of professional bodies and groupings and seen through their lenses.

It may have been Tuskegee, Pappworth and Beecher that made the public sit up and take notice. But these days, concerns about the way the Liverpool Care Pathway for dying patients was being implemented, the review of which I chaired,[33] coming from families and patients around the country, could not be ignored, as they might have been 40 years ago. The review group consisted of a variety of people, with only two doctors and one nurse. 'Lay' members were in the majority. The patient's voice was now paramount, and successive health ministers were listening to patients' stories around the UK, after poor care in various institutions, including notoriously at Mid-Staffordshire National Health Service (NHS) Hospitals, came to light.[34] Of course not all of these can be attributed to the journal's stance and work. But enough of it can be, given its promoting both of lay involvement and of the academic study of medical ethics by people other than health professionals, to pay tribute to its contribution to cultural change. Not fast enough or far enough yet, but the tone is different, and

doctors, along with other professionals, are no longer treated as deferentially as they once were, and largely no longer wish to be. What the journal has helped achieve is, at best, a true partnership between patients, lay groups doctors and other healthcare professionals, seeking only the best outcome for everyone. And that is as it should be. However, there is still much to do, as for example, we see secrecy and contempt for whistle-blowers still dogging the corridors of the NHS.

Let me conclude with a partial answer to the question posed to contributors to this anniversary issue: What is it to do good medical ethics? At least part of the answer is to put at the centre of medical ethics the patients/clients/consumers/service users whose interests medicine serves. In that respect, the *Journal of Medical Ethics*, has for 40 years, made important contributions to 'doing good medical ethics'.

Julia Neuberger has chaired the Patients Association, was Chief Executive of the King's Fund (1997–2004), chaired Camden and Islington Community Health Services NHS Trust (1993–1997), was a member of the Voluntary and Interim Licensing Authorities and the Human Fertilisation and Embryology Authority, is an Honorary Fellow of the Royal Colleges of Physicians, GPs, Obstetricians and Gynaecologists, and Psychiatrists and an Honorary Fellow of the Faculty of Public Health. She served on the General Medical Council, the Medical Research Council and the British Medical Association's medical ethics committee. She chaired the review of the workings of the Liverpool Care Pathway and continues to chair a small panel advising ministers on how the new provisions are being implemented. She has a passion for issues to do with mental health and discrimination, as well as for ethics in research. She is a member of the House of Lords and Senior Rabbi of the West London Synagogue.

Competing interests None.

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