

Highlights from this issue

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Julian Savulescu, *Editor in Chief*

There are many different kinds of good medical ethics. One example is thoughtful, logical, analytic exploration of personal experience, using the social science and ethics literature to identify and understand ethical dilemmas that arise from experience and to make progress towards their resolution. 'A long shadow: Nazi doctors, moral vulnerability and contemporary medical culture' by Alessandra Colaianni is such a paper. For that reason, I have made it Editor's Choice (*See page 435*).

Alessandra Colaianni starts (and I quote at length because this is also an unusually well written paper),

'On a rainy day in Oswięcim, Poland, I stood next to the rusty railroad tracks leading into Auschwitz in the same place where Nazi doctors performed 'selections', sentencing millions of innocent people to death or imprisonment by pointing left or right. Although I had spent weeks studying the role of physicians in the Holocaust as part of the Fellowships at Auschwitz for the Study of Professional Ethics, I was incredulous. The value of physicians to the Nazi regime is clear: their support gave scientific legitimacy to the principles of eugenics on which the Nazis built their Rassenpolitik (racial policy) and rationalised murder under the logic of medical necessity. Indeed, without active physician participation, the Nazi regime could not have achieved its murderous aims so efficiently: physicians disguised the horrors by systematising them and cloaking them in misleading medical jargon. In so doing, they subverted their own professional values. How could so many who had sworn to do no harm have become such an integral part of murder and torture?'

She then answers this important question, identifying several vulnerabilities of doctors: hierarchy and socialisation, career ambition, 'licence to sin', inflicting pain, detachment and medical terminology/euphemism. What is the solution? '[A] solid grounding in principles of ethics, individualism and human rights...[b]eing aware of the risks and potential for harm inherent in our chosen profession..., and actively modifying deleterious aspects of medical culture...'

What is especially striking about this paper is that it is written by a medical student with no formal training in medical ethics (to my knowledge). It shows brilliantly how an intelligent, open minded, rational and enquiring person can do medical ethics, well.

What are the limits to the provision of medical services? When should a doctor say 'No' to a patient's or family's request for medical treatment?

These are common questions. They are the subject of a lively discussion in this month's issue of the *Journal*. Heuser, Eller and Byrne provide interesting empirical data in 'Survey of physicians' approach to severe fetal anomalies'. They describe the approach of obstetric providers to pregnancies complicated by life-threatening fetal anomalies which are either lethal, such as anencephaly, or severe, such as Trisomy 18 (*See page 391*).

The vast majority of US obstetricians in their survey would discuss with the pregnant woman the option of termination (though a small number would not). But if she chooses to continue the pregnancy and employ measures that would increase the chance that the fetus is born alive, 7% of specialists would encourage or support her decision, while one-third would refuse her request and about one-half would try to dissuade her.

The authors also found that significant differences (or inconsistencies) exist in the management and counselling for 'uniformly lethal' as compared with 'commonly lethal' anomalies and demographic variables, particularly gender of the obstetrician, influence management and counselling. They call for guidelines to harmonise practice.

Dominic Wilkinson, a neonatal intensivist and Associate Editor of this *Journal*, in a thoughtful commentary worries that this represents an unethical deviation from the principle of non-directive counselling and 'unjustified paternalism' (*See page 396*).

Frank Chervenak and Laurence B McCullough, the great grandfathers of the ethics of maternal-fetal medicine, who have written scores of articles related to this topic, provide guidelines which state 'the pregnant woman should be offered the alternatives of aggressive and

non-aggressive obstetric management and induced abortion before viability. It is also ethically permissible to offer feticide followed by termination of pregnancy after viability in such cases' (*See page 398*).

In a related but unconnected paper, Dagmar Schmitz argues that traditional medical ethics do not deal well with decisions about prenatal testing and termination of pregnancy. Schmitz is particularly critical of 'especially indication-based approaches' which relate termination to fetal abnormality. Schmitz argues that selective termination of pregnancy raises distinct issues in medical ethics. 'First, it is not clear who is the patient in this clinical encounter. Is it the pregnant woman alone, or is the embryo or fetus also to be understood as one?' 'Second, it is not self-evident that a termination of pregnancy as a medical practice is apt to promote the good of the patient'. Schmitz argues for a human rights-based approach (*See page 399*).

Schmitz's analysis is worth applying to Heuser and colleague's findings. If one considers there are two patients—the fetus and the woman—as Chervenak and McCullough have argued for years in their concept of the fetal patient) it is hard to see how the concerns over physician failure to support continued care of lethal abnormalities are justified. Consider anencephaly. Such babies are unconscious and will remain so. At least in the UK, Law Lords in the case of Tony Bland described such patients as lacking any interests. It is not in the interests of such permanently unconscious patients to live, according to that decision, so why should doctors support a pregnant woman's desire to keep such a fetus alive with medical treatment?

The answer can only be that it is in her interests. People are distressed and suffer a number of adverse psychological outcomes when a loved one, particularly a baby dies. But in the case of lethal abnormalities, such a death is inevitable. Is sustaining life in such circumstances reasonable treatment?

Consider an analogy. Imagine distraught relatives did not wish medical treatment to be withdrawn from a brain dead relative. Should such treatment be continued? Such treatment might be

briefly continued but it would be appropriate to discourage the continuation of such treatment. It is not paternalistic to discourage or even refuse to comply with such wishes.

Another relevant factor is the limitation of resources in publicly funded healthcare. Justice may require making the treatment of fetuses with lethal abnormalities a low priority. The basic principles of medical ethics are that treatments should be provided according to principles of distributive justice and in the best interests of the patient. But psychological distress and harm from another patient not receiving medical treatment does not obviously fall under this rubric. Non-directive counselling is appropriate when it is not clear which outcome is best; it is inappropriate when it is clear treatment is futile or not in the interests of a patient, including a 'fetal patient'.

In another important empirical study, Damen and colleagues in 'Terminating clinical trials without sufficient subjects' found that a considerable proportion of clinical trials (41/107) were terminated before they had recruited a sufficient number of subjects to establish an outcome. The authors claim that '[i]n such cases, subjects are exposed to unnecessary risks and burdens'. This premature termination is more common in investigator-initiated rather than pharmaceutical company sponsored research (*See page 413*).

It is clearly scientifically undesirable to prematurely terminate a clinical trial. Is it unethical? It is wrong, at least in theory, to claim that this exposed subjects to unnecessary risks and burdens during the trial. According to the principle of equipoise, a clinical trial should not be commenced or continued unless there is as much reason to believe that the trial

intervention is as safe and efficacious as the standard treatment.

What is wrong is not that patients who have been in a clinical trial have been exposed to excessive risk but rather that all future patients, including those who were in the trial and those outside the clinical trial, will be exposed to risk by failure to gain knowledge of whether the standard treatment or the trial intervention are superior. Early termination of clinical trials then is unethical not because it exposes patients in the trial to unnecessary risk but because it fails to execute the duty to perform good research which identifies the best standard of care. Failing to publish the results of research and failing to utilise the results of existing research both also fail to execute the basic medical duty to provide the best medical treatment that distributive justice allows.