A clinical room with a view

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EDITORIAL

Reconsidering Normativity

Dear friends and colleagues, we truly hope to see you all at our upcoming EACME conference in Bristol (UK). The aim of the conference is to discuss the history of our discipline and review how ethics developed into an institutionalized endeavour: “Other voices, other rooms, then and now.” Of course, reviewing the past will also require that we outline some potential future developments.

However, this is not the only reason that makes the Bristol conference special. We also wish to celebrate EACME’s 25th anniversary. Yes, 25 years is quite an impressive age. Thus our European Association of Centres of Medical Ethics has actively accompanied the development of European Bioethics throughout the last decades. We hope that our association has also managed to shape these developments in a good way. Today, it is somewhat difficult to keep track of all the sub-disciplines of Ethics that have emerged throughout the years. It is especially difficult for those who are not so familiar with our field of work and research. Research Ethics, Clinical Ethics, Medical Ethics, Research in Ethics, Empirical Ethics - just to name some of the core specialities. Well, maybe we should pay more attention here. The lay public can easily get lost here. Most of the doctors we are dealing with in hospitals even mix up the difference between research ethics and clinical ethics, so we have a duty to better explain our own varieties to the outside world.

Still, it is all Ethics, isn’t it? We are not so sure anymore. As the discipline develops, hardly anyone discusses the very core of Ethics anymore. Now, a question to you all: in our daily working endeavour, do we really all have the same understanding of what the discipline is about? Let us give it a try here, let us confess what Ethics is about. We (Rouven and Renzo)
A look at ethics consultation in different countries shows that similar ethical difficulties are reported but that there are variations in the manner in which they are experienced by patients, and addressed by clinicians and clinical ethics consultants. Examining these differences is usually what researchers and consultants mean by exploring the impact of culture on ethics consultation. Sometimes, however, ethics consultants are called on a case or asked for guidance on a situation which also acts as a revealer for systemic and societal processes beyond the clinical space. These processes, of course, can also be quite different across borders. In such cases, the clinical room has a view.

In one recent Swiss example, a hunger strike in prison pitted doctors against judicial authorities over the question of forced feeding. Force feeding of prisoners who undertake hunger strikes is clearly banned by international medical regulations. In practice, however, the way in which such cases are handled by medical professionals as well as by authorities is highly variable. Goals put forward for force feeding can include silencing prisoners for example, but also saving their lives; and orders given by an authority to proceed with force feeding places physicians in a situation where a clear distinction between refusing force feeding and questioning the legitimacy of the ordering authority becomes difficult, however important such a distinction may remain. One defining characteristic of the Swiss case was the need for public debate combined with an urgent individual situation. This yielded substantial progress in public understanding, but also considerable pressure on health care professionals as the clinical case unfolded rather faster than this understanding. Another crucial element was the interconnectedness of the Swiss medical profession and institutions involving bioethics, which enabled remarkably fast and consensual positions in the midst of a public controversy. This, in turn, was one of the important elements supporting the clinicians in charge of the patient and may have been central to the resolution of the case. Thus, constitutive elements of Swiss polity and of the structure of societal discussions had a direct impact on the manner in which this case could be handled.

In a different example, a retired doctor performed euthanasia on a patient who had requested assisted suicide but was unable to carry out the last – fatal – act herself. This is clearly an illegal act under the Swiss penal code. Nevertheless, the doctor was acquitted. This can be understood as a direct consequence of the importance attached to specific, thoughtful, individual or local decisions in Swiss society. On one level, there was general trust that the decision to proceed with euthanasia had been reached by two careful individuals who had no alternative, leading to large public support. On a different level, the judge was able to make it very clear that this case would not constitute a precedent automatically allowing euthanasia in the future.

These cases, and others like them such as cases placing clinicians in tension with authorities responsible for asylum, reveal much about the structure of public deliberation and the place of medical ethics and bioethics within it. In the end, such cases should act as an invitation to consider broader aspects more generally in addressing even the more usual, and more individual, cases presented to ethics consultants. This, of course, we knew already. But such cases also show how specific – and sometimes elusive – the required knowledge can be if we try to take this goal seriously.

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BEHAVIOURAL EXPRESSION OF INCOMPETENT PATIENTS: SHOULD THEY GUIDE HEALTH CARE DECISIONS?

Imagine an elderly woman suffering a severe stroke that leaves her unable to speak and paralyzed on the right side of her body. In rehabilitation care she is given to eat and drink orally as swallowing is not impaired. But every time the nurses want to give her something to eat or drink, she grumbles, squeezes her lips and turns her head. Doesn’t she like the meals? Is she depressed? Is she fearful or delusional? Does she