Philosophical introduction: case analysis in clinical ethics

Richard Ashcroft, Michael Parker, Marian Verkerk, Guy Widdershoven

Medical ethics has had a rich and complex history over the past 40 years. It has been transformed from a rather clear and straightforward set of rules and attitudes, shaped largely by the medical profession itself, into a major field of academic and social inquiry. Contemporary work in medical ethics can be divided into three parts: ethical analysis and arguments of large-scale issues in science, practice and policy (such as consideration of the ethical issues concerning cloning or resource allocation); theoretical inquiry into the foundations of medical ethics; and practical analysis of particular dilemmas in clinical practice. This last area in medical ethics is normally referred to as clinical ethics, and is in many respects the most important and vibrant part of medical ethics today. It lives through its intimate connection with clinical practice and medical and healthcare education, the ways in which suggestions made by practitioners of clinical ethics are rapidly tested in clinical reality, and the growth of a practical field of work in which ‘ethicists’ support patients, professionals and ethics committees in making good decisions in difficult circumstances.

For all this vibrant growth, there has been some unease with the way clinical ethics has developed. Healthcare professionals are sometimes baffled by the argumentative curlicues of the philosophers; patients and activists are often suspicious that all this ‘ethics’ is just a way of reinforcing existing professional attitudes and authority, and that ethicists are just as blind to patients’ concerns as the medical professionals; and philosophers are generally infuriated by the apparent laziness and lack of rigour of their ‘applied’ colleagues. What most of the critics of contemporary clinical ethics agree on is the way in which clinical ethics seems to have become excessively simplified, giving the impression that ethical thinking in clinical situations is a routine and mechanical business, which collapses into a vulgar utilitarianism or an obsession with autonomy as a master value, taking precedence over any other concern. While this is a grotesque parody of the best work in practical and theoretical clinical ethics, it is a picture that is uncomfortably...
familiar to anyone who has been involved in the teaching of students, professionals or ethics committee members in the elements of clinical ethics. A particularly important debate took place in the early 1990s over the respective merits of ‘principlist’ ethics in the tradition of Thomas Beauchamp and James Childress’s seminal Principles of Biomedical Ethics, and of casuistry, as revived most notably in Albert Jonsen and Stephen Toulmin’s The Abuse of Casuistry. Other important contributions to enriching clinical ethics came from European philosophy, especially in the phenomenological tradition, exemplified by Richard Zaner’s Ethics and the Clinical Encounter. There was a considerable body of work that focused on the analysis of meaning and narrative, as a reaction to the highly abstract case reports usually used as the ‘data’ of clinical ethics; this work was typified by Howard Brody’s Stories of Sickness and Kathryn Montgomery Hunter’s Doctors’ Stories. Important contributions were made in the various feminist traditions, such as the ethics-of-care tradition springing from Carol Gilligan’s In a Different Voice, or from the political feminism of Susan Sherwin’s No Longer Patient. Finally, there was a strong upsurge of interest in ‘virtue-ethical’ approaches to thinking about problems from the point of view of the character and motivation of participants in moral decision-making, of which Rosalind Hursthouse’s Beginning Lives was a particularly fine example.

Just as in clinical ethics, within mainstream moral philosophy there was a growing frustration with standard utilitarian and Kantian approaches to normative and applied ethics, as well as a search for post-Marxist alternatives to Rawlsian liberal political philosophy. This led to a growth in moral philosophising within the European tradition, both by active philosophers within that tradition (Lévinas, Derrida, Lyotard, Deleuze, Ricoeur Gadamer and Habermas), and by English-language writers influenced by these currents in European thought. Interestingly, many of these writers took a specific interest in medicine and healthcare, publishing books or articles contributing to debates over the doctor–patient relationship, the meaning of death, and biotechnology and eugenics. This rather gave the lie to the claim that European moral philosophy since Kant had not been practical in orientation (with the clear exception of existentialism). Nevertheless, a characteristic of much of this writing seemed to be that while it could deepen and enrich our understanding of the nature of the problems faced by doctors and patients, this same emphasis on understanding (and its inevitable gaps) undermined any possibility of deriving practical recommendations about what to do.

The origins of the present book lie in a session organised by Guy Widdershoven at the International Association of Bioethics 5th World Congress in Tokyo in November 1998. Guy invited Marian Verkerk, Michael Parker and George Agich to prepare discussions of Simone de Beauvoir’s A Very Easy Death, which would illustrate how the philosophical
methodologies favoured by each contributor could produce illuminating readings and critiques of this famous autobiographical account of de Beauvoir’s mother’s highly medicalised death. Guy and his colleagues felt that while there was considerable interest in ‘European’ philosophical methods, there was a good deal of misunderstanding about what these consisted of, what they could achieve, and how far they converged or diverged from each other and from the ‘mainstream’ principlist and utilitarian methods of English-language bioethics. Somewhat at the last minute Richard Ashcroft was invited to chair the session, and subsequently Guy and Richard decided to edit the papers for publication. Over the next few months it became clear that the idea of a comparative presentation and analysis of different alternatives to principlism and utilitarianism had much more potential, and it was decided to extend the range of contributions, and to produce a book. Michael and Marian were invited to join the editorial team, and a grant in aid of the preparation of the book was obtained from the Dutch Academy of Sciences.

It was decided that organising the book around de Beauvoir’s book had various disadvantages, not least the length of her book and the difficulties we would face in reproducing substantial portions of it and in asking new contributors to spend a considerable amount of time reading and analysing it. More importantly, her book could no longer be taken to be an accurate reflection of contemporary approaches to caring for dying patients. We decided to organise the book around a contemporary case. Feeling that many of the most interesting issues arise in clinical genetics, we invited Anneke Lucassen, a geneticist colleague of Mike’s with an established interest in ethics, to prepare a case report based on her own and her colleagues’ clinical experience. The features of the case report we looked for were: that it should be described in detail with as much richness as possible in characterisation and narrative complexity, to enable close and critical reading and to convey a sense of the difficulties facing the practising clinician in real world practice; that the case should be, as far as possible, a ‘normally difficult’ case rather than some out of the way once-in-a-lifetime dilemma; that the scientific aspects should be reasonably stable in terms of how genetics was developing (so that while some details could go out of date, the nature of the moral dilemma would remain commonplace for the coming few years); and that the dilemmas faced in genetics would be reasonably recognisable to clinicians and others not working in genetics (for instance, that the issues of family practice would be reasonably familiar to primary care physicians or paediatricians).

The contributors were invited to write commentaries on the case that illustrated the philosophical approach selected, and that came to practical conclusions. Our interest was specifically in whether a given philosophical approach could do more than simply give an interesting redescription of the case and its ethical issues. We wanted to know whether different methods
were attuned to different ethical issues, whether they evaluated different factors differently or with different weighting, and whether – aside from differences en route to the ‘answer’ – they tended to agree on their conclusions or whether they diverged. In this sense the writing of the book was an exercise in experimental practical philosophy. Does it actually matter which method one uses? Or are some methods better for some purposes? How far are conclusions constrained by the method used, how far by presuppositions independent of method about goals and values of medicine such as respect for confidentiality, and how far by values of the writers themselves?

All of the contributors were invited to write because of their recognised status as leaders in biomedical and clinical ethics or moral philosophy, and because of their preference, in their written and clinical work, for using the method we invited them to discuss. Everyone is to that extent a partisan and proponent of the method they discuss. Each contributor was invited to one of a series of four meetings, held in Oxford, Maastricht, Groningen and London, where they would present their chapter draft, and it would be discussed with them in a seminar by the editors, other contributors, and passing graduate students, after which they would return home and revise the chapter in the light of the discussion. The Oxford meeting involved Parker, Holm and Ashcroft as contributors; the Maastricht meeting involved Agich, Widdershoven and Hurwitz; the Groningen meeting involved Verkerk, Campbell and Withers; and the London meeting involved Gillon and Savulescu. Initially, since the project had begun as a reaction to the predominance of principlist and utilitarian approaches to clinical ethics, the plan was to invite Raanan Gillon and Julian Savulescu to write responses to the other chapters, discussing how far their approaches could encompass or respond to the criticisms of their respective principlist and utilitarian approaches. In the course of preparing the book it became clear that this sort of ‘contest’ was inappropriate, and in a sense unfair to Raa and Julian (being put into a defensive role) and to everyone else (being made to engage in a conflict that many of them felt was no more than a difference in perspective). In a sense this was a little reaction to the very combative approach often found in bioethics, at least in theoretical work, where people take sides. Yet in clinical ethics, the aim is normally to avoid taking sides, to get participants to understand each other’s viewpoints and to seek consensus or at least understanding. We feel that this was a valuable lesson. At each meeting Lucassen presented the case for the benefit of the contributors and guests, and this process of discussion led to some refinements of her text. All contributions were then collated and edited, at which point the present Introduction, and the two concluding chapters were prepared.

The order of the book is as follows. Anneke Lucassen’s case report opens the main part of the book. Brian Hurwitz’s chapter introduces the ideas of narrative analysis and narrative ethics. This approach concentrates on the
way the case is reported, and examines how different ways of telling the story influence how we think about it, in particular how different ways personal-
ities in the story represent their points of view shapes what happens and shapes what alternatives seem to be live possibilities. Developing some of the insights of narrative analysis, Alastair Campbell introduces the approach of virtue ethics. The link between narrative and virtue approaches is in the concept of character, from the narrative viewpoint, ‘characters’ are agents in the story and we are interested in how lifelike or rounded they are. But this also has a moral dimension, when one considers how lifelike or rounded we appear to ourselves or to others, and this is intimately connected to the idea of a virtuous individual and human flourishing, which is central in virtue ethics. Guy Widdershoven’s chapter responds to this in his presentation of ‘hermeneutic’ ethics, which stresses the importance of developing a frame-
work of understanding that can encompass all parties’ different ‘horizons of understanding’ and hence stresses the importance of relationships as both sustaining and being sustained by the effort to understand.

Richard Ashcroft suggests that there are limits to understanding, and that both social structure and individual attempts to control their situation will always imply that power relationships can make relationships of regard and mutual recognition unstable. He explores whether there can be an ethic of power, suggesting that it lies in the effort to secure recognition of the vulnerability of each party. Rob Withers develops these ideas in his ‘post-
structuralist’ reading of the case, focusing on the role of time and uncertainty in the case, to suggest that an ethic of vulnerability can be grounded in a different way to that suggested by Ashcroft. Withers’ arguments about uncertainty apply to uncertainty about the motives of others and to one’s own preferences, and as such mount a challenge to utilitarianism. Julian Savulescu responds by showing what a classical utilitarian approach can do, illustrating the difference between the vulgar utilitarianism frequently prac-
tised and what a more sophisticated form can actually do. Marian Verkerk develops an account of a feminist ethics-of-care approach to the case, which gives a feminist reading of the personal and power relationships, challenging the emphases on these given by Ashcroft. Michael Parker then describes a ‘deliberative-ethics’ approach that seeks to encompass both the formal requirements of fair discussion implied in the debate between Hurwitz, Widdershoven and Campbell, Withers, Ashcroft and Verkerk, and the sub-
stantive requirements of reason at stake in the debate between Withers, Ashcroft, Savulescu and Verkerk.

Raanan Gillon describes the classical principlist approach to case analysis, arguing that its strength lies in its ability to produce clear action-guiding recommendations, although, as he shows, this can require considerable subtlety and nuance. In common with the other authors he stresses the need for good ethical judgement in addition to the formal deduction of
conclusions from premises. George Agich, in his chapter on the phenomenological approach, suggests that the solution to the need for judgement may lie in the way critical reason can uncover the constitutive assumptions that underlie the experience of the case that each party has, and thus lead to a re-conception of what is at stake, which can produce a resolution. Finally, Søren Holm indicates that a correct appreciation of the case may depend on the need for reliable empirical information and suggests how case analysis can become clarified through obtaining and reflecting on such information.

The book concludes with two looks back at the main part of the book: the first is by the philosophers on the editorial team (Parker, Ashcroft, Verkerk and Widdershoven), who draw out the similarities and differences between the approaches described and assess the outcome of the ‘philosophical experiment’ described above. Finally, Anneke Lucassen reflects on the process of writing the book and engaging with philosophers from the perspective of a working clinician.

REFERENCES


Families and genetic testing: the case of Jane and Phyllis

Anneke Lucassen

We share much of our genetic make-up with members of our biological family. This means that genetic information about one person is also sometimes, to a greater or lesser extent, information about that person’s relatives. A genetic test can sometimes therefore diagnose or predict disease not only in the individual tested but also in his or her biological relatives.

The familial nature of the information produced by genetic tests raises questions about the legal and ethical obligations of healthcare professionals to disclose or withhold genetic information about patients to their at-risk relatives. Such questions are brought into sharp focus by clinical genetic situations in which different members of the same family are all ‘patients’ of one clinician but each attends the clinic independently with separate issues and agendas that need to be addressed. In such situations each patient is owed a duty of care by that clinician, who may feel pulled in different directions by the differing needs of the family members, and may feel unclear about how to prioritise each. Such questions are particularly difficult when family members are in conflict but they also arise when members have simply lost touch with each other. In such cases, there can be an ethical conflict between preserving the confidentiality of one patient on the one hand and the right of other family members to know information about their genetic status and risk of disease on the other.

Such problems are not new. The speciality of clinical genetics has always dealt with families, and with the tensions or lack of contact between family members. Different opinions within families are certainly not new. However, in the past, and until relatively recently, the only advice geneticists were able to provide consisted largely of estimates of risk of inheriting or transmitting a particular genetic condition. With the advent of genetic testing for an increasing number of conditions, it is now possible in some cases to infer or produce reasonably accurate information about actual inheritance.

In some cases, the ability of a genetic test to deliver useful prognostic or predictive information to an individual patient is dependent on the prior
identification of the causative genetic alteration in that particular family. This is usually only possible in a living family member who is actually affected by the condition. So this means that an unaffected member of a family who wants to know whether they have inherited a condition or a tendency towards a condition may need the co-operation of an affected relative in order to make an accurate test possible. This introduces another familial element into the practice of genetics.

In many families there is a willingness – and even an eagerness – to share genetic information of this kind, but in others conflict or separation results in situations where the clinician has to choose between preserving the confidentiality of one relative and making predictive genetic testing available to another. In such cases, where an accurate and useful test is only possible if the familial mutation has been identified, such conflicts can be difficult to resolve.

The following clinical case (see also Appendix I) highlights just such a conflict. The case, which is a construct composed from several cases I have encountered as a clinical geneticist, is also informed by a number of different stories told to me while seeing families clinically.

Jane’s story

I have always known that most women in my family develop breast cancer, usually at a young age, and that they eventually die from it. I suppose when I was in my teens and twenties I knew it but it seemed remote to me. Once I reached my thirties and had my own two daughters things started to feel different. I worried more about developing cancer and about not being there for my girls. I worried that they too might have got our family curse. While my girls were little I always had other things to think about, but now that they’re a bit older I think about it all the time.

The worries often loom large in the early hours when I lie awake fretting. My husband eventually persuaded me to see the doctor. He said I should go to see her because I didn’t know what could be done these days and that treatments must be different from when mum and her mum developed cancer. At about the same time I also saw an article in the newspaper about genetic testing for women like me and I went to ask my GP about it. She was very good and gave me a lot of time. She talked a bit about mammograms and how to examine my own breasts. She didn’t know much about genetic testing but said she’d refer me on to a specialist.

After several weeks of waiting I was sent a family history questionnaire to fill in. It asked about details of the cancers in my family, which hospitals my relatives had been treated at, how old they were and all sorts of other questions. I spent days filling it in. I found it hard and upsetting to complete.
After several months I finally got an appointment to see the specialist. She told me that it did sound like there was a rogue gene in my family that could explain all the cancers. She gave me lots of information, most of which I don’t remember now, but I do remember her saying that there is a possibility that I may not have inherited the rogue gene. My mum had two copies of the gene and only one was faulty. When mum had us, she only passed on only one copy, either the normal one or the faulty one, so it was ‘heads or tails’ each time she had a child. If I didn’t get it, I’m unlikely to get cancer young; if I did, then I probably will. The only problem is that we can’t really tell whether I have or haven’t got the relevant gene as the tests aren’t yet very good. In order for me to have an accurate test, the researchers would first need to find the particular rogue gene in an affected person in my family since each family can have a slightly different type of rogue gene. For the test to be accurate in me, they need to know exactly which gene fault they are looking for before they test me for it. If they tested me without this first bit of information, and I tested negative, it could mean that I hadn’t got mum’s rogue gene but, and this was the big but, it could also mean that I had got it but the researchers had not been able to find it because their tests aren’t good enough to pick up all the different types of gene faults.

If they knew what to look for, they’d be able to offer me a straight ‘yes’ or ‘no’ answer; but if they don’t, a test isn’t really going to help me to decide not to have an operation. Since all the women in my family seem to die from cancer rather quickly there is no-one who is affected that I can ask to undertake this first stage test. Without this, testing me seems like a bit of a ‘don’t know’ test.1

At the end of the meeting, the doctor said it might help if I got some more information about mum’s relations. I think that Great Uncle Stan emigrated to Australia in the 1970s and the doctor said finding out if maybe he had had any daughters with breast cancer who were still alive could be helpful. I know very little about mum’s family really as I was only 21 when she died. I was her baby and I think she didn’t want to tell me things that she thought might upset me. I did know Auntie Phyllis was still alive although I hadn’t seen her since mum died.

When I asked him, Uncle George told me Phyllis still lived in the same house, but when I finally got in touch with her she didn’t really have any more information. She’s a rather grumpy thing. She and mum had some row over money and she went on about mum being the spoilt one. I found the visit rather depressing. She looked old and not very well but she’s only in her 50s.

By the time I went for my second appointment at the genetics clinic I’d done loads of reading around the subject and talked to a woman who ran a support group who had a very similar story to mine. She had had an operation called a prophylactic mastectomy, which removes almost all of your breasts so that you can’t develop cancer in them. The genetics doctor said that there was evidence to show that women like me who had this
Phyllis’s story

I knew I was doing pretty well to get to 50 without developing cancer, all the other women in the family had got it much before that, but when I felt the lump in my breast I knew straight away that it was cancer.

Everything moved very quickly – before I knew it I’d had the operation and I was told I was ‘doing very well’. The oncology doctor looking after me was young and very energetic. He said that because I had so many relatives with cancer that the cancer might be due to something I’d inherited. He said a blood test might show this. If it did show it then he would probably suggest a different treatment than if it didn’t. I don’t think he ever asked whether I wanted the test, he just took the blood sample. About a year later when I’d clean forgotten all about it, I got a letter from him saying that the test had found something and that he’d send me on to some genetic people to talk about it. To be honest I found the genetic people were rather wishy-washy. They never seemed to have a clear ‘yes’ or ‘no’ answer to my questions. They said the result was a faulty gene, but that there wasn’t good enough evidence to show that it should alter my treatment in any way, especially as I was now well. They were more interested in my relations who hadn’t got cancer, which was a bit of a cheek. I told the doctor how I’d nursed my mother and my sister when they were dying. Neither of them thanked me for it. My sister and I had a huge row about money just before she died – it was dreadful. I wasn’t even mentioned in her will and the family completely ignored me afterwards. I don’t feel I owe them anything. So no, I wasn’t happy with them letting others know of my test result. I’m not in touch with them. It is my result, not anyone else’s business. I’m fed up with being blamed for anything that goes wrong in our family.

The general practitioner’s story

I first realised there was a problem when I got the letter from the clinical geneticist. Phyllis wasn’t happy to divulge the result of genetic testing to her family members, but in theory the result could be used by her niece, Jane, to