

O'Neill O. *Autonomy and trust in bioethics*. Cambridge ; New York: Cambridge University Press; 2002.

1.5 TRUST AND AUTONOMY IN MEDICAL ETHICS

Answers to all of these questions are complicated because various conceptions of autonomy and of trust are in play, between which

I hope to distinguish. In doing so I shall try to say something about various conceptions of each, and to trace some of their relations to other ideas that are prominent in contemporary bioethics, such as those of respect for persons, informed consent and certain human rights.

I hope to show that some conceptions of autonomy and of trust are compatible, and even mutually supporting. It will not, of course, follow that we must adopt these conceptions of autonomy and of trust. We may find reason to prefer others. However, if we rely on conceptions of autonomy and of trust that cannot be reconciled, then we cannot have both. Correspondingly, if we would like to find a way of enjoying both autonomy and trust we must first find conceptions of each that can be reconciled.

I shall begin the inquiry by posing some intuitive questions about the relation of trust to autonomy within medical ethics, for it is in medical ethics that some of the strongest claims have been made both on behalf of trust and on behalf of autonomy. If we think back into the past, and look to that famous prototype of all professional relationships, the doctor–patient relationship, we have a paradigm of a relationship of trust. The patient approaches the doctor knowing that the doctor is bound as a matter of professional oath and integrity to act in the patient’s best interests, even that the doctor stands at risk of disgrace or disqualification for serious failure in this regard. Although there are always contractual and financial arrangements linking doctor and patient, or doctors and the institutions that organise medical care and employ them, the doctor–patient relationship is supposed to trump any considerations of self-interest and gain. It is a professional relationship that is supposed to be disinterested, long-lasting, intimate and trusting. The image in the frontispiece of this book can be seen as depicting a trusting, traditional doctor–patient relationship, one-to-one, indeed face-to-face, set in the confidential confines of a professional office.

This traditional model of the trusting doctor–patient relationship has been subject to multiple criticisms for many years. Traditional doctor–patient relationships, it has been said on countless occasions, have in fact nearly always been based on asymmetric

knowledge and power. They institutionalise opportunities for abuse of trust. Doctor–patient relationships were viewed as relationships of trust only because a paternalistic view of medicine was assumed, in which the dependence of patients on professionals was generally accepted. The traditional doctor–patient relationship, so its critics claim, may have been one of trust, but not of reasonable trust. Rather, they claimed, patients who placed trust in their doctors were like children who initially must trust their parents blindly. Such trust was based largely on the lack of any alternative, and on inability to discriminate between well-placed and misplaced trust.

If there was one point of agreement about necessary change in the early years of contemporary medical ethics, it was that this traditional, paternalistic conception of the doctor–patient relationship was defective, and could not provide an adequate context for reasonable trust. A more adequate basis for trust required patients who were on a more equal footing with professionals, and this meant that they would have to be better informed and less dependent. The older assumption that relations of trust are in themselves enough to safeguard a weaker, dependent party was increasingly dismissed as naive. The only trust that is well placed is given by those who understand what is proposed, and who are in a position to refuse or choose in the light of that understanding. We can look at the same image with a less innocent eye, and see it as raising all these questions about the traditional doctor–patient relationship. In this second way of seeing the picture the doctor dominates: the white coat and intimidating office are symbols of her professional authority; the patient's anxious and discontented expression reveals how little this is a relationship of trust.

These considerations lie behind many discussions of supposedly better models of the doctor–patient relationship, in which patients are thought of as equal partners in their treatment, in which treatment is given only with the informed consent of patients, in which patient satisfaction is an important indicator of professional adequacy, in which patients are variously seen as consumers, as informed adults and are not infantilised or treated paternalistically

and in which the power of doctors is curbed.¹⁸ In this more sophisticated approach to trust, autonomy is seen as a precondition of genuine trust. Here, as one writer puts it, 'informed consent is the modern clinical ritual of trust',¹⁹ a ritual of trust that embeds it in properly institutionalised respect for patient autonomy. So we can also read the image in the frontispiece in a third, more optimistic, way as combining patient autonomy with mutual trust in the new, recommended, respecting way. What we now see is a relationship between equals: the patient too is a professional, dressed in a suit and sitting like an equal at the desk; the patient has heard a full explanation and is being offered a consent form; he is deciding whether to give his fully informed consent. Trust is properly combined with patient autonomy.

This revised model of doctor–patient interaction demands more than a simple change of attitude on the part of doctors, or of patients. It also requires huge changes in the terms and conditions of medical practice and ways of ensuring that treatment is given only where patients have consented. Informed consent has not always been so central to doctor–patient relationships, which were traditionally grounded in doctors' duties not to harm and to benefit. Informed consent came to be seen as increasingly important in part because of legal developments, especially in the USA, and in part because of its significance for research on human subjects, and the dire abuse of research subjects by Nazi doctors. The first principle of the Nuremberg Doctors' Code of 1947 states emphatically that subjects' consent must be 'voluntary, competent, informed and comprehensive'.²⁰ Only later did the thought emerge clearly that consent was also central to clinical practice, and that patient autonomy or self-determination should not be subordinated to doctors'

¹⁸ R.A. Hope and K.W.M. Fulford, 'Medical Education: Patients, Principles, Practice Skills', in R. Gillon, ed., *Principles of Health Care Ethics*, John Wiley & Sons, 1993.

¹⁹ Wolpe, 'The Triumph of Autonomy', 48.

²⁰ See Faden and Beauchamp, *A History and Theory of Informed Consent*; Ulrich Tröhler and Stella Reiter-Theil, *Ethics Codes in Medicine: Foundations and Achievements of Codification Since 1947*, Ashgate; Lori B. Andrews, 'Informed Consent Statutes and the Decision-Making Process', *Journal of Legal Medicine*, 30, 163–217; World Medical Association, Declaration of Helsinki, 2000; see institutional bibliography.

commitments to act for their patients' benefit or best interest. Yet despite the enormous stress laid on individual autonomy and patient rights in recent years, this heightened concern for patient autonomy does not extend throughout medicine: public health, and the treatment of those unable to consent are major domains of medical practice that cannot easily be subjected to requirements of respecting autonomy and securing informed consent.²¹

From the patient's point of view, however, the most evident change in medical practice of recent decades may be loss of a context of trust rather than any growth of autonomy. He or she now faces not a known and trusted face, but teams of professionals who are neither names nor faces, but as the title of one book aptly put it, *strangers at the bedside*.²² These strangers have access to large amounts of information that patients give them in confidence. Yet to their patients they remain strangers – powerful strangers. They are the functionaries of medical institutions whose structures are opaque to most patients, although supposedly designed to secure their best interest, to preserve confidentiality and to respect privacy. Seen 'from the patient's point of view every development in the post World War II period distanced the physician and the hospital from the patient, disrupting social connection and severing the bonds of trust'.²³

From the practitioner's point of view, too, the situation has losses as well as gains. The simplicities of the Hippocratic oath and of other older professional codes have been replaced by far more complex professional codes, by more formal certification of competence to perform specific medical interventions, by enormous increases in requirements for keeping records and by many exacting forms of professional accountability.²⁴ In medicine, as in most

²¹ See chapter 2. The marginalisation of these topics may reflect their poor fit with the popular ideal of patient autonomy.

²² David J. Rothman, *Strangers at the Bedside: A History of How Law and Ethics Transformed Medical Decision-Making*, Basic Books, 1991. Rosamond Rhodes and James J. Strain, 'Trust and Transforming Healthcare Institutions', *Cambridge Journal of Healthcare Ethics*, 9, 2000, 205–17.

²³ Rothman, *Strangers at the Bedside*.

²⁴ Nigel G.E. Harris 'Professional Codes and Kantian Duties', in Ruth Chadwick, ed., *Ethics and the Professions*, Amesbury, 104–15. See chapter 6 below.

other forms of professional life and public service, an 'audit society' has emerged.²⁵ The doctor now faces the patient knowing that he or she must comply with explicit standards and codes, that many aspects of medical practice are regulated, that compliance is monitored and that patients who are not properly treated may complain – or even sue.

These new relationships may live up to their billing by replacing traditional forms of trust with a new and better basis for trust. The new structures may provide reasons for patients to trust even if they do not know their doctors personally, and do not understand the details of the rules and codes that constrain doctors' action. Supposedly they can feel reassured that the power of doctors is now duly regulated and constrained, that doctors will act with due respect and that they can seek redress where doctors fail. Although traditional trust has vanished with the contexts in which it arose, a more acceptable basis for reasonable trust has been secured, which anchors it in professional respect for patients' rights. Supposedly the ideals of trust and autonomy have been reshaped and are now compatible.

1.6 VARIETIES OF AUTONOMY

To judge whether autonomy and trust as now construed are indeed compatible, we need a rather clearer view of autonomy. This is not easily acquired. Gerald Dworkin began a book on autonomy by listing about a dozen distinct understandings of the notion. He suggested that it has been variously equated with

Liberty (positive or negative) . . . dignity, integrity, individuality, independence, responsibility and self-knowledge . . . self-assertion . . . critical reflection . . . freedom from obligation . . . absence of external causation . . . and knowledge of one's own interests.²⁶

²⁵ Michael Power, *The Audit Explosion*, Demos, 1994 and *The Audit Society: Rituals of Verification*, Oxford University Press, 1994.

²⁶ Gerald Dworkin, *The Theory and Practice of Autonomy*, Cambridge University Press, 1988, 6. See also his 'The Concept of Autonomy', in John Christman, ed., *The Inner Citadel: Essays on Individual Autonomy*, Oxford University Press, 1989, 54–76, esp. p. 54

Ruth Faden and Thomas Beauchamp suggest in their immensely interesting and useful book on informed consent that autonomy may also be identified with

privacy, voluntariness, self-mastery, choosing freely, choosing one's own moral position and accepting responsibility for one's choices.²⁷

I have no idea whether these lists include all possibilities, but suspect that they do not: we might, for example, add the terms 'self-control' and 'self-determination'.

Dworkin thinks that

The only features that are held constant from one author to another are that autonomy is a feature of persons and that is a desirable quality to have.²⁸

This is hardly an exacting claim, yet I doubt whether it is correct on either point. There are a lot of writers – they include many feminists, virtue ethicists and communitarians – who doubt whether autonomy is always of value. There are others, including various determinists, behaviourists and structuralists, who think that it is an illusion. There are also defenders of one or another conception of autonomy who think that it is not a feature of persons, either because they think that it is a feature of some but not of all persons, or because they think that it pertains not to persons but (for example) to the will, or to certain actions, or to certain principles, rather than to persons.²⁹ However, Dworkin's list provides a very valuable starting point for thinking about autonomy in bioethics,

and Thomas E. Hill Jr., 'The Kantian Conception of Autonomy', in his *Dignity and Practical Reason in Kant's Moral Theory*, Cornell University Press, 1992, 76–96, who begins the article with the observation 'Autonomy is a central concept in contemporary moral debates as well as in the discussion of Kant; but the only thing that seems completely clear about autonomy in these contexts is that it means different things to different writers.'

²⁷ Faden and Beauchamp, *The History and Theory of Informed Consent*, 7.

²⁸ Dworkin, *The Theory and Practice of Autonomy*, 6.

²⁹ Thomas E. Hill, Jr., points out in 'The Kantian Conception of Autonomy' that Kant never predicates autonomy of persons, but only of principles and willings; Mill predicates autonomy of states, but not of persons. See chapter 2.

because it shows how many different notions may be intended, and how multiply ambiguous claims about the value of autonomy may be.

Despite this proliferation of conceptions of autonomy, there is probably more agreement about it in contemporary bioethics than elsewhere. In bioethics, and in particular in medical ethics, autonomy has most often been understood as a feature of individual persons. It is generally seen as a matter of *independence*, or at least as a *capacity for independent decisions and action*. This conception of individual autonomy sees it as *relational*: autonomy is always autonomy from something; as *selective*: individuals may be independent in some matters but not in others; and as *graduated*: some individuals may have greater and others lesser degrees of independence.

Although many protagonists of autonomy in bioethics claim to derive their moral reasoning either from Mill or from Kant (in chapters 2 and 4 I shall discuss these common thoughts about provenance), it seems to me likely that prevailing views of autonomy as independence owe as much or more to twentieth-century conceptions of character and individual psychology and to studies of moral development than they do to older traditions of moral philosophy. If we cast our minds back to the early post-Second World War period, we find intense interest in the fact that some people achieve more independence in the face of catastrophe than do others. In a world in which collaboration with and resistance to evil-doing had been of immense importance, the psychological differences between those who had collaborated and conformed and those who had resisted and stood up to be counted were of great ethical importance. The theme was fundamental to Adorno's *The Authoritarian Personality*,³⁰ which contrasted the deference of those with authoritarian personalities with the independence shown by those with democratic personalities. Similar thoughts were prominent in writing on perpetrators and victims in the concentration camps, for example in the work of Bruno Bettelheim and Primo Levi, who contrasted those whose capacities for

³⁰ Theodore W. Adorno, *The Authoritarian Personality*, Harper & Bros, 1950.

independent and ethical action failed in the death camps with those who survived as persons. The contrast was also central to the notorious Milgram experiments, in which volunteers were invited to punish experimental subjects who failed to learn simple tasks by administering electric shocks. Some deferential and conforming subjects proved willing to inflict high levels of pain (in fact they administered none, since the pain was mimed by actors colluding with the experimenters) simply because they had been told to do so.³¹

Twentieth-century studies of moral development in children also often focused on conceptions of autonomy as independence. In the 1930s Piaget's pioneering *Moral Judgement of the Child*³² distinguished the immaturity of children who thought of moral requirements as a matter of obeying immutable rules, from the greater maturity of those who reviewed and revised rules. Similar distinctions were central to the cross-cultural studies of moral development undertaken by Lawrence Kohlberg, who also identified moral maturity with individual autonomy in choosing and criticising rules.³³

It is, I think, no great mystery that autonomy should have been understood as a matter of individual independence in and beyond bioethics for some decades. Yet if autonomy is a matter of independence, it is very easy to see why it bears hard on relations of trust. Independent people may be self-centred, selfish, lacking in fellow-feeling or solidarity with others – in short, the very people in whom one would have least reason to place trust and who might encourage a culture of mistrust. Alcibiades was splendidly autonomous, and betrayed all the trust placed in him. Once we interpret autonomy *simply* as independence from others, or from others' views or their preferences, the tension between autonomy

³¹ Stanley Milgram, *Obedience to Authority: An Experimental View*, Tavistock Publications, 1974.

³² Jean Piaget, *The Moral Judgement of the Child*, Penguin, 1977.

³³ Lawrence Kohlberg, *The Philosophy of Moral Development*, Harper & Row, 1981. Kohlberg was criticised in turn in the 1980s and 1990s by Carol Gilligan, on the grounds that he identifies greater moral maturity with autonomous rule-making rather than with building relationships with others, so uncritically presupposing an allegedly 'male' view of what is ethically important; see Carole Gilligan, *In A Different Voice: Psychological Theory and Women's Dependence*, Harvard University Press, 1982; 2nd edn., 1993.

and trust is unsurprising. Trust is most readily placed in others whom we can rely on to take our interests into account, to fulfil their roles, to keep their parts in bargains. Individual autonomy is most readily expressed when we are least constrained by others and their expectations. Trust flourishes between those who are linked to one another; individual autonomy flourishes where everyone has 'space' to do their own thing.³⁴ Trust belongs with relationships and (mutual) obligations; individual autonomy with rights and adversarial claims.

If we are worried about loss of trust, we may wonder whether and why individual autonomy should now be so much admired. Surely independence is admirable in some cases and contexts, but not in others? One of my students illustrated this rather well at about the time that I first encountered bioethics. She joined a group of male students in welcoming spring weather to New York City, only to have the Columbia University student newspaper publish a photograph of them streaking across Broadway. I asked her why she had done it, and she told me that she felt that she had finally proved that she was autonomous. It was clear enough that her action was independent in some ways, although possibly not in others (did she not defer to male initiative?). She may well have been thinking that she had now shown herself independent of her parents, or of social conventions. However, this sort of independence doesn't invariably have merit. Independent action can be important or trivial, heroic or brutal, helpful or selfish, admired or distressing to others. If we view individual autonomy as mere, sheer independence, its merits will be highly variable. We would need some deeper set of reasons, or a deeper conception of autonomy, to explain why individual autonomy is ethically important. The fact that individual independence in the face of evil, or of temptation, is admirable does not show that individual independence in the face of others' needs, or in the context of family or professional relationships will be good or right. Presumably there has to be something over and above mere, sheer independence

³⁴ See Thomas H. Murray, *The Worth of a Child*, University of California Press, 1996.

that has made appeals to individual autonomy so attractive and ubiquitous in contemporary bioethics.

Some sociologists of medicine have suggested that the appeal of autonomy, understood as individual independence, in medical ethics is that it gives only the *illusion* of challenging professional authority, while *in fact* leaving that authority largely intact. The autonomous patient is not actually going to be allowed to determine his or her own treatment. He or she is only going to be allowed to accept or refuse treatment proposed by professionals: the cash value of what is termed 'patient autonomy' is a right to refuse treatment that is offered, a right that is costly to exercise where there are few or no other options of treatment.³⁵ Undoubtedly such rights are of great value: they are what stand between patients and coerced treatment, and there are good reasons for taking the greatest care about any use of coercion in medicine. Nevertheless this right does not secure any distinctive form of individual autonomy or independence. Anyone who doubts this has only to consider what happens to a patient who demands treatment not available in a particular context. A limited right to refuse does not require capacities for independent, reflective choice, but it may be used to transfer formal responsibility for choice of treatment (and even for failure of treatment) to patients – who may yet feel quite powerless. Patient complaints can be rebutted with the claim that *volenti non fit iniuria*, and the power of health systems and professionals will not be greatly reduced since they will always control the agenda by determining what is to be offered. On this view what is misleadingly spoken of as 'patient autonomy' masks the fact that the patient's role is only to say 'yes' – or to do without treatment.

If we bring these thoughts to a final reading of the image in the frontispiece we reach a more suspicious reading of 'the modern clinical ritual of trust'. On this fourth reading the doctor has set out the options, and is now *telling* the patient to sign, and where

³⁵ A commercially based medical system, as in the USA, may offer more options for 'shopping around' physicians. However options will still be limited both by the fact that professional judgement is not at the beck and call of patients, and by the typical financial constraints placed by systems of 'managed care'.

to sign. Look at that emphatically pointing finger! The patient is being told firmly that he is autonomous, that he is an equal partner in treatment and that he is about to give his free consent: but the reality, as his pained expression suggests, is quite different. This scene illustrates neither traditional trustworthiness and trust, nor their failure, nor newer and better grounded trust combined with respect and autonomy: it illustrates a simulacrum of autonomy – and a simulacrum of trust, just as the orderly office with its shelves of untouched, gold lettered volumes (evidently bought by the yard!) depicts a simulacrum of the real settings of professional life.

I do not, of course, want to suggest that patients' rights to refuse are unimportant. But where options are few, where cognitive and decision-making capacities are limited, procedures of informed consent may become a burden or a ritual, and ideas of 'patient autonomy' may seem more inflationary than liberating. If autonomy is really fundamental to bioethics, we need an ethically more convincing account of autonomy. I hope to provide that account in later chapters.