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Autonomy

Relational Conceptions

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2.1 INTRODUCTION

This chapter argues that the conception of autonomy implicit in the current health research ethics guidelines is an individualistic one. On this model, people are autonomous when they voluntarily exercise their deliberative capacities to make choices based on their values. They can fail to be autonomous either for psychological reasons, when their deliberative capacities are impaired; or for epistemic reasons, when they do not have access to all the information that is relevant to a decision. The chapter outlines a contrasting 'relational' approach to autonomy. On the relational model, people can fail to be autonomous for social reasons. The social conditions that a person inhabits, including their available options, and the interpersonal context – such as family relationships and social expectations – all affect the ability to make autonomous decisions. The chapter also identifies some of the implications of the relational model for health research ethics. It examines two issues implicit in the guidelines: the relationship between autonomy and vulnerability, and the claim that informed consent is sufficient for autonomy.

2.2 AUTONOMY IN HEALTH RESEARCH ETHICS GUIDELINES

Autonomy is a one of the fundamental ethical principles identified in documents that provide ethical guidelines for health research using human subjects. Section 9 of the Declaration of Helsinki states that '[i]t is the duty of physicians who are involved in medical research to protect the life, health, dignity, integrity, **right to self-determination**, privacy, and confidentiality of personal information of research subjects'.[1] The Belmont Report outlines three fundamental ethical principles: *respect for persons*, *beneficence* and *justice*. Respect for persons requires that 'individuals should be treated as autonomous agents' and that '[a]n autonomous person is an *individual capable of deliberation about personal goals and of acting under the direction of such deliberation*'.[2] These documents propose explicitly or implicitly that the principle of respect for autonomy can by satisfied by obtaining informed consent. Section 25 of the Declaration of Helsinki states that 'no individual capable of giving informed consent may be enrolled in a

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[1] World Medical Association, 'WMA Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects', (World Medical Association, 1964). My emphasis.

[2] Department of Health, Education, and Welfare, 'The Belmont Reports. Ethical Principles and Guidelines for the Protection of Human Subjects of Research', (US Department of Health and Human Services, 1979). My emphasis.

research study unless he or she freely agrees'.[3] The Belmont Report provides that respect for persons requires that 'subjects be given the opportunity to choose what shall or shall not happen to them. This opportunity is provided when adequate standards for informed consent are satisfied'.[4] And the Government of Canada guidelines state that '[i]ndividuals are generally presumed to have the capacity and right to make free and informed decisions. Respect for persons thus means respecting the exercise of individual consent'.[5]

As has been often noted, these ethical codes were initially formulated in response to notorious examples of exploitation and autonomy-denial of vulnerable people in medical research, such as the Nazi medical experiments and the Tuskegee syphilis study of the US Public Health Service. The latter took place from 1932 to 1972 to 'record the natural history of syphilis'. Researchers recruited 600 Black men – sharecroppers who had not received medical care before – of whom 399 had syphilis and 201 did not. The men consented to participate in exchange for free medical care but were never informed about the true purpose of the study – they were told they were receiving medical treatment for 'bad blood'. They did not receive penicillin when it became available in 1947, nor were they offered the opportunity to leave the study.[6] The ethical guidelines aim to protect such vulnerable populations. The Belmont Report states that '[c]ertain groups, such as racial minorities, the economically disadvantaged, the very sick, and the institutionalized may continually be sought as research subjects, owing to their ready availability in settings where research is conducted. Given their dependent status and their frequently compromised capacity for free consent, they should be protected against the danger of being involved in research'.[7] The document also associates vulnerability with a lack of autonomy: 'Respect for human dignity entails high ethical obligations towards vulnerable persons – to those whose diminished competence and/or decision-making capacity make them vulnerable'.[8]

The ethical guidelines therefore raise three important questions. First, what is the understanding of autonomy implicit in the guidelines? Second, is the 'autonomy of the vulnerable'[9] possible, and, if so, how does vulnerability intersect with autonomy? Third, what is the connection between informed consent and autonomy? The next section claims that the conception of autonomy implicit in the guidelines is an individualistic one on which it is sufficient for autonomous decision-making that people have deliberative capacities and exercise them in appropriate ways. However, the individualistic model is limited both in its conception of autonomy and its recommendations regarding the ethical obligations of health researchers. I therefore outline a contrasting 'relational' model of autonomy that has been developed over the last several decades by feminist philosophers and others.[10] The final sections examine the

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[3] WMA, 'Declaration of Helsinki'.

[4] HHS, 'Belmont Report'.

[5] 'Guiding Principles', (Government of Canada), www.canada.ca/en/health-canada/services/science-research/science-advice-decision-making/research-ethics-board/policy-procedures/guiding-principles.htm

[6] 'The Tuskegee Timeline', (CDC); www.cdc.gov.tuskegee/timeline.htm; E. Nix, 'Tuskegee Experiment: The Infamous Syphilis Study', (History, 16 May 2017), www.history.com/news/the-infamous-40-year-tuskegee-study.

[7] HHS, 'Belmont Report'.

[8] Ibid.

[9] T. F. Owonikoko, 'Upholding the Principles of Autonomy, Beneficence, and Justice in Phase I Clinical Trials', (2013) *Oncologist*, 18(3), 242–244, 242.

[10] J. Nedelsky, 'Reconceiving Autonomy: Sources, Thoughts and Possibilities', (1989) *Yale Journal of Law and Feminism*, 1(1), 7–36; C. Mackenzie et al. (eds), *Relational Autonomy Feminist Perspectives on Autonomy, Agency and the Social Self* (New York: Oxford University Press, 2000); N. Stoljar, 'Feminist Perspectives on Autonomy', (The Stanford Encyclopedia of Philosophy, 11 December 2018), www.plato.stanford.edu/archives/win2018/entries/feminism-autonomy/

implications of relational autonomy for the notions of vulnerability and informed consent. The relational model suggests that the ethical obligations of health researchers to respect autonomy are more demanding than the requirement to secure informed consent.

2.3 THE INDIVIDUALISTIC CONCEPTION OF AUTONOMY

Autonomy is the ability of people to 'fashion' their own destiny through 'successive decisions throughout their lives'.[11] The challenge is to identify the conditions that are required to secure this ability and to promote its exercise in particular cases. The philosophical debate about autonomy offers both individualistic and a variety of relational answers. On a standard individualistic view, the conditions of autonomy are purely internal or psychological: autonomy corresponds to a capacity for rational deliberation. Gerald Dworkin argues that a person is globally autonomous when they have a higher-order capacity for critical reflection. A particular decision is locally autonomous when the capacity is exercised to evaluate, endorse or repudiate first-order preferences.[12] This view assumes that most people are rationally competent agents who engage in critical reflection and generate endorsed or 'authentic' decisions.[13] People are nonautonomous only when critical reflection is defective – when the capacity for rational deliberation is undermined by a psychological impairment such as being under the influence of drugs or alcohol, hypnosis, brainwashing or similar forms of psychological manipulation, or pathological psychological conditions, like delusions, that interfere with mental competency. The individualistic conception of autonomy has been highly influential and has led many later authors to adopt variants of Dworkin's approach.[14]

The health research ethics guidelines do not explicitly elaborate a notion of autonomy. The Declaration of Helsinki refers to respecting a 'right to self-determination'.[15] The Government of Canada Guidelines state that 'individuals are generally presumed to have the capacity and right to make free and informed decisions'.[16] Only the Belmont Report adopts the individualistic model explicitly, stating that '[a]n autonomous person is an individual capable of deliberation about personal goals and of acting under the direction of such deliberation. To respect autonomy is to give weight to autonomous persons' considered opinions . . .'[17] However, all the guidelines refer to informed consent as the ethical requirement that will secure subjects' 'free choice' or autonomy. This implies that, for individuals who are 'capable of deliberation',

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[11] J. Raz, *The Morality of Freedom* (Oxford: Oxford University Press, 1986), p. 369.

[12] G. Dworkin, *The Theory and Practice of Autonomy* (Cambridge: Cambridge University Press, 1988).

[13] The dominant view of autonomy in bioethics, due to Tom Beauchamp and James Childress, is similar, although their conception of autonomy requires that autonomous decisions are intentional not authentic: e.g. T. L. Beauchamp and J. F. Childress, *Principles of Biomedical Ethics*, 7th Edition (New York: Oxford University Press, 2012), p. 203. As Beauchamp puts it, 'This account of autonomy is designed to be coherent with the premise that everyday choices of generally competent persons are autonomous. The account is based on autonomous action in terms of normal choosers who act (1) intentionally, (2) with understanding, and (3) without controlling influences'. T. L. Beauchamp, 'Autonomy and Consent,' in F. Miller and A. Wertheimer (eds), *The Ethics of Consent: Theory and Practice* (New York: Oxford University Press, 2010), p. 65.

[14] For instance, John Christman specifies that autonomy requires both psychological *competency* and *authenticity*. Competency is critical reflection that is free from 'distorting factors' and authenticity requires what he calls 'hypothetical non-alienation'. See J. Christman, *The Politics of Persons. Individual Autonomy and Socio-historical Selves* (Cambridge: Cambridge University Press, 2009), pp. 155–156. Christman's criterion of autonomy is weaker than Dworkin's as it does not require active endorsement at all. It may be so weak as to have limited use in the health research context.

[15] WMA, 'Declaration of Helsinki'.

[16] Government of Canada, 'Guidelines'.

[17] HHS, 'Belmont Report'.

the only additional thing needed for autonomy are optimal epistemic conditions in which to deliberate. It is reasonable to assume, therefore, that the health research guidelines do not go beyond the individualistic model, and that the conditions that undermine autonomy are limited to the psychological (impaired cognitive capacities) or the epistemic (inadequate information). On this model, ethical obligations are also limited to ensuring that subjects are mentally competent and have all relevant information. However, this narrow account of ethical obligation does not fully explain the ethical failures of the research in cases such as the Tuskegee study. There is no reason to think that the Tuskegee subjects were mentally incompetent or lacked autonomy due to cognitive impairment. The individualistic model – and the guidelines – imply that these subjects could, in principle, have made an informed decision to participate in the study and therefore that the obligation to respect their autonomy could have been discharged. This model fails to address the social context of choice and is both an implausible characterisation of autonomy and an impoverished account of the researchers' ethical obligations. I now turn to the relational model of autonomy to address these problems.

2.4 RELATIONAL AUTONOMY

The starting point of relational approaches to autonomy is the observation that people are not disembodied rational subjects who, absent psychological impediments, function as fully autonomous agents. Rather, autonomy is an ability that develops and is exercised in a social context. Social relationships, as well as social and historical conditions – such as gender socialisation – foster or impede autonomy.[18] In short, the social conditions that a person inhabits, the interpersonal context of family and community relationships, as well as norms and interpersonal expectations, can all promote or undermine the ability to make autonomous decisions.

Relational autonomy is a popular framework in clinical ethics[19] but so far has received little attention in health research ethics. One exception is offered by Edward S. Dove et al., who advocate a relational approach to understanding consent to placental sampling in pregnant women.[20] Some women request to consult their partners before providing consent to placental sampling. The authors propose that such requests are better accommodated within a relational model than an individualistic model because the former acknowledges the impact of social relationships on agency and hence recognises that 'joint decision-making [could] be built into the consent process'.[21] This illustration of an application of the relational model is quite limited, however. First, it seems to conflate *joint* decision-making with relational autonomy. Joint decision-making implies that the author of a decision is a collective (the woman and her partner), whereas the relational model aims to characterise *individual* autonomy that takes into account the decision-maker's social context. Second, the potential of the relational model, both to identify social conditions that hamper individual autonomy, as well as to identify strategies to promote autonomy, is considerably richer than suggested here. There is a complex set of factors elaborated by relational theories that potentially affect subjects' autonomy and hence should be

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[18] Nedelsky, 'Reconceiving Autonomy', 12; D. Tietjens Meyers, *Self, Society and Personal Choice* (New York: Columbia University Press, 1989).

[19] E.g. J. K. Walter and L. Friedman Ross, 'Relational Autonomy: Moving beyond the Limits of Isolated Individualism', (2014) *Pediatrics*, 133 (Supplement 1), S16–S23.

[20] E. S. Dove et al., 'Beyond Individualism: Is There a Place for Relational Autonomy in Clinical Practice and Research?', (2017) *Clinical Ethics*, 12(3), 150–165, 157.

[21] Ibid., 158.

considered in the context of health research ethics. In what follows, I sketch three varieties of relational approach.

The first set of views argues that although autonomy is primarily a psychological capacity, social conditions play a significant causal role in its development. Marilyn Friedman offers a psychological test of autonomy on which being autonomy requires 'self-reflective affirmation' with respect to one's preferences and values.[22] She emphasises, however, that family relationships serve to either promote or hamper the development of the critical reflection that allows people to engage in self-reflective affirmation.[23] Similarly, Diana Tietjens Meyers argues that a person has 'autonomy competency' when she exercises a 'repertoire of skills' of critical reflection to engage in 'self-discovery, self-definition and self-direction'.[24] Social conditions, particularly lack of education or oppressive socialisation, can affect whether or not such skills develop in the first place, erode them even if they do develop or fail to promote a person's exercise of these skills. For instance, gendered expectations might deter the development or exercise of autonomy skills in girls but promote it in boys. Boys are more likely to be encouraged to debate their points of view and adopt an attitude of 'authority over their own voice'. For Meyers, well-honed autonomy competency can also counter oppressive socialisation. She comments that autonomy skills 'endow women with the capacity to fashion self-portraits and self-narratives in their own voices and to lead their own lives'.[25] Meyers's account is relational because it recognises the many ways in which deliberation is itself moulded by socialisation. She also identifies a rich array of deliberative skills that are required for autonomy competency including those of introspection, imagination, communication and memory.[26] These include emotional, bodily and interpersonal components and hence, on Meyers's approach, relationality is built into critical reflection itself.

A second category of relational views claims that the presence of certain external options is a necessary condition of autonomy. Joseph Raz argues that autonomy – and hence a flourishing life – will be thwarted if a person lacks a sufficient range of meaningful external options.[27] For instance, a 'hounded woman' on a desert island, who is pursued by a carnivorous wild animal that is hunting her down – and whose every move is determined by the need to protect herself from the beast – cannot be autonomous, even if her powers of critical reflection are fully intact. Marina Oshana also advocates an externalist approach, on which autonomy is incompatible with external conditions that interfere with the '*de facto* power and authority' that is necessary for people to direct their own lives.[28] For example, when young African American men are routinely subjected to police profiling or arbitrary stop-and-search policies, this is autonomy-undermining because it unjustifiably constrains their options and diminishes their power to direct the course of their daily lives. Therefore, on externalist views, autonomy is not only a matter of genuine self-affirmation or of exercising skills of critical reflection; it also requires meaningful external options and the absence of severely constraining external conditions.

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[22] M. Friedman, *Autonomy, Gender, Politics* (New York: Oxford University Press, 2003), p. 6.

[23] M. Friedman, 'Autonomy and Social Relationships: Rethinking the Feminist Critique' in D. T. Meyers (ed.), *Feminists Rethink the Self* (Boulder, CO: Westview, 1997), pp. 40–61.

[24] D. Tietjens Meyers, 'Decentralizing Autonomy. Five Faces of Selfhood' in J. Christman and J. Anderson (eds), *Autonomy and the Challenges of Liberalism: New Essays* (Cambridge: Cambridge University Press, 2005), p. 49.

[25] D. Tietjens Meyers, *Gender in the Mirror: Cultural Imagery and Women's Agency* (New York: Oxford University Press, 2002), p. 32.

[26] E.g. Meyers, *Gender in the Mirror*, p. 20.

[27] Raz, *The Morality of Freedom*, p. 273.

[28] M. Oshana, *Personal Autonomy in Society* (Aldershot: Ashgate Publishing, 2006), p. 2.

Finally, there is a category of relational approaches that focuses on the importance for autonomy of self-regarding attitudes, such as self-trust and self-esteem. Carolyn McLeod identifies the role of self-trust – an 'attitude of optimism about our own competence and moral integrity'[29] – in autonomy through the example of 'Anna', who suffered a miscarriage at six weeks' gestation and afterwards felt considerable emotional turmoil. McLeod analyses Anna's sense of incompetence to articulate her emotions as in part a result of others' lack of sympathy for her grief and corresponding failure to reinforce her feelings: '[O]ften women and their partners are pressured not to grieve after miscarriage because people tend not to view the fetus's death as an event that warrants grief'.[30] Comments such as 'it was a blessing in disguise' or 'it could have been worse; you could have lost a baby' fail to 'give uptake to [women's] feelings'.[31] Self-regarding attitudes – people's sense of their own competence, sense of self-worth and self-trust – are thus particularly sensitive to interpersonal conditions and the attitudes of others.

Catriona Mackenzie has extended this proposal, arguing that self-regarding attitudes such as self-trust are constitutive components of what she calls the 'normative authority' required for autonomy.[32] Mackenzie elaborates contrasting examples from the clinical context of decisions to withdraw life-preserving medical treatment. Ms B. was a forty-three-year-old single woman who had had a career in social work in a hospital before her illness. Ms B. suffered from a spinal condition that left her paralyzed from the neck down. After an attempt to improve the condition through surgery had failed, she requested that her ventilator be switched off. She was fully aware of all treatment options and thoughtful and articulate about her decision to have treatment withdrawn.[33] Mackenzie claims that she 'clearly regarded herself as a moral equal' and that 'she was motivated by an attitude of self-worth; that is, by a sense that her life should be meaningful, worthwhile, and valuable, and by a conviction that it could no longer continue to be so given her medical condition'.[34] Contrast Mrs H., who suffered an aggressive form of bone cancer that required amputation of a leg below the knee. Her husband left her as a result of her disability. Mackenzie comments that 'she does not have the kind of strongly developed sense of basic self-confidence that might enable her to envisage a different future for herself than the one she had anticipated; and she does not have a sense of her life as worth living in its own right, independently of her relation to her husband'.[35] By hypothesis, Mrs H.'s capacity for self-trust and self-esteem was damaged by both her socialisation – Mrs H. was influenced by cultural norms and gender stereotypes that seemed to suppress her sense of self-assurance – as well as gendered relationships within her family – her husband left her when she was no longer able to occupy the traditional role of a supportive wife. Mackenzie argues that self-regarding attitudes are not just the outcomes of the social context; they are also 'intrinsically relational' because they are 'enmeshed in interpersonal relationships and social structures of mutual recognition and it is for this reason that our autonomy can be impaired by failures of recognition'.[36]

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[29] C. McLeod, *Self-Trust and Reproductive Autonomy* (Cambridge, MA: MIT Press, 2002), p.6.

[30] Ibid., p. 53.

[31] Ibid., p. 55.

[32] C. Mackenzie, 'Relational Autonomy, Normative Authority and Perfectionism', (2008) *Journal of Social Philosophy*, 39(4), 512–533. More recently, Mackenzie has called this the 'self-authorization' dimension of autonomy, which she distinguishes from both the self-government (or internalist) dimension and the self-determination (or externalist) dimension: C. Mackenzie, 'Three Dimensions of Autonomy. A Relational Analysis' in A. Veltman and M. Piper (eds), *Autonomy, Oppression and Gender* (New York: Oxford University Press, 2014), pp. 15–42. However, in earlier work, normative authority was taken to be a spelling out of self-government.

[33] Mackenzie, 'Normative Authority', pp. 514–515.

[34] Ibid., p. 525.

[35] Ibid.

[36] Ibid., p. 526.

The different relational conceptions of autonomy that I have just outlined convey the complexity of the social–relational factors that potentially affect whether subjects of health research will be autonomous or not. In the next two sections, I outline the implications of the relational model for vulnerability and informed consent. I suggest that the relational model generates more demanding ethical obligations on health researchers than those derived from the individualistic model.

2.5 RELATIONAL AUTONOMY AND VULNERABILITY

Relational conceptions of autonomy help to illuminate the connection between autonomy and vulnerability (see Rogers, Chapter 1 of this volume). Recall that the Belmont Report says that vulnerable persons are 'those whose diminished competence and/or decision-making capacity make them vulnerable'.[37] Vulnerability is here being characterised as (individualistic) non-autonomy, namely as non-autonomy due to (psychologically) diminished competence. This suggests that vulnerability and autonomy are incompatible and that therefore that it is unethical for vulnerable agents to be the subjects of healthcare research. However, rather than treating vulnerability and autonomy as always opposed, the relational model potentially provides a more nuanced account of how to evaluate and ultimately promote the autonomy of members of vulnerable groups.

Theorists of vulnerability have observed that vulnerability can be *inherent* or *situational*.[38] Certain vulnerable groups, such as pregnant women, are vulnerable due to intrinsic, bodily aspects of being human. Others, such as the subjects of the Tuskegee study, are situationally vulnerable. As impoverished Black sharecroppers in the American South who had never received adequate education or medical care, these subjects were situationally vulnerable. Poverty and racist discrimination afforded them few real options and disposed them to manipulation by the medical personnel conducting the study. The situational vulnerability of subjects of the Tuskegee study generates *global* non-autonomy. Even if such subjects have the deliberative competence to make informed, locally autonomous decisions, they lacked minimally adequate options, and could not direct the course of their lives. Is health research using subjects who are situationally vulnerable and globally non-autonomous *always* ethically indefensible? Mackenzie disputes this conclusion. Vulnerability and autonomy are not always opposed, because 'ethical responses to vulnerability should be guided by the value of autonomy . . . to counter the sense of powerlessness and loss of agency that is often associated with vulnerability . . . and to counter the risks of objectionable paternalism'.[39] If she is right, it would not be impossible to conduct ethical studies using subjects who are situationally vulnerable, but the obligation to respect autonomy would be demanding in such cases. Researchers would have to actively ameliorate subjects' autonomy by, e.g. ensuring that participation in the research itself provides meaningful options and fosters positive communication to promote subjects' self-trust and sense of self-worth.

The situation is different for groups that are defined as vulnerable due to their inherent characteristics, such as pregnant women. It has been pointed out that the assumption that there

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[37] HHS, 'Belmont Report'.

[38] C. Mackenzie et al., 'Introduction: What Is Vulnerability, and Why Does It Matter for Moral Theory?' in C. Mackenzie et al. (eds), *Vulnerability. New Essays in Ethics and Feminist Philosophy* (New York: Oxford University Press, 2014), p. 7.

[39] C. Mackenzie, 'The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability' in C. Mackenzie et al. (eds), *Vulnerability. New Essays in Ethics and Feminist Philosophy* (New York: Oxford University Press, 2014), p. 45.

is homogeneity among members of vulnerable groups is problematic (see Brassington, Chapter 9 and Rogers, Chapter 1 in this volume). Labelling a group a 'vulnerable population' can lead to 'unfettered protectionism' with respect to health research on this population, which in turn can have adverse consequences for their health.[40] For instance, there is no effective malaria drug that can be used by pregnant women, thus leading to unnecessarily high rates of death from the disease.[41] The relational model of autonomy challenges the assumed homogeneity of groups that are characterised by inherent vulnerabilities. Although the conditions causing situational vulnerability often coincide with those that undermine autonomy, this is not the case for inherent vulnerability. Individual women do not have diminished mental competence due to pregnancy; nor do social conditions render pregnant women as a group globally non-autonomous. From the perspective of relational autonomy, there is no impediment to ethical research using pregnant women merely due to the inherent vulnerability of pregnancy.

2.6 RELATIONAL AUTONOMY AND INFORMED CONSENT

The ethical guidelines mostly treat informed consent and autonomy as interchangeable and suggest that securing informed consent is both necessary and sufficient to respect autonomy. The relational model challenges both assumptions.[42] On the relational model, it is possible to respect and promote autonomy without obtaining informed consent. Consider children or people with a cognitive disability who cannot provide genuine informed consent. Relational conceptions of autonomy imply that there are many ways in which autonomy can be fostered, such as providing meaningful options and reinforcing self-regarding attitudes of self-confidence, self-trust and self-worth. The ethical obligation of respect for relational autonomy is therefore distinct from the requirement to obtain informed consent. If health research on children or people with cognitive disabilities were envisioned, it may be necessary to secure informed consent from a parent or guardian. But this would not imply that the ethical obligation of researchers to respect the autonomy of subjects themselves has been discharged. Researchers would have an additional obligation to foster the relational autonomy of the subjects of the research.

The relational model also questions the assumption that informed consent is sufficient for autonomy.[43] The obligation to obtain informed consent requires health researchers to provide relevant information and an opportunity for subjects to weigh up costs and benefits on the basis of the information. This obligation is not onerous, as McLeod comments vis-à-vis informed consent in clinical contexts: '[r]arely does significant communication about a patient's options occur' besides either recommending the procedure, or in cases in which a recommendation is not possible, '[saying] to the patient that she has to choose based of her beliefs and values'.[44] As we have seen, an informed decision is not always an autonomous one. The Tuskegee subjects did not suffer cognitive impairments, so in principle they had the capacity to evaluate information and decide to participate in the study. On the relational model however, this decision is

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[40] M. O. Little et al., 'Research with Pregnant Women. A Feminist Challenge' in L. D'Agincourt-Canning and C. Ells (eds), *Ethical Issues in Women's Health Care* (New York: Oxford University Press, 2019), pp. 281–282.

[41] Ibid., p. 280.

[42] James S. Taylor also argues that securing informed consent is not *necessary* to promote autonomy. It should not be jettisoned however, because it promotes the value of well-being: J. S. Taylor, 'Autonomy and Informed Consent: A Much Misunderstood Relationship', (2004) *The Journal of Value Inquiry*, 38(3), 383–391.

[43] N. Stoljar, 'Informed Consent and Relational Conceptions of Autonomy', (2011) *Journal of Medicine and Philosophy*, 36(4), 375–384.

[44] McLeod, *Self-Trust*, pp. 134–135.

unlikely to be even locally autonomous. The Tuskegee subjects lacked recognition by others of their status as moral equals; they likely also lacked self-trust or a sense of themselves as the equals of the researchers conducting the study. If so, even informed decisions would not count as autonomous. The relational model implies therefore that health researchers have additional ethical obligations than simply to obtain informed consent. Consider again the example of placental sampling. Dove et al. suggest that requests by some women to consult their partners indicate a form of relational rather than individualistic decision-making. This may be true, but it would be wrong to assume that the requirement to respect relational autonomy would be discharged by providing subjects an opportunity to consult family members. Indeed, it has been argued that respecting relational autonomy implies quite stringent obligations, for instance an epistemic obligation to understand the woman's subjective point of view.[45] For instance, in the placental sampling case, will consulting a partner foster the woman's autonomy, or does it indicate a disposition to defer to a male partner's wishes due to lack of self-trust or self-worth? (Recall the case of Mrs H. above.) In general, respecting relational autonomy requires the provision of meaningful options – including the option to say no – and an environment that promotes rather than undermines the necessary competencies and self-regarding attitudes.

I have argued that securing informed consent, as understood on the individualistic model, is insufficient to respect relational autonomy. However, could the obligation to secure informed consent itself be revised in ways congenial to the relational approach? Guideline 9 of the 2016 *International Ethical Guidelines for Health-Related Research Involving Humans* states that informed consent should be a 'two-way communicative process', and that persons obtaining the consent should ensure that subjects comprehend the relevant information. For example, the information must be in 'plain language understandable by the applicant', and 'the researchers must make themselves available to answer questions'.[46] These latest guidelines therefore adopt some of the lessons of relational autonomy. They focus attention on the ways on which the availability of researchers to answer questions could facilitate a better-informed process and hence on the effects of interpersonal attitudes on individuals' decision-making. Yet they do not fully articulate the potential for understanding informed consent in relational terms. One promising avenue of research is the framework of 'epistemic injustice', which argues that people can suffer injustice due to unjustifiable disregard for their status as full epistemic agents.[47] For example, due to their social subordination, the epistemic agency of the Tuskegee subjects was ignored and there was no attempt to secure informed consent. Epistemic injustice can also occur in cases in which the need for informed consent is recognised. Indeed, it may be especially likely to occur in the context of health research due to the privileged epistemic position that researchers occupy as experts in the research field. As José Medina has argued, having privileged status – epistemic or otherwise – tends to make one more likely to display epistemic vices such as epistemic arrogance, or the expectation of 'not being called into question in one's opinions, that is having an undisputed cognitive authority'.[48] Such epistemic vices potentially will interfere with obtaining appropriate consent. Attention to the relational context in characterising informed consent reinforces the conclusion of previous sections that the ethical obligations of researchers who study human subjects are more demanding than set out in the current guidelines. In addition to the obligation to foster the social and interpersonal

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[45] Catriona Mackenzie outlines these obligations in the clinical context: Mackenzie, 'Normative Authority', p. 528.

[46] Council for International Organization of Medical Sciences (CIOMS), *International Ethical Guidelines for Health-Related Research Involving Humans*, 4th Edition, (Geneva: CIOMS Publications, 2016).

[47] M. Fricker, *Epistemic Injustice: Power and the Ethics of Knowing* (Oxford: Clarendon Press, 2007).

[48] J. Medina, *The Epistemology of Resistance* (Oxford: Oxford University Press, 2012), pp. 31–32.

conditions that promote autonomy, they may have special epistemic obligations, namely to cultivate epistemic virtue and attempt to eliminate epistemic vice.

2.7 CONCLUSION

This chapter has argued that that the current guidelines for health research ethics are implicitly committed to an individualistic conception of autonomy. This is an implausible conception because it does not recognise ways in which people's capacities for autonomy depend on social conditions, family and community relationships, and interpersonal attitudes. The chapter outlined a competing relational model of autonomy and argued that the ethical obligations derived from the relational model are more stringent than those derived from the individualistic conception.