CHAPTER 8
HUMAN DIGNITY AND HUMAN RIGHTS IN BIOETHICS

1. The Liberal Roots of Contemporary Bioethics

Questions of bioethics are part of the broader ethical reflection that embraces different changes of social practices in modern societies. While medical ethics has always been a part of medical practice, it was newly constructed after World War II. It emerged as a corrective to the crimes committed by physicians during the Nazi dictatorship, but with the development of new medical technologies, biomedical ethics began to add to the critique of disrespect for human rights and the underlying paternalism in all traditional clinical medicine. Moreover, since individual freedom was largely considered to be the core social value of Western societies to which medical ethics was addressed first and foremost, relying on the physicians' virtues and individual responsible behavior appeared not only to be dubious in light of the recent history but also seemed to contradict the freedom rights of sovereign citizens in modern societies. Health care providers were more and more seen as providing the means for patients to realize their choices in situations of illness and disease. Furthermore, the principle of well-being, which had served as the over-arching norm of medical action for centuries and was long considered the core principle of traditional medical ethics, articulated, for example, in the principle *salus aegroti suprema lex* (the well-being of the patient is the supreme law), seemed to belong to a paternalistic medical ethics rather than to the liberal framework of an autonomy-based ethics. Apart from the scholastic methodology of Catholic moral theology – subjecting the individual to objective moral truths, such as the sanctity of human life, which do not have their origin in the subject's choices and are, according to this tradition, unchangeable truths – most bioethical theories are by now framed either as liberal utilitarianism or liberal deontology. Their underlying concept of the liberal self, however, is at best a distortion and at worst a caricature of the philosophical reflection on the self that has shaped 20th century's critique of the sovereign subject.

In the traditional paradigm of medical ethics, *well-being* served as the supreme principle of a doctor's actions, and it was determined predominantly by his (sic!) expertise to identify the means by which illness or disease could be diagnosed and treated. In this meaning, health is conceived as 'concealed' (verborgen) – an enigma, as the English translation has it, that Hans-Georg Gadamer called the 'equilibrium' of bodily functions and the subjective sense of 'feeling well'.[1] In the

1 Cf. H. G. Gadamer, *The Enigma of Health* (orig.: *Über die Verborgenheit der Gesundheit,* Berlin 1993), Stanford 1996.

case of the rupture of this equilibrium, as in illness, the patient, it is assumed, will trust the doctor or medical team to take care of the necessary steps to restore the balance. The term 'patient' implies a passivity on the side of the ill person – rendering the doctor the agent, and the patient the receiver or addressee of the doctor's actions. As Onora O'Neill has argued convincingly, in this relationship, trust is a necessary element,[2] while mistrust is poisonous for a relationship that exposes the one partner to potentially painful physical and psychological interventions by the other.

In contemporary medical ethics, in contrast, *preferential autonomy* serves as the supreme principle; it is defined as a patient's right and a physician's obligation to respect it. The principle of autonomy means respect for the interests and preferences of a patient, which are considered as a patient's right to self-determination. Whatever these preferences are, they are limited solely by the reciprocal obligation to respect the interests and preferences of others. The principle of individual autonomy has replaced the shared notion of well-being in medical ethics, but with that, it has also replaced the understanding of the good of health that can be shared by all.

The concept of a patient's preferential autonomy requires a medically and ethically competent patient, and it reverses the asymmetry between the doctor and the patient in matters of medical-ethical decisions. The necessary decisions depend upon individual *preferences* of how a person wishes to live. With respect to medical-ethical questions, doctors and patients are conceived as "moral strangers". Whether they agree in their understanding of health and disease is irrelevant for the course of medical action.[3] "Conversations at the bedside", as a popular medical ethics book coins the doctor-patient encounter,[4] and more so, counseling individuals in their decision-making, will still convey information and medical expertise; but regarding life-choices or ethical questions, counseling is to be non-directive lest it risks manipulating the patient's own choices. The effect of this transformation of medical interaction is a moral neutralization of the doctor-patient relationship, and often health care institutions retreat to a formalized procedure to ensure a patient's consent to medical interventions.

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2 Cf. O. O'Neill, *Autonomy and Trust in Bioethics*, Cambridge/New York 2002.

3 For H. T. Engelhardt, modern societies 'produce' moral strangers and this is a strong motive for him to establish the principle of respect for the autonomy of all in his influential book: H. Haker, *Ethik der genetischen Frühdiagnostik. Sozialethische Reflexionen zur Verantwortung am menschlichen Lebensbeginn*, Paderborn 2002.

4 R. M. Zaner, *Conversations on the Edge: Narratives of Ethics and Illness*, Georgetown 2004.

Preference autonomy implicitly (or explicitly) assumes that a patient is a *particular* agent: sovereign, free, and well able to choose among several goods.[5] However, this self-concept turns out to be merely an idealized image of the modern *citizen* and *consumer* that liberalism has depicted throughout modern philosophy. While *political* liberalism turns to the relation of the individual and the state, *bioethical* liberalism is heavily influenced by its economic counterpart. Because bioethics is often seen in relation to political liberalism, I need to explain why I believe that it has mostly overlooked its link to the economic liberal theory.

Contemporary civil societies are for a good part defined as market societies, in which the individual will cooperate with others while pursuing his own interests – and it is this imagery that liberal bioethics seems to presuppose, transferring the *economic agent* into the sphere of medicine. The life sciences, the pharmaceutical industry, and the economic organization of healthcare facilities are good examples of the conflation of healthcare and market strategies. More and more, there are companies who need to make a profit in order to survive the competition, partner with healthcare institutions, including research institutions. They have a vested interest to identify potential *consumers* for their biomedical products or procedures in preventive, diagnostic, and therapeutic medicine. Whatever is declared to be in the patient's interest is also part of and subject to a system of economic incentives and motifs, often based on the assumption that one will first develop the goods that then will find the consumer.[6]

Preference autonomy may be an appropriate concept when applied to the consumer market (although there, too, it overlooks the multiple constraints on certain individuals and groups due to structural injustices), but it definitely distorts the reality of patients in need of help. It cannot attend to the vulnerability that accompanies illness, and it cannot attend to the constitutive relational and social character of human life that is not – or not entirely – driven by the struggle to push one's own interests, as the imagery of the *homo oeconomicus* has it.

5 Cf. chapter 5 in this volume.

6 Medical sociologist Peter Conrad argues that the transformation of 'traditional' medicine to a market-oriented medicine is the most striking feature of modern medicine – this analysis raises important questions for the concept of preferential autonomy as brought forward by Anglo-Saxon bioethics. I will return to this below. Cf. P. Conrad, *The Shifting Engines of Medicine,* in: Journal of Health and Social Behavior 4/6 (2005), 3–14.

2. *Communitarianism and Care Ethics in Contemporary Bioethics*

Liberalism has long been critiqued by its rival, communitarianism. Within bioethics, the communitarian version of the individual is often taken up and endorsed by a particular variant of it, namely the ethics of care. Feminist ethics as well as several religious ethics approaches claim that the emphasis on autonomy ignores the relatedness and interdependency of persons.[7] Furthermore, proponents of care ethics hold that the autonomy model stresses a self-confident agent who demands that his interests are met by caregivers and medical professionals – all this in a situation that is in fact more defined in terms of dependency, vulnerability, and suffering than by the sovereignty of agency. As much as respect is required in order to acknowledge the rights of patients, their need for the care provided by others resonates more with the concept of positive rights than with negative rights – but it is exactly the former that liberalism always had difficulties to embrace: positive rights do not just require that others *refrain* from certain actions but require actions by others as their obligations. Starting with different kinds of inter-relations between persons, inter-dependency and the specific vulnerability of patients in the context of medical services, the ethics of care concludes: ethical reflection in general, and medical or bio-ethics in particular, must not start with the assumption of an "atomic" self, resembling the consumer and contractor of liberalism, but with an inter-dependent individual, capable to grant care and to receive care. After all, as Alasdair MacIntyre has it, we are all 'dependent rational animals'.[8]

Neither care ethics nor communitarian ethics needs to be in conflict, however, with the freedom rights of the individual. As Susan Dodds argues, care is still to be oriented towards a person's or patient's autonomy:

> The provision of care can be defined as activity undertaken with the aim of providing an individual with the social, material and emotional supports that either allow that person to flourish as far as is possible, or (as far as possible) to bring the life of a person with some recognized physical, cognitive, psychological disability into a position where their autonomy can be realized.[9]

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7 Cf., among others, the following studies that emphasize the concept of care: E. F. Kittay, *Love's Labor: Essays on Women, Equality, and Dependency,* New York 1999; G. Clement, *Care, Autonomy, and Justice: Feminism and the Ethic of Care*, Boulder, Colo. 1996; A. Purdy/L. M. Donchin (ed.), *Embodying Bioethics: Recent Feminist Advances*, Lanham 1999; V. Held, *The Ethics of Care: Personal, Political, and Global,* Oxford/New York 2006; C. Levine, *Taking Sides. Clashing Views on Controversial Bioethical Issues*, Guilford, Conn. 2001. C. Mackenzie/N. Stoljar (ed.), *Relational Autonomy: Feminist Perspectives on Automony, Agency, and the Social Self*, Oxford 2000; E. F. Kittay/E. K. Feder, *The Subject of Care: Feminist Perspectives on Dependency*, Lanham, Md. 2002.

8 A. MacIntyre, *Dependent Rational Animals*, Chicago 1999.

9 S. Dodds, *Depending on Care: Recognition of Vulnerability and the Social Contribution of Care Provision,* in: Bioethics 21/9 (2007), 500–510, 501.

Dodds' normative claim is that the existential vulnerability relates the care-giver to the care-receiver in an un-altruistic way because of the underlying interdependency or a shared vulnerability that differs only in times and degrees of need. Most care-ethicists seem to share this view.

As much as this return to the concern for the patients' needs can be embraced, it can be doubted whether its inherent focus on personal relationships can address the current challenges of the medical system. Furthermore, contrary to its «proponent's implicit assumption» of inter-dependency, its normative status in medical ethics is at least as unclear as in the counterpart approach of an ethics of autonomy.[10] For care ethics may easily fall into two traps: first, caregivers may take the patient's articulation of her need as the guiding norm of their provision of care – in this case it is not different from taking seriously a patient's interests as articulated in the liberal autonomy-based ethics; or, second, the caregiver might determine the patient's needs herself and shape the content, scope and limits of what she considers to be a *responsible* care without giving the patient's voice priority. The only way to circumvent the first trap is to engage the patient in a conversation about needs, rights, and obligations, the threshold of acceptable actions and the limits of what the caregiver is able or willing to give. This could be called a hermeneutical process about the specific needs and actions, including values, rights, duties, and respect on both sides. It requires of bioethics to engage with a critical hermeneutics that tries to decipher the social norms that may inform the emergence of needs, and the competency to weigh the personal narratives to the normative, universalistic rights' perspective. We can consider that as a further development of freedom rights within the liberal tradition.

Avoiding the second trap, paternalism, however, is certainly difficult especially in those cases when a conversation cannot take place, and imagination or empathy must complement the normative reflection. This may be the case when patients are not able to articulate their needs due to their medical condition, their young age, or mental capability. Since we can presuppose that patients are not unrelated beings but embedded in different webs of relations, it may often be feasible to consult with these relevant other persons. Furthermore, liberal bioethics has developed (along the lines of an autonomy-based ethics) the so-called *standard of best interest* that is supposed to represent what a 'capacitated' person *would* will, and care ethics may counter this standard with the *standard of best care* that represents the obligations of the caregivers in light of what is commonly held to be good for him or her. This connects care ethics to communitarianism: rather

10 For an insightful critique of common care-ethical approaches cf. J. Paley, *Commentary: Care Tactics – Arguments, Absences and Assumptions in Relational Ethics*, in: Nursing Ethics 18/2 (2011), 243–254.

than referring to the individuals' interests or wills, an ethics that is ultimately grounded in a concept of the good will determines the values and norms according to the standards of a given community. Only if a community transcends the notion of a particular identity, however, and is reinterpreted as a universal community of rights[11] can the pitfalls of any communitarian ethics be overcome. For embeddedness in a social, cultural, ethnic, or religious group identity that generates common values and norms does not *as such* secure the freedom rights of the individual that motivated liberalism in the first place.[12] Quite to the contrary, whenever particular groups appeal to cultural values and the 'common good', individuals and minorities may be the first victims of the essentializing will of the majority, which derives its identity in part by the exclusion of its 'other' or 'difference' as much as by what it strives to be positively.

To conclude this short summary of the dispute between liberalism and communitarianism: liberalism is wrong to assume that the patient is a citizen or consumer who invests in cooperation with others only in order to pursue his or her notion to live a good life. Communitarianism is wrong to assume that the values and norms of communities as such justify particular notions of the good life, including what is good for a patient. Liberalism, however, is right if it claims that respect for the rights of patients, understood as negative freedom right and positive right to be cared for, is the guiding principle of medical ethics. Communitarianism is right to claim that the best interest standard must be complemented with a best standard of care that defines the obligations towards a patient not only in light of his or her declared interests but at the same time in light of her right to be cared for in the best possible way.

3. Human Rights in Conversation with Liberalism and Communitarianism

Taking up the discussion of human dignity and rights pursued in this book, I want to now propose a *qualified universalism*, in which the varying contexts are acknowledged in informing the understanding of human existence. The fundamental principle of this approach is human dignity, spelled out in the various kinds of human rights: basic rights to be protected and secured, freedom rights as negative and positive rights to be respected, and social rights to be fulfilled.[13] It

11 For an attempt to reconcile the individual rights with the requirements of a communal cohesion, Cf. A. Gewirth, *The Community of Rights*, Chicago 1996.

12 For an attempt to offer a third way from a Hegelian perspective cf. A. Honneth, *The Struggle for Recognition: The Moral Grammar of Social Conflicts*, Cambridge, UK/Oxford/Cambridge, MA 1995.

13 Another distinction of the kinds of human rights would be: civil rights (predominantly but not exclusively defined as negative freedom rights), political rights (as participation rights in the political realm), and social-economic-cultural rights (as positive rights to human security).

has the advantage to eschew a thick value system, while still resting upon a broad consensus shared across cultures. It takes as its starting point the *historically* established human rights frameworks.[14] Justification of normative claims cannot be successful without this turn to historical reason; but historical experiences *alone* cannot legitimize moral claims. For the normative justification, we need to develop a concept of 'qualified universalism' that is grounded in the equality of all human beings but takes its starting point in the concrete, contextual, and historical experience of vulnerability, moral injury, and structural injustice.[15] While this normative reflection concerns the very foundation of ethics as such, developed throughout this book, we can still try to see whether we may use it as the starting point of the normative reflection for a concept of the self that could redirect bioethics, too.

First, let us take the main starting point of liberalism, namely the freedom of the individual. Freedom as such may well serve as an anthropological concept to describe the necessarily assumed nature of the *human condition* – but without further specification, it cannot serve as a moral principle. For this reason, Immanuel Kant defined autonomy not along the lines of individual preferences but rather of the *good will: moral* autonomy, as a basic category in moral philosophy, is the concordance of the agent's moral maxims (the action-guiding, yet non-categorical, preference-based directives of one's actions) and the categorically binding moral law, which necessarily binds every moral agent, because it is not only comprehensible but also agreeable if moral agency entails both moral claims and agency. Defining autonomy as bound by the moral law that it gives itself, Kant explicitly contrasted it to the pursuit of happiness as the ground of an agent's moral identity; quite to the contrary, he addressed the self-imposed moral law that regulates the agent's actions, who is *also* still being motivated by the desire for happiness, in analogy to laws of nature that cause events to happen in a particular order. The distinction between preferential autonomy grounded in the desire for happiness and moral autonomy that not merely strives for happiness but at the same time for *goodness*, is therefore crucial: preferences function like maxims: they are agent-dependent, and when shared among multiple agents, they still do not transcend this status as maxims. They become morally justified only when they pass

14 Cf. for the first step L. Hogan, *Keeping Faith with Human Rights*, Washington 2015. She is, however, more critical than I am of the possibility and necessity of the complementary step of normative justification.

15 Cf. J. Shklar, *The Faces of Injustice*, New Haven 1990. This is where the theological-ethics discourse should be located as well. The Christian ethical "Option for the Poor" refers to a theologically grounded partiality, which focuses ethical attention on marginalization and exclusion, on unequal structures and the perpetuation of unequal balances of power. Cf. also chapter 13 in this volume.

the test of universalization: first, when they can be *conceived* similar to laws of nature, guiding every possible agent, second, when they can be *willed* as such a law, and third, when they do not conflict with the agency of other human beings, i. e. when they do not exclude the freedom of another person to act in accordance with her autonomy. Preferences as such have only a relative moral value insofar as they serve as the ends that agents set as goods; in other words: they do not present *moral* reasons. Moral autonomy is a specific practical freedom, demanding not only that an agent herself acts morally but also that she is respected by others in this 'dignity'.[16] In Kant's concept, dignity coincides with freedom and agency. It concerns a person's moral identity, but also her right not to be humiliated or used as a means to another person's ends. Although it is impossible to harmonize this concept of the self as a moral agent with that of the self as presupposed in liberal ethics, one could still hold that it can be translated into a corrected version of liberalism. For Kant, any heteronomy violates our dignity as agents – but that does not mean that we are *only* agents. Feminist ethics is right: throughout our lives, we are dependent on the care of others, but that does not mean we are not also "capable humans", as Ricœur has coined it, or vulnerable agents, as I have argued: we are vulnerable, yet responsible agents insofar as we act at all.[17]

In modern political liberalism, the social contract theory serves as the remedy for paternalism – hence the close relationship of political liberalism and democracy. Habermas' theory of communicative action modifies this, taking up instead Kant's moral philosophy and reframing it in intersubjective terms. But as much as discourse ethics or a *theory of a deliberative democracy* may be a possible (democratic) theory for *political* decisions, it does not suffice for the bioethical normative reflection. Insofar as ethics is not political theory, the equation of consensus and the justification of moral claims via a general agreement is flawed – and certainly not backed by Kant's *moral* philosophy.[18] A more specific objection concerns the over-

16 In recent years, C. Korsgaard has supported O'Neill's Kantian approach that prioritizes duties over rights, arguing that Kant's ethics is not only necessary for moral reasoning, but it can indeed be constructed as a 'necessary' part of a person's self-identity. Cf. Ch. Korsgaard, *Self-Constitution. Agency, Identity, and Integrity*, Oxford 2009.

17 P. Ricœur, *The Course of Recognition*, Cambridge, MA 2006.

18 One general objection raised against the discourse model concerns the asymmetries and/or factual power relations and power structures, especially with respect to the fundamental categories of sex, class, or race. The entire architecture of a procedural ethics is founded on the individuals' capability (and power) to articulate their claims in the public sphere, and this is exactly complicated in the case of illness and healthcare institutions. For a defense of this Kantian-based and yet procedural normative ethics, see R. Forst, *The Right to Justification: Elements of a Constructivist Theory of Justice*, New York 2012. Questions concerning this approach are raised in A. Honneth, *Freedom's Right. The Social Foundations of Democratic Life*, New York 2014.

all framing of a discourse within bioethics: in the *political* context, discourses make sense when decisions are to be made which concern everybody, but this is only the case in the political and legal regulation of medicine. The economic model became attractive in bioethics exactly because medicine does *not* function as political and public deliberation or at least not exclusively; rather, one may say that it resembles the social cooperation of individuals in civil society. This cooperation entails multiple different institutions, often having to deal with plurality, differences, and (power) asymmetries: these exist due to roles (teacher-student; parent-child, doctor-patient), due to historical inequalities (sex, class, and race relations), or cultural and religious differences between groups. One element of this overall social cooperation model concerns the economic exchange of goods, and as we know from our current structures of capitalism, it strives rather successfully to encroach on more or less all other forms of social cooperation.[19] We can see why the social cooperation model became so attractive for contemporary bioethics: it seems to provide the best means to ensure civil liberties, guaranteed in the informed consent and autonomy principle applied in medical ethics. Yet, as I have said, it does not have a way to deal with positive rights unless it takes up the notion of vulnerable agency. Now, we can add: it does not – or at least not without further reflection – explain why preferences count as moral *reasons*.

Second: as communitarianism stresses the common values and norms orienting the actions of individuals, care ethics stresses the positive rights of patients to be cared for. Neither of these approaches has good arguments, as I said, for why their maxims should be embraced by all: communitarianism will only be convincing if an overall concept of social cohesion is persuasive, and care ethics still needs to show what obligations are binding or, in other words, they have to show the scope and limits of positive rights. In the last step, I will now argue for a renewed concept of the moral self that I believe should be constitutive in any ethics and that could make better sense of the dialectic relation of a 'patient' and an 'agent', be it a doctor or anybody who deals with somebody in a situation of vulnerability.

19 Honneth gives multiple examples of the 'colonization' of almost every social cooperation by capitalist structures. A good example for this is the biomedical model of human reproduction. Cf. A. Honneth, *Freedom's Right*.

4. Ricœur's and Levinas' Contribution to Bioethics

In his book *Oneself as Another,* published in 1990, Paul Ricœur has presented an ethics that takes up the theoretical questions of identity or the moral self.[20] While psychology and sociology did not answer what exactly the criterion for a 'successful' identity is, Ricœur holds that the criterion can be derived from the self's moral perspective, namely from his or her *aiming at a good life with and for others in just institutions.* Taking up the Aristotelian model of friendship, Ricœur develops the ideal relationship between self and other as symmetrical and as at least partly an act of spontaneous *benevolence* for the other. Just institutions provide the background for these encounters, while a presupposed sense of justice provides the motivational ground for social cohesion. *Self-esteem, solicitude, and the sense of justice* are the three dimensions of this teleological view on the moral or, in Ricœur's terminology, the ethical self. One could easily interpret this teleological ethics in view of communitarian ethics, but also care ethics, and Ricœur demonstrates more often than not his sympathy for this approach. And yet, ethics cannot stop there, as Ricœur himself acknowledges: because of the actual experience and possibility of evil, defined as violence, it is necessary to transcend the teleological perspective of self-esteem, care, and the sense of justice. The self must come to acknowledge the deontological claim of morality, which Ricœur articulates in a Kantian reformulation of the categorical imperative: "[a]ct solely in accordance with the maxim by which you can wish at the same time that what *ought not to be,* namely evil, will indeed not exist."[21]

Ultimately, deontological moral philosophy will secure the validity of teleological ethics; yet, the former remains dependent on the latter, which guarantees that a common ethical life is possible, and the self develops a moral identity in which the preferences of one's life are guided not only by communitarian values but in fact by moral demands. This concept of ethical/moral identity, which emerges from the interrelation between care for the self and an interest in living together with others in just institutions, constrained by the recognition of mutual respect, seems to be a promising approach, because it combines the best of both liberal and communitarian traditions. However, we can go even further: with his concern for time, history, and memory, Ricœur provides us with a concept of responsibility that goes far beyond the immediate context of one's action: care for oneself and care for the other throughout time enables us to see how memory as *remembrance* must be seen as taking responsibility for the past; how the particular choices in the *present* must be seen as situated freedom and responsibility in the present; and the effects of the actions of today must be seen as re-

20 P. Ricœur, *Oneself as Another,* Chicago 1992. Cf. also chapter 1 in this volume.

21 Ibid. 218.

sponsibility for the *future*, for example, by way of implementing the precautionary principle Hans Jonas introduced. Ricœur's ethics equips care ethics better to answer many of the open questions that it faces. But Ricœur's concept of responsibility is also useful for the liberal tradition. It offers a strong reformulation of Kant's concept of moral autonomy that forces the self to transcend one's self-interests, however heroic they may be, and to scrutinize the maxims of one's actions according to the test of universalization and respect of human dignity, without ignoring why she performs this exercise in the first place: ultimately, it is a test for a person's preferences (or maxims), which orient the striving for the good life, with and for others, in just institutions.

Ricœur has been criticized for emphasizing too much the spontaneous or learned care for the other, leaving too little room for the normative obligation to care that is grounded in rights. Others have doubted whether he does not overestimate the mutuality of inter-action.[22] For Levinas, an important interlocutor for Ricœur in *Oneself as Another*, for instance, the effort to establish reciprocal symmetry or mutuality is *not* the decisive moral demand.[23] On the contrary, the confrontation with the "face" of the other, the symbol for another person's vulnerability, reveals an inevitable moral asymmetry. Surprisingly, it is the moral agent who is acted upon by the mere presence of the other. The agent is first a patient, called upon or, as Levinas sometimes says, 'summoned' by the other, before a person can act – rendering the person's action a response rather than an initiative that rests upon the ends set in action: the other whom I am capable to affect in my action first affects me; I cannot *not* be affected, even though I am free in the course of action that I take. Response-ability describes the two elements of moral agency: the impressionability, passivity, or, put differently, the vulnerability to the other's actions, *and* the capability to act. It is the asymmetry between the other and the self, which has also been called the 'belatedness' of the self in relation to others who always act upon oneself before one becomes an agent – and not the sharing of a lifeworld or worldview – which becomes both the *occasion of* and *reason for* morality. Unlike Ricœur, Levinas prioritizes the moral demand over any ethical striving. Levinas distances himself from an ethics that combines care for the self and care for the other by positing the absolute exteriority and alterity of the other. He not only describes the phenomenological relation of self, other, and world by starting with the other, but also anchors the concept of moral responsibility in the encounter with the other.

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22 He has corrected his view in his last major work, where Ricœur offers a much more cautious view on the possibility of mutuality. P. Ricœur, *The Course of Recognition*.

23 Cf., among others, E. Levinas, *Time and the Other and Additional Essays*, Pittsburgh, PA 1987. E. Levinas, *Otherwise than Being or Beyond Essence* (translated by Alphonso Lingis), Dordrecht 1998.

While the urgency that Levinas connects to this responsibility has led many to resist his radical reconfiguration of the self-other-encounter, Levinas himself was convinced that his account of morality must not be regarded as undue, threatening, or even as a violent intervention into the self's freedom and autonomy. To respond to the other as other first and foremost implies *enduring* the person's otherness, the difference and the gap between me and the other person; to endure the lack of certainty of what the other person might demand of me but also to *be open to* how the encounter might change my own self-understanding, my own self-perception and identity; to *question* my moral judgments; to *interact, to listen, to keep still*.[24] This respect for the other, calling for non-sovereignty, dependence and passivity on the side of the agent *before any action can take place*, has been more and more alienated from ethics. In the liberal version, the other is regarded as a limitation to the agent's freedom; in the communitarian version, the moral agent shares a common understanding of the good life with others.

Ricœur and Levinas, in their different emphases, both contribute to our discussion what it means to go beyond individualism and speak about relationality and relationships: with Ricœur, I want to stress that it is in fact appropriate to reinterpret the liberal self as a self that aims for a good life *with and for* others in just institutions. With Levinas, I want to stress, however, that this ethical identity does not exist prior to the moral claim, but rather is already an effect of the constitution of the moral self who must respond to the claims others make upon the self. This is, at the same time, a correction to Kant's notion of the moral law: not the law as such but the other, Levinas claims, forces the agent to transcend their isolated perspectives and preferences. Over against Levinas, however, Ricœur correctly warns against stopping the ethical reflection at this point: prioritizing the other over against the care for oneself may be as wrong as the reverse stance – equality of *mutual* recognition must still serve as the guiding norm of self-other encounters as well as of institutional norms. We must therefore go beyond Levinas again, and re-connect his concept of the emergence of the moral self and response-ability to an ethics that must be an ethics of equal rights as much as an ethics of responsibility over time.

My approach of vulnerable agency combines the *embodied subjectivity* that phenomenology rightly stresses with the *existential choice* that stems as much from the liberal as from the existential tradition, and it grounds self-constitution in the tension between *heteronomy and autonomy*. Through several developmental phases and social struggles to make the social identity one's own, a self will emerge as an agent – although an agent who is and remains impressionable and vulnerable to

24 Paul Ricœur agrees with Levinas on this, emphasizing passivity, with its linguistic connotation to 'passion', as part of the self's agency. Cf. P. Ricœur, *Oneself as Another*.

the actions of others, and open to the other's demands. If the moral self is constituted as much in the realization of her agency as in the impressionability and vulnerability to the other, morality cannot exclusively be grounded in the respect of the *rights* of the other; neither are the self and the other primarily occupied in a struggle of reciprocal recognition. Furthermore, acting in response to the other and acknowledging the other's otherness as well as this person's plea to be cared for is not the same as acting in the best interest of the other. Rather, in the response to the other, the agent must always recognize the inevitable gap between himself/herself and the other – a gap that may indeed unsettle the self in his/her own identity, exposing the person to his/her own vulnerability and impotence as much as to the other's vulnerability – a gap that maintains and continues to raise the question of how to respond responsibly, instead of merely applying a general normative concept of the moral law to a particular case. Crucial for the understanding of this approach is the fact that passivity as much as one's capability to act, uncertainty about one's right response as much as the determination to act at all, is a necessary part of *any* moral interaction – and not only of those interactions and relations where the other cannot articulate his or her interest. With this, the seemingly static roles of the patient and the doctor that traditional medicine depicted are transformed into a dialectic relation of passivity and activity on both sides.

Yet – the mere reference to a patient's preferences, to a doctor's (or caregiver's) benevolence in the care for the other, or to the phenomenology of the self-constituting responsibility in the experiential encounter between self and other does *not* solve the normative problem of a morally right action – or at any rate not without further mediations. All depends, then, on whether the criteria for morally right actions are based upon the assumption that we all share at least a *thin concept of a 'good life'*,[25] or whether they are based upon the ever-looming possibility that in

25 The irony of liberal ethics is that it cannot do without any conception of the good life. A good example is Martha Nussbaum's list of capabilities to which everybody should be entitled. Were this the case, then the difference between 'capabilities' and 'rights' would disappear – but this is not the case conceptually, no matter how much the content resembles the human rights 'list'. If capabilities stand for more than rights – namely, for a conception of the good life humans cannot do without – they must be called exactly that: a list of goods that one may or may not consider necessary for one's good life. Liberalism, however, never aimed at producing a 'thick' version of the good life but rather leaves it to every individual to determine the content on her own – hence, either the difference between the good and the right is conflated (interpretation 1), or liberalism offers a conception of the 'good' that is contra to its own standpoint of neutrality concerning such conceptions (interpretation 2). If the 'thin concept' is considered an anthropological or ontological condition of human life, it cannot demonstrate without further argumentation why it still excludes certain human beings from this very condition. Nussbaum's conception has the advantage of revealing this conflict and making every effort to escape the dilemma. Cf. M. C. Nussbaum, *Frontiers of Justice: Disability, Nationality, Species Membership*, Cambridge, Mass. 2006.

and through our actions, we may violate the other in his or her dignity – a violation that from the perspective of normative ethics 'ought not to be'. I hold that the latter stance, which explores the meaning of dignity via its *negative* semantic field, namely humiliation, degradation, dehumanization, or harming, is consistent with the liberal tradition. Utilitarianism, which today defends the respect for a person's preferences as an ethical principle unless another person is harmed,[26] captured an important insight for medical ethics, reversing the question of happiness to the avoidance of suffering that translates into the principle of nonmaleficence in medical ethics.

Conclusion

In conclusion, I would hold that communitarian and liberal approaches both contain indispensable insights for any ethics, namely that impressionability and vulnerability are necessary for self-constitution; that belonging to a community of care and solidarity is formative for any identity; and that agency, though it must not be separated from vulnerability and sociality, still is the capability to act of one's own accord. Morally, however, agency is the capability to respond responsibly to someone else's plea to be cared for that enables us to transition to the sphere of morality. If we reinterpret both traditions' insights into the language of vulnerable agency and moral response-ability, I believe we have gone beyond an untenable individualism that serves perhaps a particular model of social cooperation, namely economic exchanges of goods, but that clearly distorts the insights from identity theory and moral theory alike when it comes to other social practices, among them medical practices. One of the most challenging questions bioethics has yet to solve is how the here-proposed concept of moral agency and responsibility can integrate the social, structural, and institutional contexts that define responsibility as justice. I will turn to some of these contexts in the following chapters.

26 P. Singer, *Practical Ethics,* Cambridge ³2011.

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