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Human Rights and Dignity in Bioethics

Hille Haker

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 part of medical practice, it was newly constructed after World War II. It emerged as 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 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 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 psychical 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 physician’s obligation. The principle of autonomy means respect for the interests and preferences of a patient, which are considered as patients’ 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 do not only concern “objective” criteria but also, and sometimes even predominantly, 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”, and more so, counseling individuals in their decision-making, for example, will still concern 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 relation-

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3 For Hugo Tristram 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: cfr. H.T. ENGELHARDT, The Foundations of Bioethics, Oxford University Press, New York 1996\(^3\).
ship, and often health care institutions retreat to a formalized procedure to ensure a patient’s consent to medical interventions.

Preference autonomy implicitly (or explicitly) assumes that a patient is a particular agent: sovereign, free, and well able to choose among several goods. But 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, 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.4

Preference autonomy may be an appropriate concept when applied to the consumer market, but it distorts the reality of patients in need of help, because 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.

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

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4 Medical sociologist Peter Conrad argues that the transformation of the “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. Cfr. P. CONRAD, The Shifting Engines of Medicine, “Journal of Health and Social Behavior” IV (2005), 6, 3-14; Id., The Medicalization of Society: On the Transformation of Human Conditions into Treatable Disorders, Johns Hopkins University Press, Baltimore, MD 2008.
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\(^5\). 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 echoes more the concept of positive rights than the 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 particular *positive* actions as 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»\(^6\).

Neither care ethics nor communitarian ethics needs to be in conflict, however, with the freedom right 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\(^7\).

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Dodds’ normative claim is that the existential vulnerability relates the caregiver to the care-receiver in an un-altruistic way because of the underlying inter-dependency or a shared vulnerability that differs only in times and degrees of the 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 proponents’ 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. 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 serious 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 circumvention of 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. This brings us to the approach that I will argue for in a moment, namely 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.

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in light of what is commonly held to be good for him or her. This connects care ethics to communitarianism: rather than referring to the individuals’ interests or wills, an ethics that is ultimately grounded in a concept of the good will determine 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 universal community of rights\textsuperscript{9}, 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\textsuperscript{10}. 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 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 a patient as 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.

Human Rights in Conversation with Liberalism and Communitarianism

I want to propose an approach that I call a qualified universalism based on human rights, 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, protection rights, freedom rights, negative and positive rights\textsuperscript{11}. The

\textsuperscript{9} For an attempt to reconcile the individual rights with the requirements of a communal cohesion, cfr. A. Gewirth, The Community of Rights, University of Chicago Press, Chicago 1996.


\textsuperscript{11} 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).
advantage of this approach rests on the fact that human rights ethics does not necessarily assume the coherence of any given values or value systems, but still rests upon a broad consensus shared across cultures. It takes at its starting point the historically established human rights frameworks. Several of these frameworks have been acknowledged and confirmed by the United Nations or by the European Union – they are certainly open to additions and further differentiation, but they are achievements that should be considered as such. In my own view, the normative implications of historical, yet critical reasoning must be spelled out more specifically in this endeavor, and this can only be done in close examinations of historical experiences. The historical origin of human rights does not weaken the normative justification of human rights – to the contrary, it strengthens it: instead of viewing human rights in terms of a naturalization of ultimately Eurocentric values, the process of rendering human rights as the overarching moral basis of the United Nations serves as a point of departure in a dialogical process of understanding and appreciation, and it complements the normative justification. 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 experience of injustice. While this normative reflection concerns the very foundation of ethics as such and goes beyond this paper, 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.


14 Cfr. for the first step L. Hogan, Keeping Faith with Human Rights, Georgetown University Press, Washington, D.C. 2015. She is, however, more critical than I am of the possibility and necessity of the complementary step of normative justification.

15 Cfr. J.N. Shklar, The Faces of Injustice, Yale University Press, New Haven, CT 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. This ethical focus within the Christian ethic is connected to the attribute of God’s compassion and concern for justice, which translates into a practical involvement and engagement for others; cfr. H. Haker, “Compassion als Weltprogramm des Christentums” – Eine ethische Auseinandersetzung mit Johann Baptist Metz, “Concilium” 37 (2001), 4, 436-450. On a personal level, compassion means a concern for oneself and others; on the societal level, it means active solidarity with discriminated groups in achieving and reviving recognition; cfr. Id., Neue Erwägungen zu Solidarität und Gerechtigkeit, “Concilium” 50 (2014), 1, 7-18; and on the institutional level of justice policies, it must be spelled out as negation of injustices. Injustices, not justice, are based on the experiences of concrete historic (and historical) events or structures of discrimination and form the hermeneutical basis of understanding the other’s concerns.
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 line of individual preferences but rather along the line 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 of the will 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, despite being still also motivated by the desire for happiness, in analogy to natural laws 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 the test of universalization: first, when they can be conceived similar to natural laws, 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 my moral identity, but also my 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 moral agent with that of the self-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. As human beings, we are vulnerable agents,

16 In recent years, Christine 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. Cfr. Ch. KORSGAARD, Self-Construction. Agency, Identity, and Integrity, Oxford University Press, Oxford, 2009.
at times more vulnerable and “passive”, such as in times of illness but also during childhood or when we may lose our capability to take the responsibility for our actions; at other times, however, we are more active and hence accountable for our actions, such as in our economic and political cooperation. MacIntyre is of course right: throughout our lives, we are dependent on the care of others, but that does not take away our rational nature that renders us vulnerable, yet responsible agents insofar as we act at all.

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. A more specific objection concerns the overall 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, in our current structures of Capitalism, it strives rather successfully to encroach on more or less all other forms of social cooperation. We can see why the social cooperation model became so attractive

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17 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, Das Recht auf Rechtfertigung. Elemente einer Konstruktivistischen Theorie der Gerechtigkeit, Suhrkamp, Frankfurt a.M. 2007; and a critique of it in A. Honneth, Freedom’s Right. The Social Foundations of Democratic Life, Engl. transl. by J. Ganhal, Columbia University Press, New York 2014.

18 Axel 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. Cfr. Honneth, Freedom’s Right.
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 stressed the positive rights of patients to be cared for. Neither of these approaches has good arguments, as I said, 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.

Oneself as Another – The Other as Source of the (Moral) Self – Ricœur’s and Lévinas’ 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 19. 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 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-es-

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teem, care, and "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: «Act 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».

Ultimately, the deontological morality will secure the validity of the teleological ethics; 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 her 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. But 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 responsibility for the future, for example, by way of implementing the precautionary principle Hans Jonas introduced. A care ethics that takes Ricœur's ethics as starting point, seems well-equipped to answer many of the open questions that a more traditional care ethics is faced with. But also within the liberal tradition that grounds morality in the autonomy of the self, Ricœur's concept of responsibility is useful. It is a strong reformulation of Kant's concept of moral autonomy that forces the self to transcend her self-interests, however heroic they may be, and to scrutinize the maxims of her actions according to the test of universalization and respect of human dignity, without ignoring why it performs this exercise in the first place: ultimately, it is a test for one's own preferences (or maxims), which orient our 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. For Lévinas, however, the effort

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20 Ibid., 218.

to establish reciprocal symmetry or mutuality where asymmetry is caused by relations of power and ultimately violence, is not the decisive moral moment. On the contrary, the “face” of the other 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 Lévinas sometimes says, “summoned” by the other, before she can act – her action is nothing else than a response: the other whom I am capable to act upon affects me; I cannot not be affected, even though I am free in the course of action that I take. Response-ability, I would hold, describes the two elements of moral agency: the impressionability or, put differently, the vulnerability to the other’s actions, passivity, 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 it before it becomes an agent – and not the sharing of a lifeworld or worldview – which becomes both the occasion of and reason for morality. Unlike Ricoeur, Lévinas prioritizes the moral demand over any ethical striving. Lévinas 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 responsibility in the encounter with the other.

While the urgency that Lévinas connects to this responsibility has led many to resist his radical reconfiguration of the self-other-encounter, Lévinas himself was convinced that his account of the moral self must not be regarded as undue, or threatening, or even as a violent intervention into the self’s freedom and autonomy but to the contrary, as the “individuation of the self” as moral self. To respond to the other as other first and foremost implies to endure her otherness, the difference and the gap between me and her; to endure the lack of certainty of what she 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. 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.

The “individualistic” or “atomistic” liberal moral agent only includes the other insofar as he might limit the agent’s freedom or insofar as the agent might limit the freedom of the other; the “communitarian” moral agent seems

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23 As Paul Ricoeur puts it, this passivity, with its linguistic connotation to “passion” is part of the self’s agency. Cfr. RICOEUR, Oneself as Another.
to already share the aims of a good life, strives for a good life together with the other. This concept of the self likewise excludes the self’s passivity, affectability, and vulnerability to the other. Ricœur and Lévinas, 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. His concept takes up the insights of 20th century research on social identity and identity formation. With Lévinas, 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 alone is able to respond responsibly 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, Lévinas claims, forces me to transcend my preferences. Ricœur is certainly correct in warning against a morality that stops at prioritizing the other over against the care for oneself – he correctly insists on the necessity to uphold the equality of and the equilibrium between the rights of oneself and the other. We must therefore go beyond Lévinas 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.

With that, I can finally propose the “self” and “identity” concept that I would like to set up as a reinterpretation of the liberal tradition – though I cannot elaborate too much here, I can still state its elements: my approach combines the embodied subjectivity that phenomenology rightly stressed, 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, without sacrificing the “mine-ness” of one’s individuality, a self will emerge as an agent – although an agent who is and remains impressionable and vulnerable to 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 not 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, however, acting in response to the other and acknowledging the other’s otherness as well as her plea to be cared for and respected 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 herself and the other – a gap that may indeed unsettle the self in his/her own identity, exposing her to 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.

And yet, to repeat what I have said all along – the mere reference to one’s preferences, to one’s benevolence or 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 reasoning. Kant’s insight for this step is indispensable. From a relational perspective, however, symmetric and asymmetric constellations are to be distinguished, and they must take into consideration the contexts of the encounters, their backgrounds and histories. Whether one responds “responsibly”, i.e. in a way that meets the moral claims another can legitimately make, depends of course on how we construct the criteria: the step beyond Kant and communitarianism was, in my view, already made by utilitarianism when it reversed the question of happiness into one of avoidance of suffering. Ricœur made the same move in his reformulation of Kant’s categorical imperative. 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” or whether they are based upon the ever-looming possibility that in 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” (Ricœur). I hold that the latter stance, which explores the meaning of dignity via its negative semantic field, namely humiliation,

24 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 leave 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 any effort to escape the dilemma. Cfr. M. NUSSBRAUM, Frontiers of Justice: Disability, Nationality, Species Membership, Belknap Press of Harvard University Press, Cambridge, MA 2006.
degradation, dehumanization, or instrumentalization, is consistent with the liberal tradition but goes beyond it in acknowledging that violence can also rest in inaction or, as the ethics of care has it, in the denial to care for someone who is dependent on our response and action.

In conclusion, I would hold that communitarian and liberal approaches both contain indispensable insights for any ethics, namely the impressionability and vulnerability as necessary background and element of self-constitution, the necessity to belong to a community of care and solidarity, and agency as the capability to act. Morally, however, it 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 the 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 justice25. Yet, my guess is that much would be accomplished already if we could agree upon the concept of self and moral identity that I have proposed in this paper.

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25 Valuable insights into a concept of shared social responsibility can be derived from Iris Marion Young’s last, unfinished work before her death. Cfr. I. MARION YOUNG, Responsibility for Justice, Oxford University Press, New York 2011.
Abstract

Contemporary bioethics is caught in the Scylla of political liberalism that presupposes a concept of a sovereign and independent individual, thereby more and more promoting a “consumer patient” in the realm of medicine, and the Charybdis of communitarian ethics, here spelled out as care ethics, arguing for the acknowledgment of embeddedness and interdependence and interpreting care as a right and a responsibility. Both approaches, I argue, fall short to provide moral criteria that define the scope or limits of the rights and responsibilities, and they both lack a comprehensive understanding of the moral agency. I argue that the concept of vulnerable agency can better deal with the interdependence of human beings, without losing ethics’ normative claim to respect a person’s freedom. The paper proposes, first, a normative approach, a qualified universalism. This concept is based on human rights which need context-sensitive, concretizing interpretations. Second, the capability to respond responsibly constitutes the moral self as moral agent who is obliged by the plea of someone else to respond. While only normative ethics can determine how to respond, responsibility still must be anchored in the response to the other. I conclude that both the normative and the hermeneutic dimension of ethics are needed to discern the dialectic between passivity (vulnerability) and activity (agency) in the inter-action between care-giver and patient.

La bioetica contemporanea si trova tra la Scilla del liberalismo politico che presuppone un individuo indipendente e sovrano, ma genera sempre più un “paziente consumatore”, e la Cariddi dell’etica comunitarista, qui intesa come etica della cura, che al contrario propone il radicamento e l’interdipendenza e interpreta la cura come diritto e come responsabilità. Entrambi gli approcci non riescono a fornire criteri morali che definiscano le possibilità e i limiti dei diritti e delle responsabilità e mancano di una comprensione adeguata dell’agire morale. Nel contributo si sostiene che il concetto di agire vulnerabile può render conto dell’interdipendenza degli esseri umani senza sacrificare l’esigenza dell’etica normativa di rispettare la libertà della persona. Si propone, quindi, innanzitutto un approccio normativo: un universalismo qualificato basato su diritti umani che richiedono interpretazioni attente ai contesti e applicabili; poi, che la capacità di rispondere responsabilmente costituisce l’Io come un agente morale obbligato a rispondere all’appello dell’altro. Da un lato, cioè, solo l’etica normativa può determinare come rispondere, dall’altro la responsabilità non può non ancorarsi al fatto che si risponde all’altro. Si conclude che sia la dimensione normativa che quella ermeneutica dell’etica sono necessarie per comprendere la dialettica tra passività (vulnerabilità) e attività (agire) nell’interazione tra colui che cura e il paziente.

Keywords
BIOETHICS; LIBERALISM; COMMUNITARIANISM; CARE ETHICS; HUMAN RIGHTS; RESPONSIBILITY; IDENTITY; RECOGNITION.

BIOETICA; LIBERALISMO; COMUNITARISMO; ETICA DELLA CURA; DIRITTI UMANI; RESPONSABILITÀ; IDENTITÀ; RICONOSCIMENTO.