

# Autonomy and Care in Medicine

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## Abstract

This paper argues that the core principle of bioethics, autonomy, is rooted both in the 20<sup>th</sup> century history of the development of new medical technologies as in political liberalism transferred to medical practices, rendering the medical decision-making of patients a centerpiece of medical interventions. The paper shows how the ambiguity in the interpretation of autonomy reflects the ambivalence of bioethics towards making normative claims on the moral agents insofar as these go beyond the respect for a patient's autonomy. In the second part, the paper analyzes the alternative approach of care ethics, which intends to emphasize both the vulnerability and dependency of the patient and the medical professions' responsibility to care for the patient. However, neither 'autonomy' nor 'care' ethics approaches can address the social and institutional mediations of today's health care ethics; the paper therefore concludes with a proposal to embrace a critical social-ethical approach to bioethics that is based on the tradition of human rights.

**Keywords:** bioethics, autonomy, care, political liberalism, responsibility, human rights

## Introduction

Societal practices, including numerous practices in the health care sector, have radically changed during the second half of the 20<sup>th</sup> century. The changes certainly concern human reproduction, the prolonging of life with the help of modern medical technologies, and the social practices surrounding the process of dying. Even the concept of life and death have changed over the course of the last century, and a utilitarian economic reason that accompanied modern industrial societies since the 19<sup>th</sup> century, has reached the sphere of medicine, too: how we handle the human body in medical prevention, diagnosis, and therapy echoes the automation of other non-medical technical processes; the human corpse is more and more utilized for organ transplantation; but also body parts such as blood, sperm or egg cells, or human tissue are used in the ever-demanding processes of medical cures. Modern society's hospitals sometimes resemble large industrial complexes, and even small medical practices may use more technical devices than a person might ever see in his or her everyday life. In sum, the institutional changes that medicine has gone through over the last century are dramatic, and it is not so clear whether medical ethics, as it is known today, embraces the complexities of these changes, especially when it predominantly is framed as 'individual ethics'. In this article, I will show how the ambiguity of the interpretation of autonomy results in an ambivalence of what exactly moral claims are moral agents, namely patients, are faced with and I will then complement and, in part, juxtapose the principle of respect of autonomy with the medical professionals' responsibility to care for a patient. Both concepts, however, cannot claim to address the social and institutional questions of today's health care ethics, and hence I will conclude that to connect both concepts of autonomy and care with a social-ethical approach to bioethics is the most challenging task ahead.

## Bioethics as an Answer to Societal Change in 20th Century

Questions of bioethics are part of the broader ethical reflection that embraces different changes of social practices in modern societies. In the discipline of bioethics and biomedical ethics, which originated in Northern America in the 1950s,<sup>1</sup> the shifts and changes of the medical practices due to the development and application of new technologies are examined in historical, cultural, or anthropological studies, including the analyses of the transformative processes and the emergence of new norms in different contexts. Sociological analyses describe societal changes, e.g. shifts with respect to values and beliefs, and psychological studies examine, among others, the impact of these changes on the personal identity, their coping strategies with illness, etc. In the traditional labor division between descriptive and normative disciplines, philosophy, theology and law are the classical disciplines to critically evaluate the normative dimension of practices by means of rational argumentation.

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

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<sup>1</sup> (Jonsen 1998).

freedom was largely considered to be the core social value of US society, 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 right 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 considered the core principle of traditional medical ethics, (articulated, for example, in the principle: "Salus aegroti suprema lex"), seemed to belong to a paternalistic medical ethics rather than to the new framework of an autonomy-based ethics. While well-being is certainly still guiding the physician's every-day practice, it became, above all, a problem in the contested cases of biomedical ethics: especially in the conflicts concerning life and death, the course of action, it was held, should be determined by the patient rather than by the physician or anybody else. According to the revised biomedical ethics, respect for the patient's autonomy is paramount in the doctor-patient-relationship and expected to create exactly the trust that is needed in this asymmetric relationship; in practice, however, this respect is often merely spelled out as the signature on the consent form. Nevertheless, respect for the patient's autonomy reflects a radical change in the underlying concept of medical actions concerning the status of the traditional principle of well-being.

The re-orientation of the traditional medical virtue ethics by way of the establishment of several institutional Codes of Conduct, political oversight of new technologies, and the re-evaluation of traditional medical ethics was met by a major methodological 'milestone' when Tom Beauchamp and James Childress published their 'Foundations of biomedical ethics' in 1977, which is now in its sixth edition, each of which responded to the critics of the approach.<sup>2</sup> It was assumed that by constructing foundational "middle principles", both the theoretical and practical needs of medical ethics could be met without burdening bioethics with the commitment to a particular moral tradition or religious belief system. The authors hoped that on the basis of plural traditions, the principles of bioethics could be negotiated and serve as a normative reference for the new discipline of bioethics. By aid of the four principles, autonomy, non-maleficence, beneficence, and justice, norms were to be set up for most changed areas of medical practice, namely ethical issues at the beginning of life, at the end of life, or genetic testing. Together with legal norms, the principles were supposed to guide the clinical decision-making procedures 'at the bedside'. From the beginning, however, *legal*-ethical deliberations dominated the debates, framing the bioethics discourse as analysis about a physician's right action and the scope of legal regulations. In the very famous case of Karen Ann Quinlan, for example, her parents, the legal guardians, sought to end her treatment after several months because she had not responded to any effort to help her regain consciousness – the court ultimately ruled in favor of her parents' wishes. This case became a test case for biomedical ethics in the new 'era' of life-sustaining technologies, and unless the more casuistic methodology of Catholic moral theology was applied, bioethical questions were framed in view of liberal political philosophy. Mostly, they were seen as conflicts between freedom rights on the one hand – hence respect for a patient's autonomy (sometimes represented by her guardians) interpreted mainly as negative freedom right, i.e. the right not

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<sup>2</sup> (Beauchamp Childress 2008).

to be hindered by the state or medical institution to act in accordance with her wishes – and protection rights on the other hand, i.e. an institution's or state's duty to protect the life and well-being of citizens. This conflict between different kinds of rights is not unusual in liberal political philosophy; what is not so clear, however, is whether this framework of political liberalism is appropriate in order to interpret modern medical ethical conflicts.

Beauchamp and Childress's book is certainly the best-known approach to biomedical ethics; it joins the long list of US American bioethics books that presuppose the modern liberal framework, even when disagreeing whether a more deontological or consequentialist approach should be taken. And although the book was critiqued from philosophers especially for its reliance on a 'common morality', with the spread of the discipline of bioethics to almost every country of the world, the underlying framework has become the most influential methodology within biomedical ethics. Moreover, very soon the "four principles approach" succeeded in providing an instrument to ethically structure complex ethical issues in such a way that they can be regulated. Given the heavy influence of the six editions of the book so far, it is probably not too far-fetched to say that it has had the intended effect, even though today, the question of just distribution of resources (and hence the question of political and economic ethics) and the challenge of global justice (and hence the relation of political ethics, governance, and economics) reflects a shift in the bioethics debate towards the methodologies of social and institutional ethics. Bioethics, it is claimed today from a Foucauldian perspective, is also always biopolitics, mirroring not only the historically contingent and ever shifting relation, for example, between religious communities and the state, but also the pragmatic focus of bioethics as consultant and adviser of political bodies. While these approaches claim that the *clinical-ethical* approach, which is centered on the physician-patient relationship and their interaction, is far too narrow given the complexity of health care and governance of individual's health, the principle of autonomy, as introduced in the early works of bioethics, is still considered to be the core principle of the discipline.<sup>3</sup>

## The critique of autonomy as preferential autonomy

In the context of medicine the concept of what I will call preferential autonomy is defined as respect for the desire and the preferences of a patient – whatever these may be, limited solely by the respect for the preferences of others. This respect has replaced, as I said, the shared notion of 'well-being' that formed the basis of action in the traditional medical ethics. In that paradigm, it was the physician's expertise that determined whether and how an illness or disease could be transformed into what Heinz Georg Gadamer called the 'equilibrium' of bodily functions and the subjective sense of 'feeling healthy'.<sup>4</sup> In this conceptual framework, the patient would trust the doctor or medical team to take care of the necessary steps to reach this status of equilibrium – or at least to try everything possible to restore his or her well-being – at the price of not knowing or not understanding a physician's actions. As Onora O'Neill has argued convincingly, 'trust' is a necessary ingredient of the doctor-patient-relationship,<sup>5</sup> while mistrust is poisonous for a relationship that exposes the one partner to

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<sup>3</sup> For a good overview of the discussion on autonomy in bioethics cf. (Tauber 2005).

<sup>4</sup> Cf. (Gadamer 1996).

<sup>5</sup> Cf. (O'Neill 2002).

potentially painful physical and psychical interventions by the other – in a culture that values individual freedom highly, a return to the traditional virtue-ethics paradigm seems to be impossible unless it leaves enough space for information and consent. While this is not questioned, the exact interpretation of autonomy is subject to many contemporary debates.

The concept of a patient's preferential autonomy, which echoes the social value order of Western societies' individualism, requires a medically *and* ethically competent patient: If the choice is considered as a patient's self-determination of action, this changes the physician's role dramatically, even reversing the asymmetry between the doctor and the patient in matters of ethical decisions. Again, in more traditional settings, this may not become a big problem, because it will still be the 'well-being' that drives the decision and the patient will most certainly rely upon the expertise of the physician. But in the biomedical setting of today's health care provisions, this may easily change, because health and illness become much more ambiguous concepts: for example, in genetic testing, *dispositions* to develop diseases in the future may serve as cause for actions (preventive screenings, abortions, or preventive surgery are examples of such interventions), even though no actual disease is at stake. The ethical decision can therefore not be guided by a person's well-being as equilibrium of health (already) disrupted by a disease; rather, the decision involves the assessment of risks and the probability of a disease to manifest; decisions may involve the assessment of one's future quality of life, as this is, for example, the case in prospective living wills. In all these cases, medical experts can give statistical information, but since quality of life is difficult – if at all possible – to quantify, the necessary decisions do not only concern 'objective' criteria but rather individual *preferences* of how a person wishes to live with regard to possible medical options. In such a scenario that is rather the standard of biomedical decision-making than the exception, doctors and patients may in fact rather be 'moral strangers' than sharing a social understanding of health and disease.<sup>6</sup>

Since the value of an individual's freedom to act is considered as the 'highest good' of the modern (Western) ethics that in return shapes the normative principle of respect, the flipside of the value of individual autonomy is therefore *ethical pluralism*. Tolerance or respect is the normative response to this pluralism. As a result, the dominant liberal medical ethics emphasizes the normative implication of autonomy for physicians or caregivers: they not only need to *refrain* from any *action* that could interfere with the patient's own desire or interest but also from *reasoning* with the patient about underlying value judgments of their interests. Conversations are to be 'non-directive' lest they risk manipulating the patient's sovereign choice. The effect of this change 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.

Despite of the problems to implement appropriate procedures, preference autonomy seems to 'fit' well with modern societies.<sup>7</sup> However, while individuals may interpret their preferences as 'authentic' desires, they are in fact socially mediated: preferences are at least in part shaped by social values and social norms. As I have argued, in an environment of 'moral

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<sup>6</sup> 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: (Engelhardt 1986).

<sup>7</sup> For a defense of preferentialism from a utilitarian perspective cf. (Singer 2011); for a critique of the 'modern self' cf. (Taylor 1992, Taylor 1992).

strangers' or moral pluralism, these mediations can hardly be addressed – but this does not mean that the 'liberal self' comes without attributes: the concept of 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* that political liberalism has depicted; while political liberalism turns to the relation of the individual and the state, bioethical liberalism is heavily influenced by the citizen as participant in civil society. In modern societies, these are for a good part defined as market societies, in which the individual will cooperate with others while pursuing her own interests – and it is this social practice that liberal bioethics seems to presuppose, while transferring it to the sphere of health care. 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. To this aspect, I will return below. But there are other reasons to question an over-simplified interpretation of the concept of autonomy from an ethical perspective:

First, freedom as such may well serve as an anthropological concept to describe the *conditio humana* – 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 moral reasoning: *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 principles) and the categorically binding moral law, which ought to be comprehensible by everyone; defining autonomy as the foundation of morality, Kant did not think of the individual's freedom to pursue her happiness; rather, he addressed the freedom of a person to 'construct' the moral laws that regulate (and motivate) actions, analogue to natural laws that cause events to happen. The distinction between preferential autonomy and moral autonomy is therefore crucial: preferences as such have no moral qualification; hence it can be right or wrong to respect them. In contrast, moral autonomy is practical freedom, demanding not only that an agent herself acts morally (in accordance with the categorical principle, i.e. justified with a claim to universal validity) but also that she is respected in this 'dignity' – the capability to act morally.<sup>8</sup>

In the last decades, this moral approach to autonomy was elaborated further from two important sides without turning to the concept of preferential autonomy. *Discourse ethics* critiqued the Kantian justification procedure for its monological structure of reasoning, and it transformed the process of reasoning to a dialogical procedure of deliberation, as argumentative discourse. Although this approach was developed as a political ethics, it can be useful for biomedical ethics, too: in clinical ethics, it is, for example, echoed in the concept of 'shared decision-making', which transcends the imperative of non-directive interactions. Second and more radically, however, *phenomenological ethics* questioned the universalization of maxims. It takes up Kant's turn to obligations and reformulates it as

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<sup>8</sup> In recent years, Ch. 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. (Korsgaard 2009).

*responsibility*.<sup>9</sup> In this approach, the *response to the 'other'* takes precedence over the self-related actions that include the other via universalization only. In the bioethical context this means that both patients and health care providers need to ask what responsibilities arise in a given situation; a patient may even conceive of *herself* as other, resulting in the obligation to care for herself, while physicians will need to ask what they 'owe the other', the patient. Autonomy is thereby closely linked to the concept of responsibility; the latter, however, is better equipped to attend to a patient's loss (or lack) of sovereignty that so often accompanies the experience of illness.

A second reason to transcend the concept of preference autonomy concerns the concept of free choice in the context of health care services. Biotechnologies which have become more and more part of the current medical practice are a good example of the easily crossed line between the rhetoric of 'free' choice and the shaping of this choice by market strategies; for medical products are often very expensive, and they are predominantly owned by companies that need to make profit. Such companies 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, all based on the assumption that one will first develop the goods that then will find the consumer. Seen from the institutional or social-ethical perspective, however, individual choices are not only mediated socially but rather, needs are sometimes created rather than discovered, in order to create a market for its products.<sup>10</sup> A powerful example of this dynamic within the medical sector is the drug *Viagra* that was developed as medication for a specific sexual condition, but once it marketed, it was broadly advertised as a lifestyle drug for an ageing male population. Within few years, the drug has radically changed the attitude towards and the perception of sex in an ageing society.<sup>11</sup> Commodification, it seems, has also long taken the lead in reproductive technologies: For example, sex-selection in early pregnancy was developed as part of medical genetics to determine sex-related risks, as in Duchenne muscular dystrophy. By now, companies sell test kits for no more than \$25 online. Adding lab fees and shipping costs, these tests can be bought for \$250-300. According to a review study that was published in August 2011 in the Journal of the American Medical Association (JAMA), non-invasive blood-tests are highly reliable with respect to the determination of the offspring's sex; they may pave the way to offer future parents the choice to determine the sex of their future child.<sup>12</sup> Furthermore, in several countries, the most popular of which is India that has a booming market in this area, children are *purchased* from surrogate mothers changing the 'conception' of a child. With respect to enhancement technologies, biochemical or neurological stimulants are heavily marketed. As a clear-cut separation between patients' needs and consumers' interests is impossible, the distinction between treating a patient and

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<sup>9</sup> (Levinas 1998). For a more thorough analysis of the critique of liberal bioethics via an ethics of responsibility cf. (Haker 2008).

<sup>10</sup> 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. Cf. (Conrad 2005, Conrad 2008).

<sup>11</sup> Cf. (Loe 2004).

<sup>12</sup> (Devaney 2011).

satisfying a consumer is more and more blurred. Nevertheless, the rhetoric and health renders the marketing of new products or services more acceptable. Today, commodification in the health care sector is a challenge that bioethics must attend to in its overall analyses of individual autonomy.<sup>13</sup>

A third argument that questions the interpretation of autonomy as preference autonomy concerns the cultural shaping of basic concepts of human existence by the so-called life sciences. In contrast to the ever smaller role that cultural and religious traditions play in interpreting human existence, the scientific approach to human life in biology, though necessary within that discipline, becomes the dominant paradigm to understand human life – and shapes a new cultural understanding. For instance, in the 1960s, human death was defined as brain death, at least partly in order to enable organ transplantation, with the result that today ethical questions concerning the treatment of brain-dead persons predominantly concern the ‘harvesting’ of their organs and not, for example, new ways to deal with the dying person in a highly automated environment.<sup>14</sup> In the Life Sciences, human body parts, tissue, or gametes are necessarily conceived as mere body material in order to have them available as medical resources; the existential perspective may easily be dismissed. From an ethical perspective, this necessarily reductionist scientific view must be complemented with the phenomenological insight of ‘embodiment’: a patient not only ‘has’ a body among other bodies; a patient ‘is’ her body that she experiences as ‘hers’ in a non-instrumental, experiential way.<sup>15</sup> Given the dominant perspective of biology as normative framework in defining the meaning of human life, the human body becomes a crucial site of anthropological self-understanding. In Foucault’s analysis of power this dynamic has been appropriately described as “biopolitics.” The normative shifts are not based on power as domination but rather pass through the bodies of individuals. They are adopted “free-willingly,” but still form “regimes of power,” which Foucault described as “governmentalities”.<sup>16</sup> An ethics based purely on the respect of individual autonomy has no means by which it can analyze this self-induced dynamic of power.<sup>17</sup> Bioethics must, however, be able to attend to the psychic, social and cultural dimensions which shape the overall understanding of human existence, and it needs to contextualize the life sciences’ perspective in this endeavor.

Without a critical method of reflection of these dynamics, ethics loses its capacity for the normative analysis and assessment that ultimately is aimed at orientating individual agents in their actions. Contrary to philosophers who want to merely embrace the Kantian concept of moral autonomy, I am convinced that Kant’s approach alone is not sufficient to normatively address, for example, the commercialization of biomedicine and the cultural transformation of our societies by way of the life-sciences.

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<sup>13</sup> (Honneth 2008), (Dickenson 1997, Dickenson 2009).

<sup>14</sup> The role of relatives in the process of determining the brain death of a person is almost always reduced to the decision about organ transplantation; the dramatic experience of the death of a beloved person in the environment of an IUC is not part of the debate and left to psychological studies. Ethics, however, also concerns the ‘ars moriendi’ and includes practices of accompanying a person’s death. In the legal-ethical framing of bioethical questions, there is not much room for such reflections.

<sup>15</sup> (Vetlesen 2009, Merleau-Ponty 1962).

<sup>16</sup> (Burchell 1991).

<sup>17</sup> The dialectic of power as both heteronomous and self-constituting feature is explored further by (Butler 1997).

## Care for the ‘vulnerable’ as corrective of an ethics of autonomy?

Let me now very shortly turn to the ethics of care. For the last decades, the ethics of the liberal understanding of autonomy has been criticized from yet another angle that I have not presented so far: feminist ethics as well as several religious ethics approaches claimed that the emphasis on autonomy ignores the relatedness and interdependency of persons.<sup>18</sup> Furthermore, these critics hold that the autonomy model stresses a self-confident agent who knows what he wants (sic!) and 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 that the autonomy concept suggests. As much as respect is needed in order to acknowledge the freedom-rights of patients, their need for the care provided by others must not be forgotten. Starting with different kinds of inter-relations between persons, their inter-dependency and the specific vulnerability of patients in the context of medical services, the ethics of care concludes: ethical reflection must not start with the assumption of an ‘atomic’, i.e. un-related, a-social self-determination. As I have said above, phenomenological ethics, too, has presented a radical critique of autonomy as conceptual starting point of either the self or of ethics, reversing ethical reflection from the ‘ethics of the self’ to an ‘ethics of the other’, or an ethics of responsibility. This reversal seems to resonate well with some newer versions of an ethics of care, because it precludes bioethics from being received as just the return to an ethics of common values, shared understandings of well-being or ‘objective’ standards of care. Even if the concept of individual autonomy may be useful in other contexts, ethicists have claimed that it misrepresents the existential status of a person who in the medical context has turned into a patient.

But it is not only the reversal from rights to needs and responsibilities that matters in care ethics. Defenders of this approach argue that different kinds of principle-based moral theories are constrained by the rationalistic frameworks of justification so that they miss the point of moral practice.<sup>19</sup> Ethics, they claim, concerns the sometimes monological, more often dialogical or collective deliberation about the appropriate response to a given situation – and this response cannot be found in a textbook of normative reasoning but needs to be partly informed by the given situation, the persons involved, and the ‘creative imagination’ about the patient’s well-being.<sup>20</sup> According to this approach, the patient’s right to be cared for (i.e. to be assisted in her autonomy, flourishing or well-being) transforms into a positive duty: it is not enough only to passively respect the other’s needs but they must be met by way of action, response. This response, however, must be acted out as ‘responsible response’. Since any action needs to be justified, the patients’ needs, the agents’ values and conviction, professional standards, ethical principles and legal constraints all enter into the ethical

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<sup>18</sup> Cf., among others, the following studies that emphasize the concept of care: (Clement 1996, Conradi 2001, Donchin 1999, Held 1995, Levine 2001, Mackenzie 2000, Kittay Feder 2002).

<sup>19</sup> Cf. for a summary: (Dodds 2007).

<sup>20</sup> I call this ‘creative imagination’ because I do not believe that we always have clear understandings of what our well-being may involve. However, in a given situation that constrains the scope of action by various conditions, I am convinced we come up with at least the relevant factors of well-being. Yet, we may well prioritize the elements differently. But that is a concern for the actual decision-making process and not for the notion of our well-being.

analysis; the patient's perspective *alone* is certainly not to overrule all other deliberations, while his or her dignity, spelled out in specific rights, is in fact inalienable.<sup>21</sup>

So, if care ethics is concerned with responsible responses that are meant to meet the needs of another person – how are these defined? Susan Dodds argues that 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.<sup>22</sup>

Dodds is quick to add that autonomy is not always the goal of care. In some cases it may well be a rather restricted meaning of flourishing, as is the case in the care for persons with severe mental disabilities, or people in the so-called persistent vegetative status, or persistent coma. Dodds' normative basis, however, is the claim that the existential vulnerability relates the care-giver 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 re-turn 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. Rather, a systemic, 'managerial' ethics has taken over, it has been argued, "setting the stage for formations of collective actions by a large number of individuals",<sup>23</sup> whose individual actions must be organized and coordinated. 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.<sup>24</sup> 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; 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 back to 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.

To avoid the second trap, paternalism, is certainly more difficult when a hermeneutical conversation cannot take place, and imagination or empathy must complement

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<sup>21</sup> Cf. for a recent collection of essays concerning the theory of dignity and its possible foundational status in bioethics (Pellegrino 2009).

<sup>22</sup> (Dodds 2007), p. 501.

<sup>23</sup> (Stirrat 2005), p. 128.

<sup>24</sup> For an insightful critique of common care-ethical approaches cf. (Paley 2011).

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 almost always 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, and bioethics has developed (along the lines of an autonomy-based ethics) the so-called standard of best interest that care ethics may counter with the standard of best care. The normative limit of the care-ethics, however, is the same as it is for the ethics of autonomy: this is the inalienable *dignity* of the patient that must be respected, and that must be particularly respected in situations of increased vulnerability. Everything is dependent, then, on how we can conceive of dignity in the context of bioethics, and moreover, how dignity is spelled out in different kinds of human rights.

## The return of the question of methods

The limits of both autonomy and care ethics approaches show that bioethics needs to broaden the methodological framework within which medical-ethical questions are negotiated. I see a trend in contemporary approaches to bioethics to rather *describing* various individual values and social norms than normatively *evaluating* them. Ignoring this specific task, more and more empirical studies replace normative analyses; they tacitly operate on the belief that a) since pluralistic societies need to respect the patient's will, empirical studies can shed light on what individuals think; furthermore, surveys exploring a population's stance on particular practices are instruments of deciphering social values and norms; these, in turn, are taken as an important basis for legal regulations in democratic societies. The flaw of this approach is not so much that its informative value is limited – this holds true of any empirical study or poll; rather it confuses the majority votes with the validity of moral claims. A critical ethics based on the foundational principle of dignity and human rights cannot knuckle down to majority views; rather, it has to *argue* for the justification of moral claims. Many studies in bioethics overlook this task of normative justification altogether. But while ethics certainly needs to interpret existential experiences and social practices, it also needs to offer a normative framework to determine, for example, the correlation of freedom and responsibility.

Certainly, descriptive and comparative studies are an indispensable part of what I call a *critical hermeneutical ethics*. As such, bioethical approaches and approaches in cultural anthropology, ethnology and social sciences will coexist parallel to each other, and they will strive to overcome the current deficit that often exists because they remain unconnected.<sup>25</sup> However, in addition to the descriptive depiction of normative orders or the critical analysis of social practices, the reflection on normativity is indispensable. Hence, the critical hermeneutical ethics is to be complemented with a normative ethics that I call a *historically sensitive universalistic human rights approach*.

A number of bioethicists who have confronted the question of normativity refer to a *theory of a deliberative democracy*, leaving foundational ethical questions to a discourse model of decision-making. But as much as this may be a possible (democratic) procedure for *political* decisions, it does not suffice for the bioethical normative reflection. Insofar as ethics

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<sup>25</sup> (Durante 2009).

is not political theory, even though both disciplines of philosophy are connected in their objects of research, the equation of consensus and the justification of moral claims is flawed. For, to mention but one critique of any kind of discourse ethics, which is raised by feminist ethics as well as critical ethics: the emphasis on discourse is not as innocent as it appears to be, because it underestimates the factual power relations and power structures, especially with respect to the fundamental categories of sex, class, or race.<sup>26</sup> This deficiency seems to shake the entire architecture of a procedural ethics that is founded on the capability to articulate one's claims in the public realm, and brings us back to the underlying conflict of an ethics of autonomy and an ethics of responsibility. Although I certainly cannot argue for it here, I believe that the most promising resolution to this methodological dilemma is a combination of a critical hermeneutics (that examines the factual inequalities, social norms and normative orders) and the universalistic human rights approach (that is the underlying framework of discourse ethics, too, which is constructed to secure the freedom rights of any participant in social practices).

For such a *qualified universalism based on human rights theories*, 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, and claim rights. The advantage of this approach rests on the fact that human rights ethics does not necessarily assume the theoretical coherence of values but takes at its starting point the *historically* established human rights frameworks. They refer, for example, to the qualified and codified catalogue of Human Rights Declarations, which the vast majority of nations have acknowledged and confirmed – and which are open to additions and further differentiation. In my own view, the normative implications of historical, yet critical reasoning must be spelled out more specifically in this endeavor,<sup>27</sup> and this can only be done in closely examining and adhering to historical experiences: as the origin of human rights lies in a specific European tradition and historical experience, this can and should be explicated and articulated. This origin does not weaken the justification, to the contrary, it strengthens it: instead of viewing human rights in terms of a naturalization of ultimately Eurocentric values, their origin ought to serve as a point of departure in a dialogical process of understanding and appreciation, contextualizing the normative framework within a specific historical experience it and opening it up to comparative studies. Justification of normative claims cannot be successful without this turn to historical reason; but historical experiences *alone* cannot legitimize moral claims without turning to 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.<sup>28</sup> While this normative

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<sup>26</sup> For a defense of this Kantian-based and yet procedural normative ethics, see (Forst 2007), and a critique of it in (Honneth 2011).

<sup>27</sup> (Honneth 2011).

<sup>28</sup> Cf. (Shklar 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 (Haker 2001). 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: (Haker 2009); and on the institutional level of justice policies, it must be spelled out as negation of injustices. Injustices, not justice,

reflection concerns the very foundation of ethics as such, we can still try to see whether we may use it as the starting point of the normative reflection in bioethics, too.

In conclusion, I would hold that neither autonomy nor care ethics approaches are clear concepts that should be used as foundational concepts of bioethics. Rather, they capture certain aspects that may better be translated into the language of moral agency and responsibility. One of the most challenging questions bioethics has yet to solve is how agency and responsibility can be translated into the realm of institutional respect (for agency) and responsibility as justice. I have suggested that further work is therefore needed in order to develop the complementary approach of a critical hermeneutics and normative bioethics based on human dignity and human rights.

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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.

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