Silke Schicktanz
Normativity and Culture in the Context of Modern Medicine: A Prospective Vision of an Elective Affinity

> Cursed, cursed creator! Why did I live? Why, in that instant, did
> I not extinguish the spark of existence which you had so
> wantonly bestowed?
> – The 'monster' in Mary Shelley's *Frankenstein*; ch. 15

Mary Shelley's romantic novel *Frankenstein* (1818) symbolizes a particular position towards the means and achievements of modern life sciences: It is marked by hopes and fears related to the outcomes of such research as well as an ambivalent admiration for the courage of those inventors' desire to try out what is at least thinkable. Apart from the rich ambivalence of this novel, it is a kind of irony that 'Frankenstein' as term still appears in many public debates on genetic modification, transplantation medicine, or synthetic biology as a label to classify such innovations as repugnant and dismissible. Hereby, the creator and the creation are almost equated.

Almost two centuries later, pop-cultural phenomena such as the 2011 Hollywood movie *Rise of the Planet of the Apes*, directed by Rupert Watt, show, in a similar vein, the subtle ways in which science fiction serves as platform to address various ethical issues and concerns. This film tells the story of the application of a new somatic gene therapy targeting dementia in a near future. When applied in human primates it significantly boosts the primates' social and cognitive intelligence. Feeling inspired by the outstanding intelligence performances of the tested chimpanzees, the young leading researcher (here rather a failed hero than a mad scientist) is tempted to apply the new drug to his demented father. He does so by bypassing the common professional ethics of informed consent of his father or any review board assessment, though his actions seem justified as a case of 'ultimate ratio,' and by his passionate love for his father. While the movie overall presents more fiction than science, it touches upon many ethical concerns related to modern science: From animal testing and the underlying arbitrariness of a human-ape distinction, to the ethics of inserting artificially genes into the genome of a species, and finally experimental drug testing, the movie seems to leave nothing out.

Considering both, *Frankenstein* and *Rise of the Planet of the Apes*, what is most relevant is the observation that novels and other types of cultural narratives

allow the expression of concerns, feelings, or worldviews otherwise easily neglected by the rational language of scientific enthusiasm. These examples mark a period of almost two hundred years of cultural reflection on science and medicine, each embedded within a framework of understanding of science and narrative techniques typical to its own era.

It is exactly this interplay between the socio-cultural dimension and the norms expressed that is worth reconsideration. In the following, I use the terms 'socio-cultural' and 'cultural' synonymously as umbrella terms, to signify 'culture' in a wide sense. By this, despite the difficulties in defining such a highly loaded term, I mean meanings, understandings, and practices 'presenting' or 'symbolizing' our interactions with other beings or the environment by verbal or non-verbal forms. According to my definition, 'culture' stands here for the robust and historically (partly) stable system of ideas and practices within a collective, expressed in various forms of mediality.[1] By this definition, culture differs significantly from psychological attempts or spontaneous social inter-individual interactions.

Culture overlaps with economics, politics, and law, which are also collective, public endeavors, but is less explicit than those orders and rules. It is – to use Clifford Geertz's metaphor – a "web" (1973) in which we collectively feel cocooned without often being aware of it. Culture exists only when we give it a cultural meaning – and we tend to do so, when others ask for explanations of things that are not self-evident. However, I am aware – and it might be particular methodologically relevant – that social interactions and cultural forms can strongly differ with regard to their material, spatial, and temporal validity. The study of culture – as I here understand it – can therefore range from ethnographic, anthropological, sociological, or empirical-ethical approaches to the study of literature, media, or art.

For instance, a cultural study of German science fiction novels of twentieth century and an empirical study of social interactions by non-participatory observation of doctor-patient-communication during cancer care differ significantly with regard to their methodological accounts and, perhaps, theoretical assumptions. However, what these studies share (or can share, according to the idea I defend here) is that they allow us insights in the often-hidden meta-structure of providing 'meaning' to the way how norms or values and medical practices or ideas regarding the human body are mutually shaped in a particular setting (see Schicktanz 2007). The reservoir of cultural attempts can help us to reflect upon

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1 In a broad sense, I am interested in the parallels of different media (including literature, movies, artistic performances, or even images and paintings), but of course I am aware that each media has its historical meanings and methodological constraints.

both, the hidden as well as the explicit meanings that the body 'has' and that inform so even our normative reflections of what one ought to do with the body.

The relationship between applied ethics and cultural studies is not an easy one to determine. The juxtaposition of culture and normativity can provoke objection, when norms and values are seen already as part of 'culture.' However, such an almighty concept of culture seems almost impenetrable and therefore unproductive for any reflective study. Still, there exist many ways to conceptualize the relationship between culture and normativity. At one end of this spectrum, as in post-modern cultural studies, there is a trend to see things from a social-constructivist point of view (Clifford and Marcus 1986; Bauman 1993). In such a view, all explicit and hidden values and norms are construed as arbitrary, local, or contingent. Any underlying moral message is seen as just one of many possible messages, and the body is understood as a text that can be rewritten and reinterpreted in various terms. At the other end of the spectrum, where analytical (Searle 1995) or structuralist approaches (Douglas 1970, 1992; Lévi-Strauss 1961, 1963) are located, the cultural narrative provides a vehicle to infect its listener with 'true' propositions of what is and what ought to be. However, whether one of these extreme positions really does justice to the normativity embedded and entangled with cultural interpretations of our bodily practices and images must be critically questioned.

In the following, I suggest a third, alternative way to conceptualize and analyze the productive joints and links between current approaches of applied ethics and socio-cultural studies. The aim of the approach I propose is to open up future cultural studies for an 'ethical turn,' but not in the naïve sense of ethics, which conflates it with a pre-fixed set of norms and values (whether western or non-western morality does not matter here). As I will illustrate later on, the ethical perspective that can propel cultural studies further requires a reflective, participatory, and theoretically informed take.

Given the various meanings that 'culture' has gained within the broad field of cultural studies, it seems almost impossible to provide one simple working definition of the term.[2] In the following, therefore, I will use various concepts of 'body' as analytical lenses to illustrate how culture and normativity can be fruitfully brought together at the intersection of medicine and bioethics. My restriction on this particular intersection has its historical and pragmatic reasons: science and medicine have reconstructed the (late-) modern worldview with regard to

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2 This is an almost unavoidable problem that various ethicists and political philosophers struggle with when reflecting on 'culture' from a normative point of view, as Seyla Benhabib 2002 illustrates.

ontology and epistemology and almost replaced the former religious hegemony. They have also fundamentally restructured our everyday life (at least in highly-industrialized societies). Even without any explicit reference to high-tech medicine, human life is from its beginning now structured by modern practices of hygiene, birth control, or prenatal care. The body serves as a locus of all interventions, projects, and expectations. Life expectancy, still an average likelihood, is a mutually shaped result of modern medicine and social conditions, including the composition of expectations and life plans regarding education, family planning, working career, or retirement. That said, the massive impact of other factors such as capitalism, communication technologies, or political orders must be recognized as signifiers of late-modern culture. All of these culminate in the field of medicine. No current debate on medical advancements such as embryonic stem cell research, uterus transplantation, or robotics in health care can restrain the economical, communicative, or legal frameworks in which such debates *and* research practices are embedded.

It seems almost impossible to escape modern medicine's influence from the minute 'we' were created in a pre-birth stage. In a similar vein to the question that Frankenstein's monster rhetorically asks its creator, should we be anxious or thankful about medicine as structural creator of our lives? To escape the emotional stalemate of such a question, I propose to address both the ethical *and* cultural dimensions attached to this matter.

For this purpose, I want to suggest the term of 'elective affinity' (*Wahlverwandtschaft*). It is a productive concept for describing the relationship between normative ethics and socio-cultural studies of medicine that I suggest here. I use the term much as it was used by the German sociologist Max Weber, to describe the fact that two social systems or mentalities are related to or gravitate to each other, even though there is no simple causality or natural logic for such a relationship (see also Swedberg 2005, 83).[3] To construe this relationship as elective affinity is an attractive alternative to the idea that morality and culture are bound by natural kinship. Both the naturalization of cultural values as well as the universal justification attached to social norms neglect the structural differences between the study of norms (the 'ought') with the study of social facts (the 'is'). The elective decision to relate normative judgements to a social practice of morality, embedded in cultural practice, allows for a critical distance to the facts as well as to commonly made claims about how people should behave. The affinity, however, stresses the compatibility of understanding and interpreting social norms and

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3 The term *Wahlverwandtschaft* itself stems from early chemistry and was culturally made popular by Johann Wolfgang Goethe's novel *Die Wahlverwandtschaften* 1808.

cultural practice as an expression of moral judgements how things should be. By this, a pragmatic assumption is shining through, meaning that social practice is coined by and therefore expresses moral convictions.

The programmatic shift I suggest by bringing cultural studies and ethical analysis into a productive interplay – intended to allow for an important future turn in cultural studies – intersects on four different dimensions:

First, a mutual critical reflection upon underlying basic assumptions within each area – bioethics as well as cultural studies – is needed. The cultural assumption within applied ethics – here understood as a theoretical reflection on moral practice and everyday norms – often includes limited descriptive conceptions of the self, society, or hegemonic structures. On the other side, the normative premises often buried under the attempt of a 'critical' analysis in cultural studies should be made transparent, visible, and explicit.

Second, on the descriptive-analytical dimension, we need a better, more detailed understanding of the dynamics between biomedicine, lived morality, and socio-cultural factors and how they interact in specific time-space constellations. Here, we are interested on the one side in the processes of negotiations between the somatic, material body defended in biomedicine, and the understanding of the body as locus of cultural inscriptions on the other. Examining this dynamic requires theoretical openness and detailed descriptions of global, local, or glocal developments in the area to enrich our understanding of the complexity.

Third, on a methodological dimension, we should involve lay and patients' moral perspectives beyond the scholars' view. By this, we may appreciate the complexity of the sensing body as promoted by phenomenological or some feminist approaches. Until now, bioethical expertise as well as cultural scholarliness methodologically prioritize the scholar's view on problems, outcomes, and norms. While this, as such is legitimate, it limits our epistemology as well as the range of justifiable claims for generalization. Methodological experimentation and diverse models of inclusiveness need to be addressed as important innovations for the future studies.

Fourth, on a normative dimension, we need to consider integrated approaches to addressing commonalities and parallels in the ethical and cultural space. I suggest the concept of responsibility to increase our analytical sensibility for the political, social body. The 'social body' refers to the power relations defining and ascribing vulnerability, personhood, or injustice related to medical practices. The language and concepts of bioethics need to bring in such concepts for practical and social reasons to overcome the still-unquestioned paradigms of individualism and (neo)liberalism prevailing in bioethics. This opening up of a political-ethical space allows us to rejoin attempts from both sides, from the cultural and the ethical perspectives.

In the following, I will enfold each of these four dimensions. Hereby, I understand each dimension in itself as a field worthy of future research, while the combination of more than one dimension is also welcomed. My programmatic approach takes its self-reflective starting point from bioethics. Regarding the potential of future cultural studies, I do not promote a concrete way to ethicize cultural studies, but I suggest to use the approach I propose here as an analytical lens for disciplinary self-reflection and inspiration. This implies rethinking the underlying assumptions regarding political impacts, the conceptualization of the body, the tendency toward expertocracy and scholarly elitism, as well as issues of responsibility (as scholar, citizen, or society) within cultural studies.

1 Culture and Bioethics: Where to Start

Bioethics is a wide field. On one end of its spectrum, it covers political activities undertaken to implement expert advice (e.g. in form of council or committee). In this context, 'ethics' or 'bioethics' does not mean one clear-cut scholarly way of moral philosophical reasoning; instead, it extends to a broad range of social roles and practical functions. Experts involved are rarely philosophers or ethicists, but can be any kind of academics or legal scholars. Ethicization herein aims at setting up so-called 'soft-law,' often bypassing democratic structures such as parliament or civil society. It presents a governance solution to regulate new social and technological trends (Nowotny, Scott, and Gibbons 2001; Jasanoff 2003). This part of bioethical practice suffers from an underdevelopment of political-ethical theorization as well as from a lack of deliberative and participatory methodologies (Schicktanz, Schweda, and Wynne 2012).

On the other end of its spectrum, bioethics describes a purely scholar activity, based on analytical or sometimes hermeneutic approaches, for developing theories, arguments, or concepts to address ethical problems related to medical practice or life sciences research. As Stephen Toulmin (1982) once put it, this 'applied' context has saved the life of ethics within twentieth-century philosophy. Before then, the area was generally preoccupied with theoretical debates over meta-ethics and formalistic analytical approaches; and moral philosophy fell victim to this priority. The approach of bioethics as academic endeavor can be characterized by a strong analytical methodology (i.e., considering the moral status of an embryonic stem cell in comparison to a living animal, etc.) or by a narrow focus on very practical questions (i.e., solving clinical ethical conflicts).

A third alternative aims at a cultural and empirically informed bioethics. Apart from all of the challenges and limitations inherent to such an interdisciplinary

enterprise, its real advantages and strengths lie in the integration of intersubjective approaches into a wider context of political-ethical considerations. While conventional bioethics has a strong focus on doctor-patient relationships and on ethical conflicts arising for patients or citizens facing modern science, the cultural and political context (e.g., consumerism and capitalism, Western values and medical ethos, expertocracy and health illiteracy, etc.) in which such a relationship is already embedded is otherwise neglected or disregarded.

Re-contextualizing bioethics as an intellectual activity that acknowledges the political needs and requirements for the public as well as for the academic means to bring back the political-ethical argument. But why was academic bioethics stripped of political-ethical considerations?

This can be explained by at least three factors. First, as a close political-institutional perspective reveals, medicine and life sciences operate mainly outside of parliamentary political structures in many western democracies. While other areas of social life such as trade, work, or education have been highly politicized and heavily regulated since their beginnings, medicine and health care often operate in a rather loose web of political structures. The number of state laws regulating medicine and life science research is rather specific (and are often only a result of public ethical controversies, i.e., as it was the case for embryonic stem cell research, abortion, or organ transplantation). In most western democracies, it is an expertocracy that self-regulates the dos and don'ts by soft-law.[4] Differences between countries exist and it is therefore crucial to study and reflect on the medico-legal culture when examining any particular medical practice and its ethical framework.

A second perspective, in line with a more Foucauldian understanding of 'biopolitics,' acknowledges that there are strong state or institutional interests directly implemented in modern medicine and health care (Lemke 2006). However, they remain implicit and are hidden in the rational language of needs, diagnoses, or treatments. They are already internalized by modern citizens or patients looking after their healthy lifestyles, reproductive behaviors, or end-of-life planning. Such a biopolitical perspective in governance risks eliminating the individual's perspective. The political is all and everywhere, and therefore the productive, analytical tension of the political vs. the non-political is suspended (Bishop and Jotterand 2006). This supra-political perspective might be relevant to understand hegemonic grammar and hegemonic position but it underrates and

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4 This argument is supported by the immense impact not only of national academies of science and medicine but also of international organizations such as the World Medical Association or the World Health Organization etc. on the health policy regulation.

oversees practices of resistance or renitence by affected persons (Fraser 1989). Another worry about the domination of biopolitical power as discursive power is that it hides biosociality, unutterable sensation, or embodiment as human factors (Hazan 2015, 27).

A third explanation acknowledges that dominant bioethical approaches such as utilitarian, deontological, or principle-oriented approaches are always embedded in political-ethical assumptions of modern liberalism. However, this political framing became almost invisible because of its presumption of priority given to individualism, to the moral principle of individual choice, and to respect for individual autonomy. This 'naked' version of liberal bioethics suffers from the fact that political assumptions about liberalism entail much more than just this triumvirate. Political-ethical assumptions of liberalism should always include in-depth analyses of the relationship between state, expert, and the citizen; questions of tolerance and its limits; the meaning of collectivity for self-understanding and understanding other's citizens interest; and so on. All these questions surface from time to time in conventional bioethics, but are yet insufficiently addressed. The alternative would be to enlarge the bioethical analysis from the bedside beyond the doors of the hospital: to explore how inter-individual decisions, expectations, and negotiations of lays and professionals are embedded in a broader context of state-market-citizen relationships. Of course, such a zoom is methodologically challenging and limited. However, focusing, for example, on central actors or new political institutions such as patient organizations and patient collectives, allows for such an expanded perspective, which brings together the socio-cultural practices of such collectives (Brown et al. 2004), their political-ethical claims and legitimacy, as well as their impact on bioethical controversies (Beier et al. 2016; Raz, Jordan, and Schicktanz 2014; Schicktanz 2015). Such a normative perspective would complement the cultural study of the collective body – in its explicit as well as more implicit versions – reflecting on the gendered, the disabled, and the colored body, as those bodies are always collectivized.

2 The Body as Local Inscription or as Global Soma: The Dynamics of Medicine, Morality, and Culture

Cultural studies and STS (science and technology studies) have revealed many astonishing facts regarding the dynamics of medicine, cultural practice, and norms. On the one hand, there are areas that can be characterized by strong local

differences or even local resistance against global standards. One example here is the non-acceptance of postmortem organ donation and brain death in Japan and in many other countries of the Asian or Arabic world, while the western world seems to see this as self-evident and taken for granted (Lock 2002; for limits within the western world, see Schicktanz and Wöhlke 2017). On the other hand, there are cases of strong global uniformity and global conformance in medicine, based on assumptions of the body as purely materialistic soma, detached from any interpretation or value (see also Joralemon and Cox 2003).

An example for the global spread of new body technologies is the genetic selection of in-vitro fertilized eggs before they are implanted into a woman's uterus, called as pre-implantation diagnosis (PGD). It is now a commonly accepted practice in most regions of the world across the western/eastern division, if such expensive reproductive medical technologies are affordable. Given the extreme concerns expressed in the early 2000s when PGD was established, its triumphal procession since then is quite impressive and a result of an international active community of scientists and ethicists defending the idea that the fertilized eggs are not yet morally relevant as the 'adult' human body and its attached personhood.

However, there are also more complex examples, of how modern medicine is both globally spreading *and* locally adapted to fit into the respective cultural context. This process can be understood as 'glocalization.' Here, the concept of glocalization is understood to analyze the process of negotiation, refraction, and mimicry between globalization and localization (see Bauman, 1998; Roudometof 2016, 1–42). In contrast to globalization – here understood as the modern version of a market-driven soft-colonialism – glocalization as a conceptual approach sensitizes for a detailed analysis of how the global and the local are negotiated case by case in medical and health care practice. The local-global relationship of various medical practices might differ with regard to their legal-ethical frameworks (for example in the case of organ donation and its different regulations worldwide: Shepherd, O'Carroll, and Ferguson 2014; Lopp 2013; Randhawa and Schicktanz 2013). Economical aspects, regarding when and how much a new medical technology is covered by public health insurance, are also an obvious striving force for global spread. While some public health systems cover all costs for in-vitro fertilization for every woman, others cover a limited number of treatments only for heterosexual couples (Brigham, Cadier, and Chevreul 2013). Even the scientific practices might also differ, for example, in which gynecological examinations are conducted in the US, France, or Germany, as once observed by Lynn Payer (1989). More often it remains globally robust, because common medical diagnoses or treatments are now conducted along international standards to satisfy the quality criteria of the 'gold standard' of the World Medical Association.

   To provide a more detailed picture of what I mean by 'glocalization,' I will expand upon the current practice of *surrogacy* as an illustrative example of the way that medical practice, culture, and morality are mutually negotiated. Surrogacy is an artificial reproductive treatment where a so-called surrogate, the gestational mother, is implanted with a genetically often non-related embryo, then, after birth, hands the baby over to the so-called social parents. The surrogate and the intended parents are bound via a contract, and the intended parents normally adopt the child after birth or are legally acknowledged because the embryo is genetically related to them.[5]

   The idea to implant a fertilized egg into a womb of a woman not genetically related became technically possible after the introduction of in vitro fertilization, from the end of the 1970s on. Two decades later this practice has spread worldwide (see Mitra, Schicktanz, and Patel 2018, 3–6). While some South Asian regions are often portrayed in the media as hot spots for surrogacy markets, surrogacy is also now practiced in all other continents of the world. However, the concrete practice varies extremely with regard to the selection process of surrogates as well as access for potential parents. The surrogate can include a close relative acting out of 'altruistic' reasons, or an almost unknown person selected from an internet databank. Defense of a commercialized practice of surrogacy sees the surrogate as a 'womb to rent,' and the delivery of a baby as bio-labor, which needs to be reimbursed in 'fair' prices. Alternately, the proponents of 'altruistic' practice assume an emotional bond between surrogate and baby via physical unity, and therefore want to avoid any commercialization or allow bonds between the child and the surrogate. The legal justifications for eligible intended parent(s) differ strongly, too: in India, currently, only heterosexual couples are allowed for medical reasons, while in Israel religious reasons determine who can be a surrogate in relation to the intended parents (e.g., only a Jewish surrogate for Jewish-intended parents). In California, homosexual couples or single (male or female) parents can approach a surrogate as intended parents. This is for conservative reasons in many countries not possible because their sexuality is seen as 'unnatural' or 'immoral.' Moreover, the scientific practice differs among countries according to the selection procedure of fertilized eggs or the absolute number of embryos to be implanted into the surrogate's uterus. In most European countries, one, two, or a maximum of three embryos are permitted for implantation, while in the US or India more are possible, despite the significant increase of medical risks associated with multiple

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5 In some cases, sperm or egg or both stem from the social parents, but there are also cases where both, eggs or sperms, are donated by another third party.

pregnancies for the surrogate and for the fetuses. In India, selective abortion is practiced to reduce again the number of fetuses if the intended parents want this (see Mitra and Schicktanz 2016).

These variations are inevitably linked to different ethical and social debates regarding the problem of exploitive market conditions for surrogates in low- and middle-income countries (such as India or Thailand), the right of reproductive freedom for intended parents or surrogates, the question of agency of surrogates under unequal social conditions, and the right of intended parents to select or to not come for the baby. The social concerns might be even more general regarding the impact of such a medical practice on the mundane understanding of kinship and motherhood, gender, or ethnicity – always attached to the body.

While an international overview of the debate offers a broad or even balanced picture of the 'pros' and 'cons,' the question needs to be posed whether national, local discourses are also so broad. They seem rather be dominated by few or selective arguments. Such a cultural taming of the ethical debate must be understood as a result of negotiating between the local and global context in which such debates are evolving and – at least for a particular moment in time – are fixable as culturally 'significant.' From a distant, comparative view there gleam some peculiarities: for instance, Indian sociologists have pointed out, despite critiques of the large economic and caste disparities, that it would be important to see the agency and opportunities for self-determination for surrogates, even in situations of commercial surrogacy (Tanderup et al. 2015). In Germany, the agency of surrogates is rarely considered as leading point but ethicists have emphasized rather the 'best interest of the child' as a criterion of legitimization. Whether this argument results in a permission or moral veto is dependent on how the 'best interest of the child' is then concretely interpreted (see also Wiesemann 2016, 133; Beier and Wiesemann 2013). In the US, various scholars have focused on the social risks of commercialization as it might increase social disparities between races or classes and could lead to the exploitation of poor women or to a racist practice of dismissing non-white women as surrogates or egg donors (Thompson 2005, 66). Again, such points to consider are yet rarely addressed in the German context, although might perhaps in the same way be relevant once the practice is implemented.

While none of these points is made exclusively in any of these three different national discourses, it is striking how some main lines of argument prevail in each context. We need more detailed studies to understand how the bioethical discourse depends on the culture in which it is embedded. Such a descriptive-analytical reflection, however, does not solve the quest for a more rational or universal understanding of moral norms – a project still worth to be defended as an ideal orientation, not as a simple solution.

But indeed, such cultural framing of differences in the discourse[6] has led to some misunderstanding within normative ethics: This misunderstanding assumes that the socio-cultural study of differences in bioethical positions results in "normative relativism" (Schicktanz 2018, 117–119). Normative relativism means that we are not allowed to question each other about the local forms of norm validation and norm hierarchy, because all moral considerations are only locally valid. In a more pervasive form of neoliberal argumentation, such relativism is even used to justify any permissive stance towards new technologies: because nation A, B, or C (e.g. the US, India, or the UK) is doing X (e.g. surrogacy), it would be also acceptable in D (e.g. Germany) to do X. The underlying premise is then that there exists no universally valid argument to forbid it.

However, the here-defended idea of 'post-conventional' bioethics' interest in cultural and social studies of medical practice means nothing more or less than contextualizing the leading moral justification by taking into account the 'real perceived' social conditions in which the respective agents (e.g., patients, doctors, citizens) live, as well as the interpretation given to these living conditions. 'Post' because conventional bioethics neglects any cultural embedding or social factors such as gender, ethnicity, class, etc. to influence bioethical positions. Such a distinction between conventional and post-conventional bioethics might provoke objections, because the generalization does injustice to individual scholars who are already open to interdisciplinary exchanges with sociology and cultural studies. However, it is used here to mark a more general shift in the field without discrediting any of those former approaches. Furthermore, it is important not to conflate post-conventional bioethics with postmodern approaches, as the analytical focus on non-relativistic normative traditions is still viable. In a same vein, it would be productive to reflect on normativity within cultural studies by leaving the conventional paths of anti-normativity or radical constructivism. In such a sense, future cultural studies could try to embed their analysis in the lived experiences of moral reflections – not just considering moral standards and values as taken for granted, but to put more emphasis on the human practices of doubts, concerns, sensing dilemmas, seeking deliberation, and how this is culturally mediated.

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6 This might be explained by national law and local regulation, though the law also depends on cultural accounts of what is seen as ethical acceptable or not, see Hansen 2012. According to most philosophers the proper way should be that law follows ethics and not the other way around. However, in political practice, legal regulation is sometimes quicker implemented than a thorough ethical deliberation takes place. Therefore, it is important, from a cultural point of view, to assume a rather complex interplay between law and ethics.

The production of hopes, expectations, or fears is accessible through the study of cultural media by understanding the body as text or as narrative (see Dekkers 1998; Frank 1995; Squier 2004, 20–21). Visual and performative art as well as literature are media that allow access to the emotional dimensions in form of a bodily narrative. Examples for this can be found in the work of the French artist Orlan. She examined in her own body art the relationship of pain, medical surgery, beauty, gender stereotypes, and norms. A very different example is Philip Roth's novel *Everyman* (2006), where he examines aging, dying, and end-of-life-planning, and how they impact the relationship of body, personhood, and narration. Both Orlan and Roth share the attempt to display pain and fear of death by pointing to scars, fragility, dependency, and by narrating a lived body in its particular social, moral, and cultural embedding. And both provide a narration of moral doubts and concerns: where are the advantages of modern medicine, where are limits?

However, it is also necessary to contextualize the moral claims made in a historical course of the discourse. The search for reasons for differences or similarities in arguments and norms – and by this, the transgression of geopolitical boundaries – serves as part of a rationalization of each claim made. This is a main condition for the 'elective affinity' of applied ethics and cultural studies and can be seen as productive future for both disciplines.

The challenge of such an approach is not to lead to 'factual fallacy.' Such a factual fallacy would mean jumping directly from empirical or descriptive findings of how people actually think or how practice currently works to the normative conclusion about how it *should* be. Such a normative positivism must be avoided. Instead, we need a critical assessment of how any moral claim or argument brought forward is culturally embedded in a hegemonic presentation. A transparent strategy for a comprehensible, proper making of a *practical-moral judgment* refers to an uncontroversial understanding of practical-moral judgment as *mixed* judgment. The mix consists of a prescriptive (normative) *and* descriptive (empirical, factual) statement combined, but avoids any crypto normativity.

Let us consider for a moment the above-mentioned example of surrogacy. Consider that somebody states in a public debate that surrogacy should be allowed in Germany, because it allows women a good income and women want this. This claim is a conclusion as practical-moral judgment and built on normative premises (A) *and* on descriptive premises (B). The normative premises can be summarized as the following: A1) Surrogacy is as such morally not wrong and A2) all women should have the right to a good income. Descriptive assumptions that underlie such a conclusion are: B1) Good income is the main interest for women, which presents an empirical question as to whether this is true and women would not value other opportunities to gain more money elsewhere; and B2) It is culturally

uncontroversial what defines 'good income'; or B3) Women have no other chance to get a good income than by surrogacy. What we see by this is that even if we would agree all on A1) or A2), the moral conclusion depends in a paretic version from the descriptive part. This descriptive part requires therefore socially robust knowledge (Nowotny, Scott, and Gibbons 2001, 116–119) about social practice, effects, opinions, etc. Hence, practical-moral judgments do not only depend on common, shared reflections about what is ethically right or wrong, but in a similar way on shared robust interpretations of the world.

3 The Sensing Body as Situated and Affected: Enlarging the Experts' View

Conventional bioethics has a one-sided tendency for the expert discourses. Such a tendency has its historical roots in the analytical tradition of ethics as well as in the close orientation towards the legal discourse. While the analytical approach is not necessarily expertocratic, its formalistic methods and abstract language often hinders non-experts in participation. The legal discourse definitively has an expertocratic manner, given the fact that public education never ever touches upon it and we mainly leave it to specialists, apart from some areas where lay judges are involved. For post-conventional bioethics, the critical assessment of expertocracy is a central element (Schicktanz, Schweda, and Wynne 2012). Cultural insights similarly foster skepticism towards the idea that those not directly affected by or outside of the messiness of everyday life struggles (such as physicians, academic ethicists, or lawyers) can anticipate hypothetically and properly such a complexity in its ambivalence.

Whether this intellectual representation works for the perspectives of persons who are socially marginalized or excluded must be problematized, though, for these persons, as social and political inequality hampers their opportunity to be represented in exclusive circles of academia or other elite groups. Marginalization is here mainly based upon involuntarily, non-mutual membership such as belonging to a particular gender, ethnicity, or nationality. Such a group membership was not voluntarily chosen by these persons, but assigned to them from outside. Marginalization only takes place if a particular group identity is seen as 'negative' (Williams 1998, 15–18). As Melissa Williams has convincingly shown, typical examples of such marginalization have concerned women, people of color, or people with disabilities, depending on particular historical or political-cultural conditions. In relation to such a social exclusion from many intellectual resources or access to socio-political decision making, there is a serious risk that social

stereotypes related to such a negative group assignment hinder those in power to decide to trust testimonials of those from marginalized groups. By this, many public and legal discourses suffer from "epistemic injustice" (Fricker 2007) due to unbalanced power relations in the presentation of knowledge. Counter-measurements include awareness increasing participation or representation by members of one's own group. These very general considerations are particular relevant in the field of medicine (Schicktanz 2015). This is because persons with chronic illness or with a disability have very specific perspectives and insights in the challenges of pain/bodily experiences or social and spatial exclusion when it comes to bioethical issues related to their condition. Being marginalized and affected (meaning that decisions will have a causal effect on them, see Schicktanz, Schweda, and Franzen 2008; Schicktanz 2015 for a detailed definition of 'affected persons') justifies a significant ethical priority of such voices. The embodied or affected experiences as well as the illness identity are legitimate and valuable sources for a privileged understanding of the everyday complexity relevant to the bioethical issue at stake. People in the fourth age, with dementia, or with autism, are too quickly excluded because of the non-translational content of their experiences (Hazan 2015, 47).

Experts, in contrast, cannot phenomenologically rely on such experiences. Of course, they can indirectly reconstruct such experiences by referring to social, cultural, or psychological studies. But finding the right language, the right translation, to transform these special experiences into a social, publicly shared space is not trivial. Hence, the direct involvement of affected persons – in one way or another – is a necessary element for any future bioethics. Because limited resources and basic needs of persons affected might restrict their interest or factual opportunity to take actively part in such discourses and debates, new, joint methods in the cultural and socio-empirical studies can bridge the need for such a reconstruction. Here I see a particular area for future cultural studies to explore various means and methods to bring the affects, interests, vulnerabilities, and needs of those excluded into the broader discourse. In terms of exploration, more anthropological or ethnographic studies of people in the fourth age (Hazan 2015, 46–47, 71) or with dementia are needed to challenge stereotypical and often discriminating views of them as "almost dead" or "cognitive zombies," to enlighten their untypical, but yet human nature. Experimental designs are required to explore the social and ethical issues of biotechnical innovations and their impact on our understanding of humanity. Following the course of cloning novels served Solveig Hansen in her dissertation (2016) as an orientation to examine the historical practice of social othering. By her joint cultural and ethical analysis of how clones have been anticipated and depicted in cultural discourse, she provides a thorough and complex picture of how our moral relationships are

built upon assumptions of sameness in quality (and not in quantity as the clones imply) but also independence and self-reliance as a basis for mutual respect. The limited socio-empirical perspective access to these future scenarios can be productively complemented with such cultural studies of novels and anticipations.

However, this does not mean to incorporate any view of an affected person in an uncritical way. All perspectives shall be reflected with regard to their moral and epistemic claims. Assuming that affected persons are neither able nor willing to transcend their own personal interest into the social sphere is, however, problematic. Emotional as well as biased views are similarly common in experts' debates about patients, persons with disability, or others who are particularly affected. Therefore, any particular position or moral perspective needs to be understood as "situated knowledge" (Haraway 1988) or "situated ethics," but this does not hinder the opportunity to enter a mutual discourse for finding the better argument.

Transferring these thoughts to a future of cultural studies means, for example, to radically revisit the divide of high/classical and pop culture. Especially for any work on medicine and literature, pop culture, such as 'trashy' science fiction or medical thrillers, provide deep insights in common moralities and understandings of modern medicine and biotechnology (see, for instance, Pethes 2005).

4 Body and Responsibility: The Certainty of Moral Tensions as Conjunctions of Deliberation

To illustrate my understanding of post-conventional bioethics as a continuous challenge between practice and theory, between descriptive and normative claims, I want to refer to the performance *Zerreißprobe* (tensile test) of the Austrian artist Günter Brus from 1970. As a performance artist he shocked the public by making his body to the subject of artistic performances. He injured himself by cutting his head and thigh with a razor blade and arranging his vulnerable, naked body half stretched and half hanging within a web of strings crossing a room. Hereby, the vulnerability of the flesh was shown by means of the extreme display of a body disfigured by pain and by interventions from the outside. By being thus displayed, the body itself becomes both the medium of the artistic work, and the scene in which it takes place. It is this mutual meaning and interaction that symbolizes the performance of bioethics by focusing on particular events or single bodies but being aware of the embedding of such entities in a broader context. In a second line of thought, the work of Brus also marks in an abstract sense the particular meaning the 'body' has as intersectional space between bioethics and

cultural studies (see Barkhaus and Fleig 2002, 9–23, 27–36). Although the cultural irritations such artistic presentations of the body produce on their own is not the point here, I assume that almost every viewer of such a performance feels moved, touched, or disturbed. This common sense of vulnerability of the human as body *and* as person is a certainty that provokes the claims of relativism and arbitrariness – Brus's tensile test serves here as a litmus test for the tensions built into modern medicine and biotechnology where they produce, via their innovations, such anticipations of bodily vulnerability and personhood.

So it is precisely the field of body modification and related bioethics where we observe a clash of perspectives in two ways, but which can also serve us as a productive intersection for an elective affinity.

In the first place, there is a serious distinction in the normative ways of ethically judging how we assess the right of self-determination towards our bodies; secondly, there are solid variations in how the body and embodiment are theoretically addressed. I have suggested earlier a methodological approach of making the tension between different meanings of body and autonomy explicit by setting out a dialectical method for heuristic use to be made of the recent dichotomies in bioethics (Schicktanz 2007). By this we cannot easily resolve moral dilemmas, but we can proceed in a dialogical way for addressing theoretically the various descriptive and normative claims. At least, we will overcome simplistic pro- and contra- debates and we are opening up instead of closing down debates for various theoretical relationships between autonomy (and other relevant normative concepts) and body/embodiment. This provides a central interface for the ethical reflection about who can decide what, when, and how about one's own body. What elements of a person can be regarded as available or unavailable at which points in time during the process of this person's life or dying? Whether the 'body boom' in ethics is something avoidable can be questioned (see also Shildrick and Mykitiuk 2005). Even supporters of the liberal conception of self-determination, who primarily recognize the principle of non-maleficence (the general rule not to harm) as morally equivalent, need to clarify the idea of socio-cultural dimensions of embodiment and the framework for the meaning of bodily unavailability within social interaction. Who or what is the other entity that must not suffer damage, and what constitutes damage (Schicktanz 2007)?

Having said this, I need to propel my own focus on the relationship of the normative principle of 'autonomy' on one hand, and the conceptualization of the body/embodiment a bit further. The political-ethical sphere of social interaction requires a constant concern for more than individual autonomy. The most important concepts are then justice and responsibility. Starting from cultural observations and political practice, the bioethical enterprise is not only to set out ideal theories of justice or responsibility but to address witnessed forms of injustice and

irresponsibility. For sure, our sense for such immoralities is neither independent nor free of theoretical presumptions of what justice or responsibilities are. The *ex negativo* start is often more robust regarding our intuitions and knowledge, but it does not free us from a reflective approach to clarify such presumptions.

Considering an opening-up of cultural studies for ethical thinking might be facilitated by art or performative acts that confront us with the limits of textual analysis, rising issues of affects. However, it would be a great self-restriction to limit the ethical perspective to the sphere of aesthetics. Critical sociology and cultural studies studying the presentation or performances of the liminal, excluded, or resistant human existences share a long-standing tradition with concerns about injustice along class, gender, ethnicity, national belonging, or injustice regarding the exclusion of disabled or sick persons. Their arsenal to address injustice is manifold, be it a dense description of exclusion mechanisms or a quantitative summary of the suffering of discriminated parties. They can bring often-unheard voices into the discourse and highlight the agency of parties often neglected or denied: women, children, the ill, or others often overseen (de Beauvoir 2000). This sociological practice, according to Wayne Brekhus (1998), devotes greater epistemological attention to "politically salient" and "ontologically uncommon" features of social life. Addressing women, the elderly, homosexuals, etc., means "marking" those excluded entities, but this practice unreflects or even repeats the hegemonic grammar and leaves the "unmarked" (whites, heterosexuals, men, etc.) unrevoked. Brekhus' critique of the epistemic practice of identity labels and problematic singling-out is important and highly relevant to overcoming simplistic, unreflective assumptions of the good and bad guys. We need to acknowledge that this epistemic practice within sociology is already embedded in a normative theory of justice and fair treatment of which ethics can help to unmask them in future co-operations.

I have suggested somewhere else (Schicktanz and Schweda 2012) that the concept of 'responsibility' is particularly helpful in linking everyday languages of morality and ethical-normative reflection. Providing a theoretical formula for what the concept of responsibility entails offers a way to explicate moral claims of self-responsibility, social or professional responsibility, or family responsibility ubiquitous in medical practice, health policy, or health communication. While of course only working in limitations, the concept of responsibility is not just a moral idea among others, but as a meta-ethical concept, it provides a meaning of how ethical properties are formulated, logically expressed, and epistemically assessed. Therefore, using terms of responsibility means that we are explaining normative claims embedded in social presumptions about relationships. This helps to translate ordinary folk language into a more abstract form to proof for consistency or to detect contradictions.

This need for translation – from the everyday moral grammar to the theoretical-analytical level and back – is an endeavor that goes beyond the conventional understanding of 'education.' It requires theoretical sensitivity for what constitutes a responsible social relationship: It is always embedded in space and time and the relationship is enriched by cultural assumptions (i.e., in the case of the earlier mentioned surrogacy: what constitutes good parenthood; who counts as morally relevant actor: only the intended parents, or also the mother, the doctors, the government, etc.)?

Responsibility, however, in current sociology – especially medical sociology – has been narrowed down to a critical notion of moral imperatives, synonymous with the social practice of blaming and shaming (Rose 2006, 4; Arribas-Ayllon, Featherstone, and Atkinson 2011), and applied to criticize biopolitical strategies. As such, the sociological notion of 'responsibilization' emphasizes a very special application of the term 'responsibility' focusing on the individual or the family as both the moral agent and the moral object in biopolitics. As an alternative, the productive junction with ethical theory alludes that this application has a strong tendency to reduce the understanding and practical usage of responsibility and that there are better, more refined ways to address responsibility in its many dimensions by using a detailed, transparent description of normative complexity (Schicktanz 2016).

5 Summing Up: An Elective Affinity between Bioethics and Socio-Cultural Studies of Medicine and Life Sciences

I have suggested in the beginning the concept of 'elective affinity' to bring forward a new relationship between bioethics and cultural studies – and would mean somehow a double turn-over: a cultural turn for bioethics and an ethical turn for cultural studies. Whether cultural studies have already adopted such an ethical gaze, I am not sure. However, a current trend to differentiate 'critical' cultural studies can be read as tendency to explicitly address issues of marginalization, discrimination, and exclusion. Being informed by various strands of critical theory might, however, not be the only future direction for cultural studies. Other approaches stemming from applied bioethics to address various ethical and social concerns can be innovative and helpful, as suggested here.

Normative studies and moral languages provide access to moral practice and help to signify the consistency as well as inconsistency in moral practice and

ethical thinking. There exists no absolute demarcation between moral practice in everyday life and theoretical ethical reflection, rather it is a continuum with smooth transitions. The theoretical concept of "reflective equilibrium" serves as dialectical model of normative judgment between theory and practice to describe and reflect on this continuum as philosophical method (Daniels 1996).

It is, however, seen as a legacy of Max Weber's idea of value-free sociology and economical sciences that until today lead to an unrealistic or even wrong ideal of value-free sociology or cultural studies. As the dispute over 'value-free' (*Wertfreiheit*) vs. 'value judgment-free' (*Werturteilsfreiheit*) revealed already almost a half century ago (Albert and Topitsch 1971), it is not only a strange mythos of modern social and cultural studies to be value-free, as the study of values as well as the explication of values is part of any scientific activity – in social and cultural sciences, as well as life science areas such as medicine or agriculture aiming for 'saving life,' 'curing disease,' or providing 'better living conditions' or 'sustainability.' However, such scholars should be explicit and transparent when making value judgments instead of allowing crypto-normativity in scientific terms or scholarly language. Terms and concepts such as 'critique,' 'power,' 'social inequality,' 'vulnerability,' and 'colonialism' always reflect a pejorative, moral meaning that we cannot escape as either speaker nor listener (Fraser 1989, 17–20). However, not any value judgment can claim to count as well-considered judgment. Applied ethics and moral philosophy provide the methodological arsenal to win this battle over crypto-normativity and hidden values in scholarly work.

A flourishing, productive elective affinity between bioethics and cultural studies requires a crucial clarification about all own normative premises on the why, the how, and the what of ongoing research. The 'why'-question focuses on the motivations and programmatic reasons behind a study and for singling out a problem to being relevant for in-depth examination. The 'how'-question follows the lines of a chosen methodology and asks how far normative premises are already embedded in the research program (Merton and Storer 1973, 229–250). For example, does the selection of qualitative vs. quantitative methods only refer to epistemic assumptions of generalization or depth, or might it also include who should be in the focus of examination (the lay public, the experts, the media, etc.). The 'what'-question critically reflects which underlying assumptions of injustice, responsibility, or vulnerability are already attached to the selection of a particular topic (the topic of terror in Europe, the topic of dementia in India, the topic of education in Africa, etc.). How does the spot on this topic risk shading other topics, and is the priority well-justified?

From a bioethicist's point of view, there are many good arguments as to why and how socio-cultural studies are important or even indispensable for a well-defined and well-argued problem definition (what is the moral problem we

want to solve) as well as the practical recommendations often following bioethical inquiries 'how to solve' the conflict in the future. The concrete function of socio-cultural empirical insights for norm justification is instead very controversial and perhaps for the purpose of the here-proposed collaboration modus not needed.

Cultural studies provide not only, but still importantly, a challenge to monological or one-sided perspectives on bioethics. From a theoretical point of view, the solution to the problem of legitimacy lies not in simple forms of public participation in research and policy making, but in a conceptual analysis of the kind of perspectives needed. I am here assuming that there is no single, ultimate perspective. Only a combination and pluralization of different perspectives can offer us an approximation of the 'whole picture.' This requires a systematic adoption of other perspectives (Schicktanz 2015, 251–252). With this increased complexity, we enhance our understanding of the dependence of morality on affects and social dimensions of power. Thinking with stories, narratives, or images as cultural studies provides the arsenal and methodology that help us to test for consistency, for the wideness of the chosen perspective, or for the peculiarity of it. However, there are new risks such as more hidden morality, exclusivity, and ambiguity awaiting such concerted efforts. It would be worth going still further in this direction in the future.

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