41.

Race and Bioethics

Alexis Shotwell and Ami Harbin

Racial difference has been of central concern in many canonical cases in bioethics. Consider two historical cases: Nazi medical experimentation and the now-infamous Tuskegee Syphilis Study. It was in response to revelations about Nazi experiments on human subjects that the Nuremberg Code was formulated. The Code sets out standards for informed consent, treatment of research subjects, and the necessity of predictable benefit from any given experiment. Nazi experimentation was based on an explicitly racializing notion: that Jews were a separate, and lesser, racial group and therefore appropriate subjects for experimentation. The Tuskegee Study of Untreated Syphilis (or "the Study") was a forty-year (1932-1972) clinical study that observed the progression of (mostly) untreated syphilis in a group of black men living in poverty in the US. These men were told that they were receiving free health care, when in fact they were not given effective treatment for syphilis even after such treatments were medically established. The Study was ended only when journalist Jean Heller broke the story. Responses to Tuskegee included the establishment in the United States of an Office for Human Research Protections, which aims to curtail the kinds of research abuses evident in the Tuskegee Study. In this chapter, we will use the Tuskegee Study as a touchstone for considering how racialization and bioethics matter to one another.

Racialization may be an unfamiliar word – it is less common, certainly, than *race*, or *racism*. We follow sociologists like Michael Omi and Howard Winant in thinking of race as “racial formation,” which they define as “the process by which social, economic and political forces determine the content and importance of racial categories, and by which they are in turn shaped by racial meanings” (Omi & Winant 1994: 61). This means that what we think of as “race” arises out of social relations, instead of coming from some biological reality “underneath” those social meanings. Racial formation is a way to understand the way that physical, social, and material things in the world are classified as racial – things like people’s hair, bodies, ways of speaking, and so on. This sort of conception of race as a dynamic, in-process social effect is also often termed “racialization.”

The Study is a useful starting point for thinking about racialization and bioethics for several reasons. First, reference to the Study has been important in formulating critical conceptions of the importance of informed consent in medical research and clinical treatment; talk of it circulates widely. Second, invocations of the Study within bioethics may well be deficient precisely in their considerations of race, and so extending the considerations of race in bioethics using the example of the Study may be instructive. As Susan Reverby writes in her exhaustive history of Tuskegee:

> Bioethicists kept knowledge of the Study alive in research publications and teaching, but only in narrow ways. … A survey of the key bioethics encyclopedias in their multiple editions and the major edited collections and texts reveals that the Study came in and out of use, primarily named as an example of the lack of informed consent and the ability of researchers to take advantage of the vulnerable. It provided a way to say that race matters and then to never really interrogate in what ways (Reverby 2009: 193).

So, centering the Study can help us interrogate *in what ways* race matters to bioethics. In particular, the Study opens more adequate ways to understand the racial content of our bioethical judgments than can be encompassed by talk of consent in situations of inequality.

Yet taking the Syphilis Study as a touchstone for a discussion of bioethics and racialization may also problematically limit understanding. Much of the time, discussions of race focus primarily or exclusively on the United States, and within that context, narrowing to a near-complete focus on Black/white racial inequalities. For example, the promisingly-titled but ultimately limited article "Why Bioethics Cannot Figure Out What to Do with Race" concludes that the main problem with the discipline of bioethics' failure to adequately treat race is a failure to decide whether to include the (US) Black Church in bioethical debates (Burton 2007: 10). While the specific historical context of the US is very important for understanding the relation of race and bioethics, it would be a serious mistake to accept that the only forms of racialization relevant to bioethics arise from the US Black/white context. Our hope is that in taking the Tuskegee Study as a key example the discussion below provides multi-use conceptual tools for thinking about racialization in many contexts even while it skirts these dangers.

In looking at these early cases, we can see that some of the legal and cultural norms that established the professional and academic field of bioethics are entangled with race. And though it is not obvious that race is at work in every bioethical question we face, we will argue that race is intimately bound up in even the most everyday bioethical judgments.

Race and racisms

Although this chapter focuses on the question of how race matters to bioethics, from the start we need to nuance central concepts – “race” and “racism.” As described above, a commonsense way to think about race is as biological differences between people – and, indeed, historically this has been one way of understanding what race is. In this chapter, we reject the idea that there are bright lines of biological difference between groups that could delineate one race from another. When we say that we hold a racial formation or racialization view of race we don’t mean that there’s no such thing as race, or that race has no effects. We mean, though, that bioethicists should understand the effects and material realities of race as not biologically determined. Indeed, we agree with writers like Anne Fausto-Sterling, who argue that biology itself takes shape through and with social formations (see Anne Fausto-Sterling 2005; 2008).

For its part, racism is often understood as the direct, explicit expression of interpersonal ill-will, which can take the form of explicitly discriminatory policies or hateful speech (Garcia 2004). It is also seen as ignorance, whether actively shaped or passively absorbed (Mills 1998; 2007; Outlaw 2007; Sullivan and Tuana 2007; Types 2007). Of course, even people with the best intentions can be racist. There are other sorts of racism, which are not formulated in words. There is another sense altogether in which we might understand racism as not thoroughly described by explicit expressions of personal ill will or prejudice. Structural or systemic racism may never take the form of racist expression; indeed, perhaps more racial wrongdoing is effected by seemingly bloodless bureaucracy than self-proclaimed or subtle individual racist people (Arendt 2006).

Interlocking systems of oppression

Whenever discussing the process of racial formation, we do best to also remember that other markers of social identity change the experience and meaning of the social dynamic we call “race.” Individuals’ experiences of gender, sexuality, class, disability, religious orientation, and more will shape their experience of race – and, indeed, attending to any of those axes of oppression and liberation requires concurrently attending to race. This mode of taking complex social relations into account in our theorizing and understanding is known as having an “interlocking oppressions” or “intersectional” analysis (see Collins 1998; Crenshaw 1991; Razack 1998). Because different forms of oppression and privilege are bound up with each other, we cannot think effectively about only one bit of the whole picture as though it is disconnected from others. In this chapter, we will for the most part use the phrase “interlocking oppressions” to name the relational co-production of social relations of inequality. This is a departure from some of the ways such analysis has been codified and made part of a feminist intellectual canon (see Carastathis 2008).

There are (at least) three levels on which we can see the importance of taking racialization into account in bioethics: Individual, group/collective, and systemic. At each level, many different social relations come together to shape the particular experience or problem under consideration. In thinking about racialization and bioethics it is particularly useful to note the ways someone may be harmed or oppressed in some ways while being benefitted or privileged in others. For example, someone may be harmed – or even oppressed – because of their gender, while receiving social goods because they are not disabled. Thus, people can be simultaneously, unevenly, oppressed and benefitting from oppression.

Individual experiences of racialization

On an individual level, racialization matters to bioethics. Individual physicians and researchers may have responses and make medical decisions based on their and their patients' racial position. After controlling for socioeconomic and access-related discrepancies between individuals belonging to different racialized groups, there remain significant disparities in health care across racial and ethnic lines. The Institute of Medicine (of the US National Academy of Sciences) investigated these disparities and concluded that "racial or ethnic differences in the quality of health care" resulted at least in part from physician bias, stereotyping, or prejudice (Smedley et al 2003; Balsa and McGuire 2003; Brody 2009). Current work on the concept of "implicit bias" indicates that even – and perhaps especially – people who do not believe they are discriminating based on race and other social identities actually do respond differently relative to these social categories (Wear; Jost et al.; Stivers and Majid; Penner et al.). More fundamentally, when discrimination based on race arises in health contexts, whether treatment or research, it always manifests in individual people's actual bodies and experience. So we must think about racialization on what Brody et al call the "micro-level," at the scale of people experiencing illness in part because of how they are racialized (Brody et al 2012: 309). Although the force of racialization may be more obvious as it manifests in the lives of people of color, we could see every experience of health or illness as racialized – people who hold the social position of whiteness will have a different interaction with their doctor than will people of color. And other things being equal, a white patient's interaction will have more dignity and show more respect for patient autonomy (Cooper et al 2012). A white patient's interaction will also likely produce better health outcomes. The U.S. Department of Health and Human Services' (2012) National Healthcare Disparities Report tracks specific disparities in acute preventive care for numerous conditions, by race and other markers. Of course, other things are rarely equal, and white people living in poverty, disabled white people, queer white people, will almost certainly have health outcomes worse than, for example, higher class, non-disabled, straight white people based on their entanglement with the harmful aspects of interlocking systems of privilege and oppression.

In the Tuskegee Study, recall, doctors followed a group of African-American men who had untreated syphilis in order study the progression of the untreated disease. Participants in the Study were told they were signing up to receive free health care, and they were also guaranteed a funeral paid for by the Study. We can see that individual-scale racialization manifested most obviously in the interactions between the doctors running the study and the people participating in it. The Black men enrolled in the Study were told that they were being treated, though not what for, when in fact they were being given merely aspirin and iron supplements. Most damningly for the doctors overseeing the Study from the Public Health Service (PHS), in cases when the men could have received effective treatment, they were not informed of these possibilities. For example, a number of the men enrolled in the Study pursued enlistment in the US armed forces. Unbeknownst to them, the PHS had provided a list of their names to the Army with an explanation of their participation in a valuable medical study (Jonsen 2003: 148; Reverby

2009: 61). The US Army had a policy of treating incoming recruits for syphilis, so when it rejected men from the Study we can see that they were directly denied treatment. Far more of the participants, along with their sexual partners, were indirectly denied proper treatment through relations of omission.

Race shaped the Study in terms of who was enrolled, how they were denied treatment, and how physicians, nurses, and researchers interacted with the participants. On an individual level, particular black men were enrolled in the study not treated for syphilis. The men who participated in the PHS Tuskegee Study were never provided with the opportunity to give anything like informed consent, because they were not told that they had syphilis, or that they were not being treated for a disease they had, or that treatment was available, or a host of other salient facts. This failure to secure informed consent has been the central focus of much of the response in bioethics. The doctors, nurses, and researchers who participated in the Study were ignoring the broadest duty to provide a clear account of what facts were known, possible treatment options, and likely future results of engaging in the Study. In some cases their behavior exhibited disbelief that study participants were capable of understanding their situation (Reverby 2009: 55, 60, 116, 128; Brandt).

How race and racism were involved in these ethical failures is not, however, as simple as it might seem. There were now-obvious problems with the failure to allow for informed consent and with the exploitation of a vulnerable population for research purposes. There has been a temptation to tell the story of the Study as though the racial dynamics were simple: bad, racist white doctors lied to and took advantage of illiterate Black sharecroppers to secure their careers (see Brandt 1978 for an early and important intervention in the racial dynamics of the Study). This story is accurate, but it is not complete. Not only was the Study hosted at the pre-eminent Black research institution in the US South, and not only were there Black medical personnel involved all the way through, but the participants and practitioners were working within the constant background of everyday, unacknowledged racism. If, as we hope to show, health care and health research always functions within the context of racialization, it will not be enough for medical ethics to ask about the intentional actions and omissions of "bad racist" practitioners. Bioethicists must consider the broader questions of ethical action in relation to group identity as well as in relation to systems of inequality.

The implications of racialization for groups

On a group or collective level, medical practice may be informed by racialization in harmful ways. In virtue of their group membership, and perhaps also in ways that define their group membership, racialized people can be picked out for differential treatment. For example, historically, racialization was involved in group-level decision making in the form of eugenicist medical practices. Forced sterilization – and a concomitant valuing and encouragement of white women to have children – interact with racialization in the medical domain not only in terms of the individual-level effects to the women sterilized (Silliman et al. 2004; Smith 2005). Other invasions of women of color's reproductive health include research informed by racialization, as in the case of Dr. J. Marion Sims (1813-1883), an Alabama surgeon who conducted experimental surgeries on black slave women in his development of treatment for vesicovaginal fistula (Axelson 1985; Wall 2006).

In much bioethics training today the way that students and clinicians are taught to engage with group-differentiation uses the language of cultural competency for working with multicultural populations in health situations (Carrese and Sugarman 2006; Paasche-Orlow 2004; Washington 2009; Wear 2003). Although often there is some commitment to think about cultural competency as relevant to queer, disabled, non-majority language-speaking, or elderly patients, the term "culture" frequently supplements and, often, actually stands in for "race." Although it is important for medical practitioners to be competent to treat people who come from various backgrounds, there is a difference between racialization and culture (or ethnicity). This is particularly the case in medical contexts in which researchers and medical practitioners believe that there are biological differences between races (Kahn). An early, and still-important, definition set out cultural competency as "a set of congruent behaviors, attitudes, and policies that come together in a system, agency or amongst professionals and enables that system, agency or those professionals to work effectively in cross-cultural situations" (Cross et al. 1989; cited in Brach 2000: 182). Much racial grouping, even when it is framed as cultural, takes the form of treating people as though racial identity were a biologically determinable reality. Given this, it is striking that much clinical practice focuses on better managing the interpersonal manifestation of racialized group identities through increasing cultural competence in the medical professional. The PHS Syphilis Study should not be seen as primarily a failure of cultural competence.

As a symbol of paradigm racialized wrongdoing, "Tuskegee" grouped Black people in a particular place into a racialized group that was then understood as biologically distinct. A danger is that such clumping solidifies an implicit or explicit belief that there are biological differences between races. This was certainly a dynamic at the outset of the Study – researchers believed that African Americans had different (deficient) brains, and thus that the neurological effects of late-stage syphilis would be different by race (Reverby 2009: 45; see also Crenner 2012). Further, at least some of the individual wrong-doings on the level of consent and exploitation were the result of a perception that it was acceptable to sacrifice the interests of the men involved in the Study to the interests of Black people in the US more generally. At the time of the study, there was a belief that Black people were biologically categorically different than white people, and therefore that it was medically beneficial to others to follow the progression of the disease (Reverby 2009: 159–161). Presumed group identity can, in cases like these, degrade the care individuals receive. The Study serves, in the present, as a short-hand for talking about group-differentiated distrust of medical authority; racialized people in the US, especially Black people, are represented as holding Tuskegee in mind (Brandon et al 2005; Gamble 1997; Freimuth et al 2001; King, W. 2003). Some writers argue that medical practitioners should be knowledgeable about Tuskegee specifically in order to show knowledge of why race matters to medicine (i.e., as part of cultural competence) (Chiu and Katz 2011; Corbie-Smith 1999).

A perhaps surprising example of this slide is marked by the first drug approved by the FDA for race-specific administration in the US, BiDil (two previously-approved generic drugs, hydralazine and isosorbide dinitrate, which when combined are meant to treat heart failure in African Americans). As Johnathan Kahn has argued (see Kahn 2005; 2007), the specification of this drug as effective for, and only for, African-American cardiac patients has dubious beginnings and some pernicious effects. The dubious beginnings help us think about the difficulties in grouping people by racial group. The researcher who patented the BiDil combination re-examined past data, theorizing from a small (53 person) sample that the drug was more effective for African Americans. A second study was conducted with 1,050 self-identified African American participants, and based on that data, the drug was approved for use in only African-Americans. BiDil costs nearly six times its generic equivalents, leading some to believe that the re-patenting did not arise primarily out of a desire to benefit Black heart patients. The pernicious effects of the approval include the medical reification of social groupings based on self-identification (Lee et al 2001). Since there is no scientific definition of who, in BiDil's terms, counts as "black people," it is difficult to say who would be appropriate subjects for its administration. Since there is no biological test for racialization, there can be no biological ground for prescribing BiDil – leaving anyone from the patient's doctors to their insurance company to the FDA responsible for their racial classification for medical purposes. As Kahn argues:

> Researchers using race to develop drugs may be motivated by good intentions, but such efforts are also driven by the dictates of an increasingly competitive medical marketplace. The example of BiDil indicates that researchers and regulators alike have not fully appreciated that race is a powerful and volatile category. When used to bolster the commercial value of a drug, it can lead to haphazard regulation, sub-standard medical treatment and other unfortunate unintended consequences. The FDA should not grant race-specific approvals without clear and convincing evidence of a genetic or biological basis for any observed racial differences in safety or efficacy. Approving more drugs such as BiDil will not alleviate the very

> serious health disparities between races in the U.S. We need social and political will, not mislabeled medicines, to redress that injustice (Kahn 2007: 45).

Kahn here points to a third way in which we can understand racialization as significant for bioethics: health disparities arising out of systemic or structural inequality.

Racialization and systems of oppression

Systemically, race, in concert with other systems of privilege and oppression, is one of the most significant determinants of health or illness. As Ruth Wilson Gilmore has argued, we can track racialization in part by examining the statistical likelihood of dying young; this political point is underlined by the now vast public health literature addressing health disparities (see Institute of Medicine 2002; Fiscella et al 2002; Lasser 2006). Racial and socio-economic status differentially shapes the health of children (Chen et al), making it necessary to track both race/ethnicity and class status in giving an account of health inequalities (Kawachi et al 2005; LaViest 2005). As such, further close attention must be paid in bioethics to how multiple systems of inequality function together to affect health, with care to not neglect the importance of race in such processes.

We mentioned the US Institute of Medicine's report on health disparities ("Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care") above; as Alan Nelson, a member of the committee that prepared the report said, the committee "finished its work convinced that the real challenge lies not in debating whether disparities exist, because the evidence is overwhelming, but in the developing and implementing of strategies to reduce and eliminate them" (Institute of Medicine 2002, 667). However, the recommendations the committee makes remain at the level of improving doctor-patient communication, patient empowerment, allocating more resources for civil rights investigations about health wrongs, with relatively scant mention of changing the US's health system. To address the health disparities created and sustained by racialization, bioethics must take into account the complexities of racism at individual, groups, and systemic levels.

Future directions

Encouragingly, bioethicists have begun to examine the impact of social and racial inequality on health. They have begun to highlight how the following kinds of questions must be asked in order to develop anti-racist approaches to bioethics.

How can bioethicists address racism beyond concerns about informed consent, self-determination, and autonomy?

Patricia King (1998; 2004; 2007) argues that despite widespread recognition in US bioethics that the Tuskegee Syphilis Study stands as a common trope for recognizing racism in medical research:

> There has been inadequate attention paid to race, either in the sense of negative and differential treatment or in terms of pervasive scientific racism, in the construction of bioethics in the United States. American bioethics, from its inception, has resisted taking account of social context. In American bioethics, individualism, self-determination, and autonomy are paramount. Other values, and other ethical

> issues, have historically enjoyed lesser status. Even today, the failure to obtain consent from the Tuskegee subjects continues to receive greater attention than the social and economic conditions in which the subjects found themselves (King, P. 2004: 149-150).

The central insight here is that all our ethical decision-making happens in a context of relations with other people and longstanding social realities (e.g., racism). Aiming to correct racism in health care practice by focusing only on the one-to-one level of interpersonal interaction (e.g., making sure that a physician is trained not to say anything racist) fails to attend to this broader social and historical context. In situations of systemic inequality, systems of oppression and benefit, all parties involved in health care practice would do well to take the social and historical context into account. Take the case of the Study, seen from a health equity perspective (and see Braveman 2006 on terminology). As even some doctors involved reflected, while they were not providing care to the men they studied, in some real ways focusing on their own individual wrong-doing is a red herring. Most, and perhaps all, of the men who participated in the Study lacked access to basic health care. With the exception of the men who could have joined the military, they would not have received care for syphilis even if they weren't enrolled in the Study. Would it have been better to not study (and not treat) people who were not being treated anyhow? (This argument fails at the point at which penicillin was available in public health clinics, from which many of the men seem to have been turned away.) Focusing on the ethical wrongdoing of the doctors and nurses leaves the ethical wrongs of an inequitable system uninterrogated. A focus on issues of informed consent and vulnerable populations obfuscates the bigger ethical problem, which is not seen as ethical at all: How can we have bioethical reasoning in a situation of fundamental inequity distributed by race?

How might bioethicists be well positioned to investigate the ways health care, economic, educational, criminal justice, carceral, and other systems work together to harm racialized individuals?

Bioethics might be well-positioned to take a quite expansive role in re-defining the meaning of race. We can think about race as a social fiction with material effects – a construct that becomes social reality. When we say "race" from this point of view, we mean "racialization." Recall that *racialization* names the social process through which individuals and groups of people come to be defined as a racial group. This is a process that brings together ways of talking about people (or discursive practices) with material conditions in order to define a group of people as a race. Such ways of talking have used, for example, biological explanations (there are real biological differences between races); geographical explanations (where a group of people live shapes their racial ontology); phenotypic explanations (physical morphology makes someone "really" one race or another); social or cultural explanations (how people live either comes from or produces their racial identity). To use the concept of racialization is to see the production of race as *not* a biological or cultural given, but rather a social process through which people's bodies, cultural practices, and social/geographical locations come to carry and hold particular racial meanings. Bioethicists have the potential to be able to think relationally and holistically about how multiple social systems work together to harm racialized individuals – and about how multiple systems would need to coordinate to prevent harms or meaningfully benefit such groups.

How can public health ethics correct narrow understanding of health disparities and the harms of racialization in health care practice, research, and theory?

Many bioethicists write persuasively in the field of public health, some arguing compellingly for the need for bioethical accounts that focus on the way power dynamics shape relationships at all levels in health care (Fagan 2004; Baylis et al 2008). Madison Powers and Ruth Faden argue that the health inequalities arising from "systemic patterns of disadvantage are the inequalities that are most morally urgent to address. Justice here demands aggressive public health intervention to document and help remedy existing patterns of systemic disadvantage and their detrimental consequences" (Powers and Faden 2006: 87). Annette Dula and Sara Goering's *It Just Ain't Fair: The Ethics of Health Care for African Americans* (1993) offers a sustained consideration of race and health disparities in the US context, including discussions of infant mortality, HIV, rural health care, homelessness, black medical students, and surrogacy (see also Dula 2003; 2007). With increased focus on narrative medicine (Gotlib 2009), further attention should be paid to how narratives of experiences of racialization and racism could be important parts of improved health care. For example, when medical practitioners started listening to the people affected by the Tuskegee Study, they better understood the severity of harms experienced and could better anticipate where similar harms might be experienced in the future. The hope for public health ethics approaches is that they will begin already at a group-level of understanding oppression in health care ethics, and so may be more able to resist reducing questions of race in health care practice to the imperative that individual racist health care providers become more racially competent.

How can race and racism shape diagnostic categories, including (and not only) in domains of mental health and illness?

Bioethicists have worked from insights in science studies, biology, philosophy, and other domains to offer critical reflections on how classification systems can shape the health and lives of individuals subject to them. Of particular interest have been contentious diagnostic systems (e.g., classifications for sexual and reproductive illnesses; the Diagnostic and Statistical Manual of Mental Disorders). Bioethicists have highlighted the ways in which categorization and diagnosis has the power to shape not only the kind of treatment individuals receive, but the ways individuals perceive their own experience, and the possibility of individuals receiving care for conditions at all. Some bioethicists have investigated, for example, the ways perceptions of gender, class, and sexuality shape diagnoses of mental illness and the likelihood that individuals will be harmed by diagnostic categories. For example, bioethicists now know to be concerned about how readily characteristics of 'sexual deviance' have been made diagnosable as mental illness (Martin 2001; Nissim-Sabat 2001; Potter 2004, 2005). New directions in bioethics will further attend to the ways racialization has shaped diagnostic categories in ways which harm individuals subject to them.

How do questions of race and racism arise in the development and use of medical technologies?

Bioethicists have become able to appraise technological advancements in medicine and health research with a critical eye to what drives the development of technologies, what populations they are meant to aid, and how they can be used for goals beyond those for which they were intended (Gillis and de Melo Martín 2010). Attention to racialization could be productive in further considerations of all these questions. For example, how do genetic technologies intersect with racialization (Braun 2002)? How can practices of 'biobanking' biological samples for research harm racialized groups in ways not obvious to those whose specimens are taken (Halverson and Ross 2012; Tutton 2009)? If researchers discover differences in how diseases and illnesses affect people by ethnic group, will health insurance coverage for different groups be affected? How do reproductive technologies reinforce racialization (Russell 2010)? In the domain of public health, area-based research and technologies of 'geo-coding' can investigate the ways location/place intersects with race, gender, and socio-economic status to lead to health disparities (Kreiger et al 2003). Engaging further with extensive literature on how medical technologies affect populations could facilitate future bioethical investigations of race and medical technologies.

How does racialization limit communities' ability to direct and conduct research to reflect their needs?

In questions of research ethics in medicine, bioethicists have been deeply critical of research conducted on communities that are not likely to benefit from the research, and of strategic neglect of the research questions of communities that are not likely to be profitable or universally relevant. Racialized communities have been harmed by both of these phenomena, and bioethicists could offer directions for building the particular needs and vulnerabilities of racialized communities within public and private medical research agendas. How does racial grouping by researchers affect an individual participant's willingness to participate in a given study (Goldenberg et al 2011)? How can bioethics help clarify the successes and challenges of research directed by racialized communities themselves?

Are models based on 'cultural competence' adequate for understanding race and racism?

There are numerous problems with "cultural competency" approaches as a way to engage group differentiation by race. (For critical assessments see Kumagai and Lypson 2009; Beagan and Kumas-Tan 2009.) One problem is that in attempting to describe medically salient features of different cultures the full heterogeneity of those cultures is occluded; it can become received wisdom that all Native Americans prefer to not have end-of-life decisions talked about explicitly, when in fact that preference may be specific to one tribe or nation, or to non-Christian first peoples. Another problem arises from the documented prevalence of implicit bias and stereotyping among white, Christian, Anglo nurses and doctors (Cooper et al 2012) and how difficult it is to overcome bias even once it is made explicit. As we have discussed, perhaps the most significant problem with focusing primarily or exclusively on cultural competency training as a solution to the harms of racism in health care is when such a focus eclipses broader structures and systems that perpetuate inequality.

In sum, the challenge for bioethicists committed to developing anti-racist approaches in all domains of bioethics is to see racial inequities as a problem both perpetuated and partly addressable by clinical and theoretical bioethics. Bioethical thinking and practice can be improved, particularly with regard to the complex manifestation of race and racialization as health and illness. Doing justice to the individual, group, and systemic levels of racialization is difficult work, but both bioethics as a field and the lives of the people about whom bioethicists think and care would be better for it.

Related Topics

Chapter X, "Social Determinants of Health and Health Inequalities," Sridhar Venkatapuram and Michael Marmot

Chapter X, "Biomedical Research Ethics: Landmark Cases, Scandals, and Conceptual Shifts," Jonathan Moreno and Dominic Sisti

Chapter X, "Excluded Groups and Pregnant Women in Research," Toby Schonfeld

References

Axelson D E. (1985) Women as victims of medical experimentation: J Marion Sims's surgery on slave women, 1845–1850. Sage. 2210–13.13. [PubMed]

Balsa, A. I., and T. G. McGuire. (2003) "Prejudice, Clinical Uncertainty and Stereotyping as Sources of Health Disparities." *Journal of Health Economics* 22 (1): 89–116.

Baylis, F., N. P Kenny, and S. Sherwin. (2008) "A relational account of public health ethics." *Public Health Ethics* 1 (3): 196.

Beagan, B. and Z. Kumas-Tan. (2009) "Approaches to Diversity in Family Medicine: 'I have Always Tried to be Colour Blind." *Can. Fam. Phys.* 55: 21-28.

Brach, C., and I. Fraserirector. (2000) "Can Cultural Competency Reduce Racial and Ethnic Health Disparities? A Review and Conceptual Model." *Medical Care Research and Review* 57 (4 suppl): 181–217.

Brandon, D. T., L. A. Isaac, and T. A. LaVeist. (2005) "The Legacy of Tuskegee and Trust in Medical Care: Is Tuskegee Responsible for Race Differences in Mistrust of Medical Care?" *Journal of the National Medical Association* 97 (7): 951.

Brandt, A. M. (1978) "Racism and Research: The Case of the Tuskegee Syphilis Study." *Hastings Center Report* 8 (6): 21–29.

Braun, Lundy. (2002) "Race, Ethnicity, and Health: Can Genetics Explain Disparities?" *Perspectives in Biology and Medicine*, volume 45, number 2: 159–74

Braveman, P. (2006) "Health Disparities and Health Equity: Concepts and Measurement." *Annu. Rev. Public Health* 27: 167–194.

Brody, H., J. Glenn, and L. Hermer (2012) "Racial/Ethnic Health Disparities and Ethics The Need for a Multilevel Approach" *Cambridge Quarterly of Healthcare Ethics* 21, 309–319.

Brody H. (2009) *Race and health disparities In The Future of Bioethics*. New York: Oxford University Press 138–41.

Burton, O. (2007) “Why Bioethics Cannot Figure Out What to Do with Race.” *The American Journal of Bioethics* 7 (2): 6–12)

Carastathis, A. (2008): “The Invisibility of Privilege: A Critique of Intersectional Models of Identity.” *Les ateliers de l'éthique* 3.2 23-38).

Carrese, J. A., and J. Sugarman. (2006) “The Inescapable Relevance of Bioethics for the Practicing Clinician.” *CHEST Journal* 130 (6): 1864–1872)

Chen, E., A. D. Martin, and K. A. Matthews. (2006) “Understanding Health Disparities: The Role of Race and Socioeconomic Status in Children's Health.” *Journal Information* 96 (4).

Chiu, C. T., and R. V. Katz. (2011) “Identifying the ‘vulnerables’ in Biomedical Research: The Vox Populis from the Tuskegee Legacy Project.” *Journal of Public Health Dentistry* 71 (3): 220–228.

Collins, F. S. (2004) “What We Do and Don't Know About ’race’,’ ethnicity’, Genetics and Health at the Dawn of the Genome Era.” *Nature Genetics* 36: S13–S15.

Collins, Patricia Hill. “It's All in the Family: Intersections of Gender, Race, and Nation.” *Hypatia* 13.3 (1998): 62-82

Cooper, L. A., M. N. Hill, and N. R. Powe. (2002) “Designing and Evaluating Interventions to Eliminate Racial and Ethnic Disparities in Health Care.” *Journal of General Internal Medicine* 17 (6): 477–486.

Cooper, L., D. Roter, K. Carson, M. C. Beach, J. Sabin, A. Greenwald, T. Inui (2012). The Associations of Clinicians' Implicit Attitudes About Race With Medical Visit Communication and Patient Ratings of Interpersonal Care.

(5): 979-987.

Corbie-Smith, G. (1999) “The Continuing Legacy of the Tuskegee Syphilis Study: Considerations for Clinical Investigation.” *The American Journal of the Medical Sciences* 317 (1): 5–8.

Coughlin, S. S., G. D. Etheredge, C. Metayer, and S. A. Martin Jr. (1997) “Remember Tuskegee: Public Health Student Knowledge of the Ethical Significance of the Tuskegee Syphilis Study.” *Ethics in Epidemiology and Public Health Practice: Collected Works*: 221)

Crenner, C. (2012) “The Tuskegee Syphilis Study and the Scientific Concept of Racial Nervous Resistance.” *Journal of the History of Medicine and Allied Sciences* 67 (2): 244–280.

Crenshaw, K. (1991) “Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color.” *Stanford Law Review* 43.6: 1241-1299.

Cross, T. L., B. J. Bazron, K. W. Dennis, and M. R. Isaacs. (1989) Towards a Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed. Washington, DC: CASSP Technical Assistance Center, Georgetown University Child Development Center.

Davis, A.Y. (2003) *Are Prisons Obsolete?* New York: Seven Stories Press.

Donchin, A., L. Purdy, and International Association of Bioethics. (1999) *Embodying Bioethics: Recent Feminist Advances*. Rowman & Littlefield.

Dula, A. (2003). Racism and Health Care: A Medical Ethics Issue In Tommy Lee Lott & John P. Pittman (eds.), *A Companion to African-American Philosophy*. Blackwell Pub.

---. (2007) "Whitewashing Black Health: Lies, Deceptions, Assumptions, and Assertions—and the Disparities Continue" in African American Bioethics: Culture, Race, and Identity Ed. Lawrence J. Prograis and Edmund D Pellegrino (Georgetown University Press).

Dula, A. and S. Goering (ed). (1993). *It Just Ain't Fair: The Ethics of Health Care for African Americans.* Praeger.

Fagan, A. (2004) "Challenging the Bioethical Application of the Autonomy Principle Within Multicultural Societies." *Journal of Applied Philosophy* 21 (1): 15–31.

Fausto-Sterling, A. (2008) 'The Bare Bones of Race', *Social Studies of Science*, 38, 657 -694

Fine, M. J., S. A. Ibrahim, and S. B. Thomas. (2005) "The Role of Race and Genetics in Health Disparities Research." *American Journal of Public Health* 95 (12): 2125.

Fiscella, K., P. Franks, M. P. Doescher, and B. G. Saver. (2002) "Disparities in Health Care by Race, Ethnicity, and Language Among the Insured: Findings from a National Sample." *Medical Care* 40 (1): 52)

Freimuth, V. S., S. C. Quinn, S. B. Thomas, G. Cole, E. Zook, and T. Duncan. (2001) "African Americans' Views on Research and the Tuskegee Syphilis Study." *Social Science and Medicine* 52: 797–808.

Gamble, V. N. (1997) "Under the Shadow of Tuskegee: African Americans and Health Care." *American Journal of Public Health* 87 (11): 1773–1778.

Garcia, J.L.A. (2004) '"Three Sites for Racism: Social Structures, Valuings and Vice"', in *Racism in mind*, ed by Michael P. Levine and Tamas Pataki. Cornell University Press.

Gillis, M. and I. de Melo Martín (2010). "Editors' Introduction: Biomedical Technologies". *Hypatia* 25 (3): 497-503.

Gilmore, R.W. (2007) *Golden gulag: Prisons, surplus, crisis, and opposition in globalizing California*. Vol. (21) Univ of California Press.

Goldenberg AJ, Hull SC, Wilfond BS, Sharp RR. (2011) *"*Patient perspectives on group benefits and harms in genetic research." *Public Health Genomics; 14(3):135-42.*

Gotlib, A. (2009) "Stories from the Margins: Immigrant Patients, Health Care, and Narrative Medicine." *IJFAB* 2(2): 51-74.

Griffith, E. E. H. (2007) "Personal Narrative and an African American Perspective on Medical Ethics" in African American Bioethics: Culture, Race, and Identity Ed. Lawrence J. Prograis and Edmund D Pellegrino (Georgetown University Press).

Halverson C. and Ross L. (2012) "Engaging African-Americans about biobanks and the return of research results." J Community Genet. 3(4): 275–283.

Haslanger, S. (2004) 'Oppressions: Racial and Other', in *Racism in mind*, ed by Michael P. Levine and Tamas Pataki. Cornell University Press. pp. 97-123.

Hill, T. (2012 "How clinicians make (or avoid) moral judgments of patients: implications of the evidence for relationships and research," *Philosophy, Ethics, and Humanities in Medicine*, 5 (2010), 11

Institute of Medicine. (2002) *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*.

Jost, John T. et al. (2009) "The Existence of Implicit Bias Is Beyond Reasonable Doubt: A Refutation of Ideological and Methodological Objections and Executive Summary of Ten Studies That No Manager Should Ignore." *Research in Organizational Behavior* 29: 39–69. Print.

Kawachi, I., N. Daniels, and D. E. Robinson. (2005) "Health Disparities by Race and Class: Why Both Matter." *Health Affairs* 24 (2): 343–352)

Kahn, J. (2005) *From Disparity to Difference: How Race Specific Medicines May Undermine Policies to Address Inequalities in Health Care,* 15 Southern California Interdisciplinary Law Journal 105-129.

--. (August 2007) "Race in a Bottle." *Scientific American*, 40-45.

-- (2012) *Race in a Bottle: The Story of BiDil and Racialized Medicine in a Post-Genomic Age*. Columbia University Press.

Kilbourne, A. M., G. Switzer, K. Hyman, M. Crowley-Matoka, and M. J. Fine. (2006) "Advancing Health Disparities Research Within the Health Care System: a Conceptual Framework." *Journal Information* 96 (12)..

King, P. A. (2007) "Race, Equity, Health Policy, and the African American Community" in African American Bioethics: Culture, Race, and Identity Ed.

Lawrence J. Prograis and Edmund D Pellegrino (Georgetown University Press

King P. A. (1998) "Race, justice and research." In: Kahn JP, Mastroianni AC, Sugarman J, eds. *Beyond consent: seeking justice in research*. New York: Oxford University Press. 88–110.110.

King, P. A. (2004) "Reflections on Race and Bioethics in the United States." *Health Matrix* 14: 149.

King, W. D. (2003) "Examining African Americans' Mistrust of the Health Care System: Expanding the Research Question. Commentary on' Race and Trust in the Health Care System'." *Public Health Reports* 118 (4): 366.

Krieger, N., J. T. Chen, P. D. Waterman, D. H. Rehkopf, and S. V. Subramanian. (2003) "Race/ethnicity, Gender, and Monitoring Socioeconomic Gradients in Health: a Comparison of Area-based Socioeconomic Measures—the Public Health Disparities Geocoding Project." *Journal Information* 93 (10).

Kumagai, A. K., and M. L. Lypson. (2009) "Beyond Cultural Competence: Critical Consciousness, Social Justice, and Multicultural Education." *Academic Medicine* 84 (6): 782–787.

Lasser, K. E., D. U. Himmelstein, and S. Woolhandler. (2006) "Access to Care, Health Status, and Health Disparities in the United States and Canada: Results of a Cross-national Population-based Survey." *Journal Information* 96 (7).

LaVeist, T. A. (2005) "Disentangling Race and Socioeconomic Status: a Key to Understanding Health Inequalities." *Journal of Urban Health* 82)

Lee, S. S. J., J. Mountain, and B. A. Koenig. (2001) "Meanings of Race in the New Genomics: Implications for Health Disparities Research, The." *Yale J. Health Pol'y L. & Ethics* 1: 33.

Martin, N. (2001) "Feminist Bioethics and Psychiatry" J Med Philos 26 (4): 431-441.

McWhorter, L. (2004) 'Sex, race, and biopower: A foucauldian genealogy', *Hypatia*, 19, 38–62;

---, (2009) *Racism and sexual oppression in Anglo-America: A genealogy.* Indiana Univ Pr,.

Mills, C. W. (1998) *Blackness visible: Essays on philosophy and race.* Cornell Univ Pr.

--- (2007) 'White ignorance', *Race and epistemologies of ignorance* 11–38)

Nissim-Sabat, Marilyn. (2001) "Review Article: Psychiatry, Psychoanalysis, and Race" *Philosophy, Psychiatry & Psychology* 8 (1): 45-59.

Omi, M, and H. Winant (1994) *Racial Formation in the United States : From the 1960s to the 1990s*. New York: Routledge.

Osborn, C. Y., M. K. Paasche-Orlow, T. C. Davis, M. S. Wolf, and others. (2007) "Health Literacy: An Overlooked Factor in Understanding HIV Health Disparities." *American Journal of Preventive Medicine* 33 (5): 374)

Outlaw L. T., (2007) 'Social ordering and the systematic production of ignorance', *Race and epistemologies of ignorance.*

Paasche-Orlow, M. (2004) "The Ethics of Cultural Competence." *Academic Medicine* 79 (4): 347–350)

Penner, L. et al. (2010) "Aversive Racism and Medical Interactions with Black Patients: a Field Study." *Journal of experimental social psychology* 46.2: 436–440.

Potter, N. (2004) "Gender." *The Philosophy of Psychiatry: A Companion*, ed. Jennifer Radden, Oxford University Press.

---. (2005) "Liberatory psychiatry and an ethics of the in-between." *Ethics of the Body: Postconventional Challenges*, ed. Margrit Shildrick and Roxanne Mykituik. Cambridge, Mass: MIT Press, 113-133.

Powers, M., and R. Faden. (2006)*Social Justice: The Moral Foundations of Public Health and Health Policy.* Oxford: Oxford University Press.

Razack, Sherene. (1998) *Looking White People in the Eye: Gender, Race, and Culture in Courtrooms and Classrooms*. University of Toronto Press, Scholarly Publishing Division.

Reich, W. T. (1996) *Bioethics in the United States*. San Francisco, CA: International Scholars Publications.

Reverby, S. (2009) *Examining Tuskegee: The Infamous Syphilis Study and Its Legacy*. Univ of North Carolina Press.

---. (2010) "Invoking' Tuskegee': Problems in Health Disparities, Genetic Assumptions, and History." *Journal of Health Care for the Poor and Underserved* 21 (3): 26–34.

Russell, C. (2010) "The Limits Of Liberal Choice: Racial Selection And Reprogenetics." *The Southern Journal Of Philosophy*, Volume 48, Spindel Supplement, 97–108.

Sankar, P., M. K. Cho, C. M. Condit, L. M. Hunt, B. Koenig, P. Marshall, S. S. J. Lee, And P. Spicer. (2004) "Genetic Research and Health Disparities." *JAMA: The Journal of the American Medical Association* 291 (24): 2985–2989.

Shields, A. E., M. Fortun, E. M. Hammonds, P. A. King, C. Lerman, R. Rapp, and P. F. Sullivan. (2005) "The Use of Race Variables in Genetic Studies of Complex Traits and the Goal of Reducing Health Disparities: a Transdisciplinary Perspective." *American Psychologist* 60 (1): 77.

Sherwin, S. (1998) *The politics of women's health: Exploring agency and autonomy*. Temple University Press.

———. (2000) "A relational approach to autonomy in health care." *Readings in Health Care Ethics*: 57–68.

Silliman, J., M. Fried, L. Ross, and E. Gutierrez. (2004) *Undivided Rights: Women of Color Organizing for Reproductive Justice*. South End Press.

Smedley BD, Stith AY, Nelson A., eds. (2003) *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Washington, DC: National Academies Press.

Smith, A. (2005)*Conquest: Sexual Violence and American Indian Genocide*. South End Press.

Stewart, A. L., and A. M. Nápoles-Springer. (2003) "Advancing Health Disparities Research: Can We Afford to Ignore Measurement Issues?" *Medical Care* 41 (11): 1207–1220)

Stivers, T., and A. Majid. (2007) “Questioning Children: Interactional Evidence of Implicit Bias in Medical Interviews.” *Social Psychology Quarterly* 70.4: 424–441.

Sullivan S. and N. Tuana, (2007) *Race and epistemologies of ignorance.* State Univ of New York Press.

Thomas, S. B. (2001) “The Color Line: Race Matters in the Elimination of Health Disparities.” *American Journal of Public Health* 91 (7): 1046.

Thomas, S. B., and S. C. Quinn. (1991) “The Tuskegee Syphilis Study, 1932 to 1972: Implications for HIV Education and AIDS Risk Education Programs in the Black Community.” *American Journal of Public Health* 81 (11): 1498–1505.

Tutton, R. (2009) “Biobanks and the Inclusion of Racial/Ethnic Minorities.” *Race/Ethnicity: Multidisciplinary Global Contexts* 3(1): 75-95.

Types, T. (2007) ‘Epistemologies of Ignorance’, *Race and epistemologies of ignorance*

U.S. Department of Health and Human Services (2012). “2012 National Healthcare Disparities Report.” www.ahrq.gov/research/findings/nhqrdr/index.html (Accessed July 22, 2013).

Wall, L. L. (2006) The medical ethics of Dr J Marion Sims: a fresh look at the historical record. *J Med Ethics.* June; 32(6): 346–350.

Ward, E., A. Jemal, V. Cokkinides, G. K. Singh, C. Cardinez, A. Ghafoor, and M. Thun. (2008) “Cancer Disparities by Race/ethnicity and Socioeconomic Status.” *CA: a Cancer Journal for Clinicians* 54 (2): 78–93.

Washington, D. A. (2009) “Critical Race Feminist Bioethics: Telling Stories in Law School and Medical School in Pursuit of Cultural Competence.” *Alb. L. Rev.* 72: 961)

Wear, D. (2003) “Insurgent Multiculturalism: Rethinking How and Why We Teach Culture in Medical Education.” *Academic Medicine* 78 (6): 549.

Wear, Stephen. (1998) *Informed Consent: Patient Autonomy and Clinician Beneficence Within Health Care*. Georgetown University Press.

Williams, D. R., and P. B. Jackson. (2005) “Social Sources of Racial Disparities in Health.” *Health Affairs* 24 (2): 325–334.

42.

Transgender

Jamie Lindemann Nelson

A recently coined term that has already developed a somewhat complicated and controversial history of meanings, “transgender” will be used in this chapter to characterize people who are uncomfortable—sometimes deeply so—with the gender to which they’ve been assigned at birth, as well as a loose collection of ways in which some of those people express that discomfort.

For some transgender people, medicine plays a significant role in how they deal with their unwelcome identities as women or as men—as it has in Karl’s life. On the basis of the standard indications that are so carefully noted at birth, Karl was identified as female, and raised in one of the many ways that are more or less distinctive for girls. As life went on, however, Karl found that he could not find a rewarding or even coherent way of living as a woman, and that it made much more sense to see himself, and be seen by others, as male. Eventually, he obtained some rather invasive medical interventions—in his case, his ovaries and uterus were removed, his chest re-contoured and he was started on a regular regimen of testosterone—that helped him to do so.

Carrie has lived out an analogous story. Identified and reared as a boy from the start, growing up into what almost everyone thought of as just one guy among others, Carrie had a private but powerful conviction that life as a man simply could not be made to fit with her own grasp of who she was and wanted to be. As part of finding a way of living that seemed more in keeping with her feelings and hopes, she also turned to medicine: Carrie started taking estrogen and a medication that reduced the effects of testosterone. She later underwent a number of surgical procedures that reshaped her genitals and otherwise provided her with physical traits associated with women, and rid her of those associated with men.

For present purposes, then, "transgender" will be taken to include people like Karl and Carrie, who are also often referred to as "transsexuals," and in whose experience medicine plays a special role. Yet there are also people who, while rejecting (or at least revising) the gender identities thought to be determined by their bodies, don't look to medicine to provide physical changes, perhaps because they have no access to the kind of intensive interventions required, or possibly because they don't like the balance of risks and benefits involved, or maybe because they don't accept that a person's genitals, hormones or other "sex characteristics" necessarily determine gender. They use medicine largely for more ordinary kinds of health care, although they can face some extraordinary barriers to getting it.

Some transgender people take themselves to have permanently "migrated" from one gender to another, using clothing and accessories, verbal and nonverbal forms of expression, and self-ascription, rather than hormones and surgery, to help provide passage. Others cross back and forth between gendered presentations, perhaps because the ways in which they most value their lives overall won't accommodate permanent moves, or perhaps because they don't see gender as a deep identity-determining fact about who they are, but as something that should be treated less seriously, as a set of tools for access to different experiences, for personal growth, for amusement, even for profit. Still others are resistant to the seemingly relentless drive, at least in contemporary Western societies, to fix everyone as female or male. Rather than "migrating" from femaleness to maleness, or "visiting" femaleness from maleness, they tend to be suspicious about whether those very categories are good places for them—or perhaps for anyone—to inhabit. Some such people might selectively use surgery or hormones; many do not.

These people often identify themselves as transgender, too—in fact, in some uses of the term, they occupy the center of the concept, while people who are transsexual are admitted to the term by courtesy if at all. So, while all transgender people will have health care needs like anyone else—and perhaps more so on average than people who confront less stigma (IOM 2011)—there is not a necessary connection between transgender and scalpels or syringes.

Yet, while some transgender or otherwise gender-variant people have tried to dismantle or at least substantially reconfigure gender, and some theorists have recommended people adopt skeptical or ironic attitudes towards it, gender remains a gravely important status socially as well as subjectively. Transgender people often strenuously try to understand themselves and be understood by others as women or as men as these notions are typically used. Success can be vital to transgender people, in part because being seen as gender-ambiguous or nonconforming can make a person vulnerable to various harms: harassment, vocational insecurity, and violence, including deadly violence (Beemyn and Rankin 2011). Further, the disharmony between how some transgender people feel, how their bodies are shaped, and how others see them can threaten their ability to live lives they see as authentic. For some of those people, medicine does play a centrally important role.

Yet if medicine is not a necessary means for expressing transgender objections to some of the standard ways gender is understood and enacted, neither are all objections to gender's operations necessarily examples of transgender. Feminism, for example, might also be a name for some people’s deep discomfort with how the gender to which they have been assigned plays itself out in their lives. It may be tempting to say that many feminists’ objections to gender are inherently political, whereas transgender peoples’ dissent tends to be fundamentally personal. Yet feminist theories and practices themselves have made the “personal/political” distinction difficult to see as very helpful. It might be more accurate to suggest that feminism’s range of complaints against how gender is practiced is broader than those typically pressed by people insofar as they are transgender.

Further, some feminists see these forms of objection to standard gender practices as operating at cross-purposes. They have complained that transgender practices and understandings don’t really grasp how deeply gender structures lives—one’s identity as a woman or a man, so the complaint goes, is not something that decisions, or desires, or dress, or even surgery and hormones, can change. This line of thought has led to general critiques of medicine’s involvement in gender reassignment procedures as exploitive of those who seek them out, and as disrespectful to women generally (most notably, Richards, 1979). Some feminists have worried that forms of transgender expression reinforce what’s objectionable about gender categories: a transgender woman’s concern about high heels, for example, may end with the fact that she can be punished for wearing them, while a feminist’s objection may start with the fact that they can be punishing to wear. The tendency to construe genital surgery as the heart of gender reassignment strikes some feminists as reducing gender from a complex, encompassing social phenomenon to mere bits of biology that are themselves quite inoffensive; an authoritative social institution, medicine, that provides the interventions and the mental health screening that “justifies” access to the operating room, has been charged with reinforcing such naïve and politically retrogressive attitudes (See, for instance, Hausman, 1995).

Yet it may not do to press the notion that the scope of feminist objections to gender is wider that those of transgender people too hard. Transgender individuals who see themselves as demonstrating with their lives that gender is as porous as it is problematic have also criticized many of the uses made of gender categories. Some transgender people are themselves explicit feminists: transgender-based dissatisfaction with how gender is practiced may be influenced by feminist convictions (e.g., Aragon, 2006; Bettcher 2009); some feminists have written sympathetically and insightfully about transgender and its possibilities for enriching feminist thought. (e.g., Scheman 1997; Salamon 2008). Despite the many ways that gender can limit and damage human lives, many transgender people’s experiences testify to how vital a habitable gender identity can be to a rewarding or even merely tolerable life.

At the same time, transgender desires and actions may help undermine what some writers have identified as fundamental “natural attitudes” about gender: that being male or female is given, and exclusive and immutable. Everybody gets one and only one gender and the one they get is unchangeable. Medicine contains a wealth of experience with various disorders of sexual development that put enormous pressure on this “natural attitude”—as do the lives of people with intersex conditions. The interest in medical and surgical interventions on the part of some transgendered people however, in part perhaps because such interventions are often sought by people whose bodies seem perfectly “normal” physically, may make it harder to ignore just how much social stage-setting and personal effort is required to maintain gender distinctions in their familiar forms. In light of what’s been done by people such as Carrie and Karl (and the health care professionals helping them), any effort to insist that gender distinctions, roles, identities, or practices are as natural as breathing, rather than complicated and carefully monitored social practices, becomes much harder to defend (Kessler and McKenna 1978).

Medical Practices, Transgender Goals, and Bioethics

While some transgender people, then, do not take medicine to be a special ally in how they express their genders, others do want substantial interventions: surgeries on genitals and reproductive organs, and procedures aimed at changing body contours or rendering faces more typically feminine or masculine; the use of hormones and hormone blockers to suppress menstrual cycles or erections, or to stimulate mammary growth or facial hair. Some physicians were providing some such services as early as the 1920s (Meyerowitz 2002; Ebersoff, 2000). More recently, medicine in many parts of the world has largely regularized how it responds to such requests; there are diagnostic criteria and treatment protocols that are widely accepted as constituting good practice. There is, further, at least some ongoing research into the social and physical impact of transgender interventions, as well as into just why some people are so powerfully convinced that their given gender assignment is so profoundly wrong for them.

Bioethicists, it seems, should find these ways in which medicine so dramatically connects with such a central and problematic organizing concept of human life a rich source of fascinating moral and philosophical questions. Is “gender reassignment surgery” a paradigm of problematic “medicalization” of a social problem? Is it an effective treatment for a bona fide disease? Or, rather, might it best be seen as a way of reducing unhappiness and releasing human potential? Might medicine's response actually increase the incidence of the condition, channeling various forms of intense discomfort with gender norms that might be expressed politically into a single diagnosis-treatment pair? Or is gender reassignment itself a kind of social and political action against prevalent understandings of gender? Do people who ask for medical help with their gender crossing show themselves by that very request to be mentally ill? Or are they exhibiting a valuable form of human diversity that ought to be respected and facilitated, rather than tolerated and treated?

Oddly enough, although other scholars have raised questions of this sort, bioethicists for the most part have not. (Nelson 1998; 2012). Academic efforts to come to grips with medicalized gender transitions were readily available though the 1980s—in addition to work by feminists, cultural theorists interested in gender and social scientists interested in health care made contributions (e.g., Billings and Urban's sharp skepticism about the motives of professionals involved in gender identity clinics in their 1982)—but the amount of bioethical attention to the issue, was meager in quantity if not quality. (Lavin's 1987 critique of the idea that "sex change" procedures were inherently mutilating or deceptive stands out for its thoughtfulness, but also for its simple presence.). In the early 1990s, an interdisciplinary field of transgender studies started to emerge (touched off by Stone's 1996 reply to Raymond), and social trends started to make transgender a less outlandish topic generally. Yet bioethicists still showed little interest. While some attention focused on a related area—"gender normalization" procedures performed on children born with disorders of sexual development (Dreger, 1999, Chase 1998)— bioethics failed to keep pace with other bodies of scholarship. Until very recently, such bioethical literature as did address specifically transgender issues often relied on older theoretical understandings, rather than trying to develop or even question them (e.g, Draper and Evans 2006, drawing importantly on Raymond 1979). Well into the first decade of the 21st century, it would not have taken long—certainly the inside of a non-taxing fortnight, more likely a moderately paced week—to read with due care all the literature on transgender related themes contained in the twenty or so most prominent journals publishing bioethics.

There are, however, signs that bioethics is finally starting to take a closer, more considered look at medicine's efforts to help transgender people to achieve or consolidate their desired gender identities, and about health care's broader interactions with transgender people as well. An initiative started in 2010, "Bioethics, Sexuality, and Gender Identity," spearheaded by Autumn Fiester and Lance Wahlert from the University of Pennsylvania, aims to enrich bioethics with research from queer studies, an interdisciplinary field that includes the study of lesbian, gay, transgender, and related forms of sexual or gender expression. (See http://www.queerbioethics.org.) The initiative now involves a large number of bioethicists from many centers and programs, some of whose work includes an interest in transgender. In 2012, it sponsored a conference, and has organized special issues of bioethics journals around its themes. Further, at the national meeting of the American Society for Bioethics and Humanities (ASBH) held in Washington DC in October of 2012, there were for the first time several presentations explicitly addressing bioethics and transgender.

Then, of course, there is this very entry in the *Routledge Companion to Bioethics* -- apparently the first general discussion of the issue to appear in an anthology designed for a general readership in the field. Essays of this sort often provide something of a critical summary of the leading issues and contributions of a given field to a particular issue. Yet this strategy hardly fits bioethics and transgender, precisely because the record of engagement is so sparse. If there could be said to be a standard topic for bioethics and transgender, it most likely has been whether it is legitimate to use medicine to facilitate gender reassignment, either at all, or for special populations, such as children. Against this background, however, new issues are starting to emerge.

For example, Alison Reiheld's ASBH paper (2012) reminds the field that transgender people have "ordinary" health needs too, and that some have faced serious obstacles in the way of getting quite standard kinds of care; track records of disrespect or rejection by health care professionals, or even the anticipation that a bad experience may be in store when a person's gender-nonconformity is revealed, can delay or derail needed treatment. (See also Harbin, Beagan, and Goldberg 2012). Reiheld argues that some of those obstacles may not be just plainly poor practice, but ethically more complex: a provider may understand her refusal to care for transgender people as a matter of "conscientious objection," the result of a considered ethical judgment that transgender is sinful or otherwise immoral and that providers ought not to be compelled to support such forms of life by providing health care.

At another session of the same meting, Cameron Waldman in effect argued against seeing any such objection as an ethically complex issue; he maintained that it ought to get no more hearing than would a professional's claim that she could not in good conscience treat people of color. Waldman also was skeptical about whether bioethics had anything of substance to contribute to society's achieving the sort of moral progress that would be marked by such questions about the treatment of transgender or otherwise queer people being simply placed off the table (Waldman 2012).

This exchange hints at the rich payoff bioethics might expect to gain from taking on transgender issues more fully; consideration of what might seem a straightforward issue—abandoning patients—quickly develops into deeper questions about tensions between personal integrity and professional values, about what moral issues decent societies ought to regard as definitively settled, and about what bioethics' role might be in *constricting* the set of open moral questions.

Research that focuses on transgender people also poses ethical issues that are starting to attract notice. The Institute of Medicine's recent report on the health care needs of lesbian, gay, bisexual, and transgender people called for further investigation of relevant topics—for example on the long-term health impacts of continued hormone use by transgender people (IOM 2011). To aid research on such relatively small populations, the IOM report recommended that transgender people be routinely identified in their medical records; this proposal raises questions about how to define such a fluid and contestable term, about who has the authority to use or withhold the label, and about privacy and safety for a group of people whose gender identities put them at risk for suffering from just the kinds of stigma the IOM report itself carefully notes.

Perhaps a more fundamental issue is whether the "causes" of people's understanding themselves as transgender is an appropriate target of research at all. Such investigations have gone on, often generating considerable controversy, although not typically among bioethicists. Some transgender scholars and activists for example have expressed vehement opposition to investigations supporting the view that the desire to change gender is a form of paraphilia—i.e., what is sometime called by lay people a "perversion," a phenomenon driven by fundamentally erotic desires, targeted at an unconventional object.

A substantial part of the criticism in that particular case surrounded issues of research methods and research ethics used by Michael Bailey in his defense of his paraphiliac analysis of transgender (Bailey 2003); apart from a 2008 article by Alice Dreger, the dispute did not generate much attention in the bioethics literature. Yet the deeper research ethics issue may lie simply in seeing transgender desires and behaviors as inherently more puzzling than why our gender identities have the shape and significance that they do to people in general. Singling out transgender as a kind of gender identity particularly in need of explanation can convey the thought that there is something problematic with transgender ways of making sense of oneself—for example, that transgender is, or may be in some of its forms, a kind of mental disorder (cf. Wahlert and Fiester 2012).

Transgender and Mental Disorder

Whether transgender identities as such, or some ways of expressing those identities, should count as an illness or a disorder (terms that are used as rough synonyms) is a question falls properly to the philosophy of medicine. It has ethical implications, though, perhaps chiefly for what was earlier identified as the basic question that bioethicists have tended to ask when transgender has been considered: is gender reassignment an ethically defensible use of medicine? The "illness or not" issue also has some significant personal implications for transgender people. As the passionate debate that surrounded the delisting of homosexuality from the APA's Diagnostic and Statistical Manual testifies, the difference between being considered mentally ill and being thought of as simply part of life's rich pageant can matter deeply to people (Bayer 1981).

Karl and Carrie, along with several tens of thousands of other people (Olyslager and Conway 2007), chose to undergo extensive surgeries on biologically healthy tissue that at least compromised their reproductive abilities, and subjected them to the standard dangers of surgery, including the possibility of death. They elected hormone treatments that may increase long-term risks of certain serious illnesses. They were well informed about the possible consequences. Were their informed choices sufficient to authorize professionals to provide the desired interventions?

Not if those professionals are guided by standard treatment protocols. The accepted standards of care pivot on a diagnosis—"gender identity disorder," or, in more recent diagnostic manuals and clinical guidelines, "gender dysphoria" (APA 2013, WPATH 2011)—as diagnosed by mental health professionals. According to the guidelines then, a person's own reflective and informed choice is not sufficient to authorize gender reassignment interventions. What is perhaps more troubling is the hint that, if a person wants such interventions, her choice may not be a *necessary* part of the authorizing conditions either.

The problem is that the idea of being mentally disordered is often associated with the notion that your ability to make good decisions is doubtful, at least in areas affected by the illness, if not globally. Having a mental disorder does not mean that a person cannot make authoritative choices about her life. Yet a psychiatric diagnosis, and the insistence on using mental health professionals as gatekeepers to hormonal treatment and genital surgeries, can carry powerful stigmas. The transgender desires and choices of people in Karl or Carrie's position then, might not be regarded as authentic expressions of who they most fundamentally and rationally take themselves to be, authorizing willing providers to intervene. Rather, they might be seen as symptoms of an illness, whose appropriate therapy is to be determined by professionals.

If mental health professionals involved in gender reassignment thought their job were to help people make a complicated and consequential decision well, that would probably not prompt great controversy. If they took themselves to be determining whether people requesting transgender medical procedures were suffering from serious depression, or other mental disorder that might impair decisionmaking, might seem somewhat less contestable. Yet as things stand, if a candidate completes the screening with the authorization for surgery in hand, she or he hasn't emerged with a clean bill of mental health. What the candidate gets is a potentially stigmatizing psychiatric diagnosis.

Yet incorporating the desire to "change sex" into medicine's list of pathologies also came with advantages to both providers and recipients. Physicians and other health professionals could feel that their efforts were not merely glorified plastic surgery, serving idiosyncratic desires. Rather, their aim was to ameliorate a very serious mental disorder that, untreated, was extremely painful, correlated with serious depression and even suicidal behavior. Further, practicing under a recognized diagnosis, secured via official criteria applied by mental health professionals, reduced anxiety that a person who had received surgery might change her or his mind about whether the interventions had really been beneficial.

For their part, transgender people in search of medical interventions could feel that they weren't merely in the grip of some private perversion. Rather, they could understand themselves as ill with a recognized disorder, for which medicine had reliable responses. They were not "bad," then, merely sick. In principle, at least, they could approach physicians, not as supplicants, but as sufferers, for whom appropriate treatment could be regarded as a reasonable expectation built into the social contract between physicians and the public—at least for those who could afford it. And a recognized diagnosis could help there, too. Even though some insurance plans explicitly rule out coverage for transgender interventions, some have covered hormones, and even surgery—as the American Medical Association, explicitly advocates (AMA 2012).

Yet many transgender people do not see their discomfort with their assigned genders as warranting a psychiatric diagnosis and are not particularly keen to be seen as mentally diagnosable by others. The stresses in dealing with social stigmas and expectations surrounding what is normal for women and for men to be, to do, and to appear—like many forms of stress—may make someone prone to illness; various forms of gender transition may bring medical problems in their wake—surgical complications, for instance, or the impact of long-term use of hormones. Yet at most these considerations suggest that being transgender can be a health risk, not that it is itself an illness. The thought that people seeking transgender interventions were simply delusional—"this person with a penis thinks that he is *really* a woman"—have become less plausible, as understandings of what constitutes "reality" in this area have become more sophisticated, and as the ways available to transgender people to understand their own experience have also developed. While transgender desires can cause intense discomfort, this may not be diagnostic of an illness, but simply reflect that people typically are hardly indifferent to their gender. It seems reasonable to imagine that many non-transgender people would find life quite difficult if they found themselves having to live out a gender role that felt thoroughly alien to them.

Can bioethics—aided, perhaps, by the philosophy of medicine—help resolve this issue? Not conclusively, or at any rate, not so far. Consider, for example, Jerome Wakefield's "harmful dysfunction" analysis. Wakefield's account is attractive in that it incorporates biological and social elements in its understanding of disorder, rather than trying to assimilate disorder to one or the other of these categories, as earlier theories have attempted (e.g, Boorse 1977, Englehardt 1975). His thought is that for a person to count as having a mental disorder, two conditions must be fulfilled: at least one of the person's physical or mental systems must not be operating according to its naturally selected function, and the effects of that failure of to operate are generally regarded as harmful, in the disordered person's social context (1992). As Wakefield sees it, then, both biological and social considerations must be met for a condition to count as a mental disorder.

Transgender desires and feelings can clearly meet the social condition. In ways of life that make so much of gender distinctions as do contemporary societies, many people who feel that the gender they were assigned at birth does not fit them experience pain, and other substantial limits to their ability to form and pursue their interests. It is, however, at least unclear whether Wakefield's biological clause holds. Gender identity is such a socially shaped, varied, and—in particular—such a heavily monitored status, that it is curious to see it as a natural result of a well-functioning biological mechanism emerging from evolutionary processes. The amount of social pressure that is exerted to police gender norms, punishing those who stray too far, seems peculiar if gender identity reliably emerges from some properly functioning neural structure.

The case that transgender desires, even if they are intense enough to prompt people to seek medical interventions, constitute a mental disorder, then, is under some strain. It might seem in the interests of transgender people, simply as a pragmatic matter, to let the current situation stand, if it keeps open the possibilities for receiving desired interventions—and maybe even having their costs reduced. Yet taking such a wholly strategic approach the diagnosis and treatment enterprise may be experienced by some transgender people as damaging to their integrity; some health care professionals might feel something of the same sort themselves.

Consider the "clinically correct story"—the kind of transgender life story that many gatekeeping mental health professionals have seen as diagnostic for bona fide gender dysphoria (Nelson 2001). According to classic versions of the story, the desire to change sex emerges early and enduringly; it concerns identity rather than sexuality, involves revulsion at discordant body parts, includes cross-dressing and cross-living, and comes complete with a set of plausible accounts of the teller's actions and decisions that might not seem to fit in to a narrative of life-long conviction that down deep, where it mattered, one was *really* a man or a woman (e.g., "Joining the Marines/ Getting pregnant was part of my struggle to suppress the truth about myself.")

Unsurprisingly, many transgender people came to be able to relate this narrative by heart, whether or not the story accurately captured their own experience. Equally unsurprisingly, canny professionals knew that the narrative was no secret, and had strategies to detect the overly glib (Stone, 1996). Those who were focused on getting medical interventions might then anticipate and counter the detection strategies. And so on. The problem, however, was not only staying ahead of the game. The deeper problem is that there is something deeply dissonant in having to falsify the story of one's life in order to obtain medical interventions, when for many the drive to obtain those interventions is rooted in a powerful commitment to authenticity.

Requiring strict adherence to the clinically correct story may have eased as people's notion of what behavior is acceptable in women and men, and thus transgender people, became more accommodating. Still, as Judith Butler noted:

> It won't do, for instance, to walk into a clinic and say that it was only after you read a book… that you realized what you wanted to do, but that it wasn't really conscious for you until that time. It can't be that cultural life changes, that words were written and exchanged, that you went to events and to clubs, and saw that certain ways of living were really possible and desirable, and that something about your own possibilities became clear to you in ways that they had not been before. You would be ill-advised to say that you believe that the norms that govern what is a recognizable and livable life are changing, and that within your lifetime, new cultural efforts were made to broaden those norms, so that people like yourself might well live in supportive communities as a transsexual, and that is was precisely this shift in public norms, and the presence of a supportive community, that allowed you to feel that transitioning had become possible and desirable (Butler 2004: 80-81).

Yet this may be the kind of narrative that most adequately does capture a given transgendered person's experience and sense of self.

The most recent edition of the Standards of Care of the leading organization of medical professionals involved in transgender care, the World Professional Association for Transgender Health (WPATH) is sensitive to the stigmas associated with mental disorder, and reads very much seems as if it is trying to split the difference between the benefits and the liabilities of diagnosis (WPATH 2011). That edition—the seventh—states clearly that transgender self-understandings are not, simply as such, to be regarded as symptoms of mental disorder. It is eloquent about how transgender and analogous phenomena are human variations widely distributed among cultures and throughout history, and are to be respected. However, it retains the idea that when a person's transgender feelings make surgery or hormone treatments seem like a good way to live better, that person has gone from being (merely) "gender noncomforming" to "gender dysphoric," in the terms WPATH borrows from the 5th edition of the American Psychological Association's *Diagnostic and Statistical Manual* (APA 2012; 2013). And when a person becomes gender dysphoric, then their unhappiness with their bodies and/or their lives has crossed the threshold from a human variation to be respected, to a medical problem that requires the services of mental health professionals and the confirmation of a diagnostic category before surgery or hormones would be deemed appropriate.

The WPATH standards are clear that a diagnosis of this kind should not be thought of as grounds for taking away anyone's rights or diminishing their dignity: "A disorder is a description of something with which a person might struggle, not a description of a person or a person's identity" (WPATH 2011: 5). Yet there remains the danger that in continuing to assert that the desire to obtain medical interventions for gender transitions constitutes a mental disorder, the authoritative professional group will undermine transgender people's sense of acceptance of their own identities, and may delay fuller measures of social respect.

Further, there are available alternatives for how medical professionals and transgender people might see their relationship. Jacob Hale has argued that the gatekeeping position assigned to mental health providers by the WPATH standards violates "the dominant principles of bioethics in the contemporary United States"—in particularly, non-maleficence, beneficence, and respect for autonomy. (Hale 2007:493).

There are, as Hale acknowledges, risks to long-term hormone use as well as to invasive surgery, including the possibility of regret (Pfäfflin and Junge, in their 1998 article relied on by Hale, report an incidence of post operative regret of less than 1 percent for people obtaining female-to-male procedures, and of 1 to 1.5 percent for those undergoing male-to-female procedures.) Yet he suggests that health care professionals who have developed and enforced these standards overstress the risks, while underplaying the value of the potential benefits, and that properly weighed, the risks do not justify curtailing respect for the autonomous choices of patients. Hale notes that other decisions people make carry serious risks as well, offering the example of vasectomy, to which might be added the decision to bear and rear a child. It is also worth noting that although neither unwanted fertility nor pregnancies count as diseases, physicians are involved in how people respond to them, and insurance plans, both private and social, very often cover them.

Since the publication of Hale's article, the newest WPATH Standards of Care have relaxed the requirement that surgical candidates undergo extensive psychotherapy, which is a significant alteration. However, the Standards still require mental health screening, particularly when genital or gonadal surgery are in prospect. Portraying the difference between gender nonconformity and gender dysphoria as a difference between healthy and disordered states remains a controversial feature of the relationship between transgender people, and health care providers, and a live topic for bioethics. Arguments for understanding the difference in this fashion drawn from the philosophy of medicine appear at best to be inconclusive, and the possibility of reinforcing stigma cannot be taken lightly. At the same time, the low levels of post-operative regret cited by Hale himself might be understood as strong evidence that the current procedures, relying on mental health screening for surgical candidates, are working very well to avoid bad outcomes.

Further, there are cases where reasons separate from the very desire to transition prompt concern about some people's ability to make self-regarding decisions. In principle, this includes transgender people who uncontroversially suffer from certain forms of mental illness, or who are cognitively or emotionally handicapped. In practice—or at least in the literature—the brunt of bioethical attention has fallen on gender variant children.

Some young people, including pre-pubertal children, report strong and persistent transgender desires; sometimes those desires persist into adulthood, and sometimes they do not (Meyer 2012). In such cases some clinicians have advocated the use of puberty-delaying drugs (e.g., Spack, et al, 2012). The effects of such drugs are reversible if suspended, and they buy time for children to mature, and for their sense of their gender identity to consolidate, without their having to deal with physical changes that are deeply unwelcome, and whose impact they might have to try to reverse if they did elect gender reassignment. Some bioethicists (e.g., Giordano, 2008) have defended this response, and called for it to become a more widely available option for transgender children.

Both the clinical and the bioethical justifications offered in the literature concerning puberty suppression hinge on the claim that such children have a serious problem that is made worse by social forces, but is at base medical. As such, they have a substantial claim to available medical care. It seems quite possible that any successful effort to de-pathologize gender dysphoria could make it harder for them to get hold of that resource. The main alternative justification pressed on behalf of transgender adults, stressing their right to make informed and free choices about their lives, is less clearly applicable to children.

Bioethics and Transgender: Coming out From Behind the Curve?

The founding of university-based gender identity clinics began during the mid to late 1960s—roughly speaking, the same historical moment that saw the founding of research centers dedicated to the development of bioethics as a distinctive, interdisciplinary approach to understanding and guiding the growing power of medicine (Meyerowitz, 2002; Jonsen, 1998). While there was always a regulatory strain in its practice, bioethics was from the first interested in medicine's impact on how people understood and dealt with questions posed by our embodiment: what constitutes life, and what signals death; what distinguishes health and illness. Unlike questions concerning the nature and value of natality, mortality, and morbity, gender stayed off the bioethics map for a long time. It is interesting to speculate on how contemporary discussions in transgender heath care, but perhaps more generally about gender and social life as well, might have gone on had bioethics risen to that particular occasion, and interesting too, to speculate on why it did not.

It seems plain, however, that whatever thicket surrounded the topic and kept it insulated from bioethics is down now. Bioethicists are starting to take on a number of pertinent questions—e.g., about the authorization and financing of transgender-focused medical interventions, about the stigmas that may be inherent in transgender-oriented research agendas, as well as about the relationship between disorder and health. Newer issues are starting to come to light, too. For example, there is a small but growing literature concerning the interest of people undergoing gender reassignment in preserving their fertility and becoming parents (e.g., Hembree et al, 2009; Murphy 2012). There is reason to expect theoretically significant and practically helpful results from such work.

However, bioethics may now be less likely on its own to make as big an impact on how transgender is understood by medicine and society generally as it once might have done. In the past decade or so, many people looking to medicine for help with achieving a more desirable gender identity have started develop a political consciousness that resembles how many people with disabilities, or with intersex histories think of themselves. Many transgender people now regard themselves more as agents empowered by their identification with a social group, than as individuals significantly defined by their connection with surgeons and endocrinologists.

Bioethics has much to contribute to responsible thinking about the uses of medical power in connection with gender transitions; its contributions may well grow. However, the future relationships of transgender people with health care providers may be affected more by the political clout of a LGBT movement that is successfully transforming other central features of social life than by academic or clinical reflection.

For example, whether or not future editions of the *DSM* or the WPATH Standards of Care include “gender dysphoria” as a psychiatric diagnosis, the advantages and disadvantages of doing so as weighed by bioethicists may be less important than how transgender people themselves respond to the question. Insofar as they and their allies refuse to see health care concepts or practices as stigmatizing, forge their self-understandings chiefly from their own shared experiences, and assert the legitimacy of their own place in social life, bioethical thinking about transgender will need to go on with transgender people not merely as subjects of analysis, but as partners in conversation.

Related Topics

Chapter X, “Medicalization, ‘Normal Function,’ and the Definition of Health,” Rebecca Kukla

Chapter X, “BIID and the Question of Ethics,” Nikki Sullivan

References

American Medical Association (2012). AMA Policies on GLBT Issues. http://www.ama-assn.org/ama/pub/about-ama/our-people/member-groups-sections/glbt-advisory-committee/ama-policy-regarding-sexual-orientation.page? Accessed 1 November 2012.

American Psychiatric Association. (2012). DSM-5 Development. http://www.dsm5.org/ProposedRevision/Pages/GenderDysphoria.aspx. Last accessed November 5, 2012.

_______________. (2013). *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition.* Arlington, VA: American Psychiatric Publishing. Aragon, A. P. (2006). *Challenging Lesbian Norms: Intersex, Transgender, Intersectional, and Queer Perspectives.* Binghampton, NY: Harrington Park Press.

Bailey, M. (2003). *The Man Who Would Be Queen.* Washington, DC. Joseph Henry Press.

Bayer, R. (1981). *Homosexuality and American Psychiatry.* New York: Basic Books.

Beemyn, G. and S. Rankin. (2011). *The Lives of Transgender People.* New York: Columbia University Press.

Bettcher, T. (2009). "Feminist Perspectives on Trans Issues," *Stanford Encyclopedia of Philosophy* http://plato.stanford.edu/entries/feminism-trans/. Last accessed November 8, 2012.

Billings. D. and T. Urban. (1982). "The Socio-Medical Construction of Transsexualism: An Interpretation and Critique," *Social Problems* 29 (3): 266-282.

Boorse C. (1977). "Health as a theoretical concept," *Philosophy of Science* 44:542–73.

Butler, J. (2004). *Undoing Gender.* London: Routledge.

Chase, C. (1998). "Hermaphrodites with Attitude: Mapping the Emergence of Intersex Political Activism," *GLQ: A Journal of Lesbian and Gay Studies* 4 (2): 198-211.

Draper, H. and N. Evans. (2006.) “Transsexualism and Gender Reassignment Surgery.” In *Cutting to the Core: Exploring the Ethics of Contested Surgeries* ed. D. Benatar, 97-110. Lanham: Rowman & Littlefield.

Dreger, A. (1999). *Intersex in the Age of Ethics.* Fredrick, MD: University Publishing Group.

___________. (2008.) “The Controversy Over *The Man Who Would Be Queen.*” *Archives of Sexual Behavior* 37 (3): 366-421.

Ebersoff, D. (2000). *The Danish Girl.* New York: Viking Penguin.

Englehardt, H.T. (1975). “The Concepts of Health and Disease,” in H. T. Englehardt and S. Spicker, *Evaluation and Explanation in the Biological Sciences,* Dordrecht and Boston, MA: Reidel.

Girodano, S. (2008). “Lives in a Chiaroscuro: Should We Suspend the Puberty of Children with Gender Identity Disorder?” *Journal of Medical Ethics* 34 (8): 580-584.

Hale, C.J. (2007). “Ethical Problems with the Mental Health Evaluation Standard of Care for Adult Gender Variant Prospective Patients,” *Perspectives in Biology and Medicine* 50 (4): 491-505.

Harbin, A., B. Beagan, and L. Golberg. (2012). “Discomfort, Judgment, and Health Care for Queers,” *Journal of Bioethical Inquiry* 9: 149-160.

Hausman, B. (1995). *Changing Sex: Transsexualism, Technology, and the Idea of Gender.* Durham, NC: Duke University Press.

Hembree, W.C., P. Cohen-Kettenis, H.A. Determarre-van de Wall, et al. (2009). “Endocrine Treatment of Transsexual Persons: An Endocrine Society Clinical

Practice Guideline." *Journal of Clinical Endocrinology and Metabolism* 94 (9): 3132-3154.

Institute of Medicine. (2011). *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding.* (Washington, DC: National Academies Press).

Jonsen, A. (1998). *The Birth of Bioethics.* New York: Oxford University Press.

Kessler, S, and W. McKenna. (1985.) *Gender: An Ethnomethodological Account.* Chicago, IL: University of Chicago Press.

Lavin, M. (1987) "Mutilation, Deception, and Sex Changes," *Journal of Medical Ethics* 13: 86-91.

Meyer, W. (2012). "Gender Identity Disorder: An Emerging Problem for Pediatricians," *Pediatrics* 129 (3): 571-573.

Meyerowitz, J. (2002). *How Sex Changed: A History of Transsexuality.* Boston: Harvard University Press.

Murphy, T. (2012). "The Ethics of Fertility Preservation in Transgender Body Modification," *Journal of Bioethical Inquiry* 9 (3): 311-316

Nelson, H. L. (2001). *Damaged Identities, Narrative Repair.* Ithaca: Cornell.

Nelson, J. (1998). "The Silence of the Bioethicists: Ethical and Political Aspects of Managing Gender Dysphoria," *GLQ: A Journal of Lesbian and Gay Studies* 4 (2): 213-230.

_________. (2012). "Still Quiet After All These Years: Revisiting 'The Silence of the Bioethicists'," *Journal of Bioethical Inquiry* 9: 249-259.

Olyslager, F. and L. Conway. (2007). "On the Calculation of the Prevalence of Transsexualism." Presented to the World Professional Association for Transgender Health Symposium, Chicago, IL.

Pfällin, F. and A. Junge. 1998. *Sex Reassignment: Thirty Years of Follow-Up Studies after Sex Reassignment Surgery. A Comprehensive Review, 1961-1991.* Trans. R. B. Jacobson and A. B. Meier. Dusseldorf: Symposium Publishing.

Raymond, J. (1979). *The Transsexual Empire: The Making of the She-Male.* Boston: Beacon Press.

Reiheld, A. (2012). "'She Walked Out of the Room and Never Came Back: Is Provider Refusal to Treat Transgender Patients a Legitimate Case of Conscientious Objection, or a Betrayal of the Patient-Provider Relationship?" Presented at the American Society for Bioethics and Humanities National Meeting, Washington, DC, 18 October.

Salamon, G. (2008). "Transfeminism and the Future of Gender." In J.W. Scott (2008) *Women's Studies on the Edge.* Durham: Duke University Press.

Scheman, N. (1997). "Queering the Center by Centering the Queer: Reflections on Transsexuals and Secular Jews." In D. Meyers (1997), *Feminists Rethink the Self.* Boulder, CO: Westview.

Stone. A. (1996.) "The Empire Strikes Back: A Posttranssexual Manifesto. In Staub K. and J. Epstein (1996). In Straub, K. and J. Epstein (1996). *Body Guards: The Cultural Politics of Sexual Ambiguity.* New York: Routledge.

Spack, N., et al, (2012) "Children and Adolescents With Gender Identity Disorder Referred to a Pediatric Medical Center," *Pediatrics*. Originally published online February 20, 2012; DOI: 10.1542/peds.2011-0907. Accessed November 1, 2012.

Wahlert, L, and A. Fiester. 2012. "Questioning Scrutiny: Bioethics, Sexuality, and Gender Identity," *Journal of Bioethical Inquiry 9:* 243-248.

Wakefield, J. 1992. "The Concept of Mental Disorder: On The Boundary Between Biological Facts and Social Values" *American Psychologist* 47 (3): 373-388.

Waldman, C. (2012). Presentation, "What is Progress for Lesbian-Gay-Bisexual-Transgendered Health in Bioethics?" panel, American Society for Bioethics and Humanities National Meeting, Washington, DC. October 20th.

World Professional Association for Transgender Health (WPATH). 2011. *Standards of Care for the Health of Transsexual, Transgender, and Gender Nonconforming People,* 7th edition. http://www.wpath.org/publications_standards.cfm.

43.

Organ Transplantation Ethics From the Perspective of Embodied Personhood

Fredrik Svenaeus

Transplantation Ethics

Organ transplantation is a medical procedure that presents stunning possibilities in saving and improving the lives of ill and suffering people (Tilney 2003). Although organ transplantations are in this sense are ethically commendable things to do, the procedure has presented doctors and law and policy makers with a series of problems that have engaged medical ethics ever since the first transplants were carried out about half a century ago (Munson 2002). The ethical issues can roughly be grouped under four headings.

First, there are questions about the form of consent required from donors of organs. These questions regard both living donation – primarily kidney transplantations – and donation after death. Should consent be explicit or may it in cases of dead donation be presumed? What say should relatives have in the case of dead donation? How well informed must a donor be and what risks should he or she be allowed to take in the case of living donation? Should any form of compensation for the gift of organs be permitted?

The issue of compensation brings us to the second heading, namely questions regarding the buying and selling of organs. Should trade in human body parts be permitted? In nearly all countries of the world it is forbidden to buy or sell human organs, but the black market is large and growing. Kidney trafficking is a big business and the reason for this is the shortage of organs available for transplantation in rich parts of the world. Those in favor of lifting the ban on organ trade point out that legalization would improve the situation of vendors in poor parts of the world (Radcliffe-Richards et al. 1998). Under a legal organ trade vendors would receive a bigger share of the money that now ends up in the hands of organ brokers and they would presumably receive better medical treatment if selling was made legal. In addition to this, legalization would increase the supply of kidneys for transplantation in the world to a point at which the present lack would possibly cease. Costs for dialysis and other health care measures for people with kidney failure could be reduced, and the patients in question could live much better lives with a new organ in their body. In many cases a new organ would mean life rather than death to these patients (Tilney 2003).

Arguments against a legal organ trade can be made in different ways. The claims that trade would lead to better consequences for everybody involved can be challenged. Would not donation rates fall if people expected to get paid for their organs instead of giving them away for free? Will not poor people be forced to sell their organs, having no better options to relieve their present misery, especially if they are in debt to unscrupulous profiteers who could now make use of this new opportunity of income (Wilkinson 2003)? Another way of defending a prohibition on selling and buying body parts is to point towards ways in which legalization of an organ trade would expand market behavior into yet another zone of human interaction (Waldby and Mitchell 2006). To give an organ – or several organs if we are talking about posthumous donation – is a way to contribute to the life and well fare of other human beings without profiting from it. It is a commendable act that serves as a model for how we should live together in a society (Campbell 2009).

The third heading involves questions about when persons are dead and/or when they have any interests that could be violated by letting them die by way of removing their organs. Most countries in the world have changed their legal definition of death (primarily, though, admittedly, not only) as a consequence of the new opportunities of treatment with which organ transplantation presents us. The brain has succeeded the heart as the organ that needs to be functioning if the person should be considered to be alive. Presently it is the functions of the whole brain that should be determined absent and beyond chances of recovery for the person to be proclaimed dead in the legal definitions of most countries (Russell 2000). But the possibilities of keeping patients alive (or dead) in respirators have also raised the question whether persons who are beyond chances of regaining consciousness (although parts of their brains are still functioning) should not be considered in lack of any interests to be kept alive, whereas their organs could be used to favor the interests of many other persons who are presently conscious and suffering (Singer 1995).

The fourth heading concerns what we *owe* to people who are ill and suffering. The concept of justice is, indeed, central to all questions of organ transplant ethics, since the question if anybody *deserves* to be in need of a new organ (being ill and facing death) is a pressing one. Does not the principle of justice oblige us all to give the needy that which we could dispense with and still go on living a good life (i.e., one kidney)? Does it not oblige us to give them that which we do not need ourselves once we are dead (i.e., all our viable organs)? Whether people are obliged to become organ donors as a matter of justice is a central ethical question in the organ transplant literature (Fabre 2006).

Embodiment and Selfhood

The ethical questions grouped under the headings above all touch upon the relationship a person (a self) has to his or her body. It seems to be presumed by most philosophers that organs are something that *belong* to each person respectively. That is presumably why the persons must always consent to their organs being removed, although they may not be allowed to do *anything* they like with their organs for various reasons – consider the prohibition against selling. The two latter headings – the questions regarding when a person is dead and if we are obliged to give away our organs when we do not need them anymore – also concern issues of what belongs to the self. Can ownership rights be overruled in certain situations when the person is no longer there and/or parts of his or her body can be used to save the lives of others? These are the fundamental questions of transplantation ethics as it is currently pursued.

But what if our organs – kidneys and hearts will be my main examples in what follows – are not things that belong to us as commodities, but instead are to be looked upon as something that we *are*? How would such a *phenomenological* view upon selfhood, as fundamentally embodied, change our views on the ethics of organ transplantation? This is the question I will explore in this chapter, introducing some concepts from phenomenological philosophy and giving detailed descriptions of two cases of kidney and heart transplantation, respectively. Phenomenologists take their starting point in the first-person perspective when exploring an issue and I will try to stay true to this ideal in what follows (Zahavi 2005). This first-person perspective includes the second-person perspective (the dialogue with other persons), but it is to be contrasted with taking an impersonal third-person perspective of science as your philosophical starting point.

At first it may look as if the phenomenological view on the body would weaken the incentive or duty to give away one's organs when one can dispense with them, because it would equal giving away something of one's *self* instead of merely giving away one or several *things* that belong to you. However, as I will attempt to show, an embodied account of organ transplantation will rather make apparent that although different organs contribute to our embodied selfhood in various ways, this essential belonging of the person to his or her organs – rather than the other way around – shows us that our embodiment *connects* us to the lives and sufferings of other people in a fundamental way (Leder 1999).

The connectedness by way of the body goes back to the way we are delivered to the world as fundamentally *dependent* on other persons, a predicament made obvious in situations in which we become ill or disabled in various ways and need the support of others (Mackenzie 2010). We share the same fundamental needs and desires as human beings because we are embodied in similar ways. This does not mean that we are unable to, or, should not, care about other embodied creatures than humans, but our particular form of embodiment is an essential part of the life form in which we develop an ethics of human interaction. The "face of the other", as the phenomenologist Emmanuel Levinas puts it, is the basic source of ethical obligation, and it is not by accident that this metaphor is connected to embodiment (Diprose 2002). I encounter the other person by seeing, hearing, touching, even smelling him or her, and by this bodily encounter our belonging together is made possible. If not embodied, we would not desire and fear things that may happen to us, as a matter of fact, in order to have any kinds of feelings at all, we need to be embodied (and not just "embrained") (Damasio 1999). It is doubtful whether radically enhanced, post human persons, who have left the current limitations of human embodiment behind, will ever come into being, but if they do, they will probably not have an ethics that is similar to ours (Agar 2010).

Kidneys, hearts, and other types of organs, according to such an embodied view, are not just functional parts of the biological body; they are parts of what the phenomenologist calls "the lived body" (Zahavi 2005). The lived body is the body as it appears from the first-person perspective of the person *being* it, enabling the person to encounter and understand things around her in the world as meaningful for her in various ways. Our "being-in-the-world," as the phenomenologist Martin Heidegger puts it (1996), is consequently basically a bodily phenomenon, an insight elaborated by yet another influential phenomenologist, Maurice Merleau-Ponty (1962). The body to a large extent organizes my experiences already on a preconscious level by way of neurological systems centered in the brain that coordinate my movements and perceptions (Gallagher 2005). To the ways of the lived body also belong the processes of my biological organism: breath, digestion, blood flow, etc., which are mostly absent from my awareness but nevertheless provide the backdrop for my intentionality – my being directed towards different things that I engage with (Leder 1990).

Normally, when we engage in the world, busy doing various things, we do not pay much attention to our own bodies. They perform their duties inconspicuously in the background and make it possible for us to encounter things and other persons in the world around us, a world that we share as embodied, human beings. Sometimes, however, the lived body *shows up* in resisting and disturbing our efforts to do things. It "dysappears," rather than disappears, to use a term coined by Drew Leder (1990). The body plagues us and demands our attention by revealing itself, not only as our home, but as an *alien* creature. Organ transplantation, and also the process of falling ill, which in most cases (if one does not end up in the operating room because of an accident) precedes the transplantation, to a large extent inflicts such changes in self-being when our bodies display an unhomelike character. As phenomenologist Richard Zaner writes in his study *The Context of Self*:

> If there is a sense in which my own-body is "intimately mine", there is furthermore, an equally decisive sense in which *I belong to it* — in which I am at its disposal or mercy, if you will. My body, like the world in which I live, has its own nature, functions, structures, and biological conditions; since it embodies me, I thus *experience myself as implicated* by my body and these various conditions, functions, etc. *I* am exposed to whatever can influence, threaten, inhibit, alter, or benefit my biological organism. Under certain conditions, it can fail me (more or less), not be capable of fulfilling my wants or desires, or even thoughts, forcing me to turn away from what I may want to do and attend to my own body: because of fatigue, hunger, thirst, disease, injury, pain ... (Zaner 1981: 52)

I will now proceed to a more direct phenomenological analysis of organ transplantation in developing examples of what it is like to have a kidney and a heart transplant, respectively. In the examples I will attend to the ways the body shows up as "other" (unhomelike, alien) in situations preceding and following transplantation and the way these different types of otherness should be understood. The phenomenological analysis of organ transplantation situations will then be reconnected to the ethical issues concerning the relationship to one's body and the bodies of others surveyed above.

The Kidney Transplant

In the book *Holograms of Fear*, Slavenka Drakulić tells the story of her first kidney transplantation, which takes place in Boston in 1986 (Drakulić 1993). Drakulić has left her homeland of Yugoslavia, her family, friends, and even her young daughter, in order to live in New York as a journalist. This radical decision is forced upon her not by political oppression but by a genetic disorder affecting her kidneys: polysystic kidney disease. The medical care she is getting in Yugoslavia is not sufficient (she watches her fellow patients in the dialysis ward deteriorate and die), and she has poor chances in Yugoslavia of getting the transplant she needs to survive. In the book she tells how the disease and her dysfunctional kidneys force her to undergo dialysis every second day in the hospital for several hours:

> I had no choice. Every other morning at five o'clock I went for my dialysis at the hospital on 72nd Street. I didn't consider the possibility of not going. The healthy can choose. Life is simple when you're sick, as it is for people in jail or in the army. There are rules that are more than rules because breaking them can only mean one thing. At first this is non-freedom but later, it is just certainty. . . . Here the blood flows in streams: in veins, capillaries, pumps, rubber hoses, in clear plastic tubes, in cylindrical dishes with filters. As if the white room was woven with a red web. Everyone is quiet, deathly tired. They communicate in code, in subdued tones. (Drakulić 1993: 3-4)

To be in dialysis treatment means that your life becomes *regimented* in a new way. This concerns not only the hours you have to spend connected to the dialysis machine but also the way you have to watch and regulate your body, considering diet, how much to drink, sleep, exercise, etc. to keep the disease under control. But the most thoroughgoing effect of the kidney disease is that the body shows up in new and disconcerting ways that become central to your everyday experience, self-reflection, and life story:

> The thing moved from person to person like bad luck. No one could tell who it would attack. It attacked my father. It attacked me. It left my brother unharmed. We almost thought that it had skipped us, too, that those ancestors who had died in the past had nothing to do with us. But at the first signs — nausea, vomiting, tiredness — I knew that it had come. The doctors didn't tell me right away although they suspected it. I was already pale, my pulse was fast and every time I lay down I thought I might not be able to get up. Later my father came down with it as well. They told us that these days it was possible to live with it, that there were machines, kidney transplants. Various deals could be struck with the sickness, negotiating with bad luck. (Drakulić 1993: 6-7)

The uncanniness of such experiences is hard to deny. The body reveals itself as incorporating alien, unhomelike elements in illness (Svenaeus 2000). The uncanniness concerns the way the body becomes an obstacle and a threat, instead of my home territory and basic affordance, but in this (and most other severe) case(s) of illness it also concerns the ways I address the meaning of my life and my relationship to others. Bodily connectedness is made even stronger in cases of inherited diseases in which the family bonds are not only the source of security, joy or annoyance, but of a possible deadly curse.

Waiting for the transplant, knowing that you are on the waiting list but with no knowing when, if ever, the doctors will find a suitable kidney for you, is a pressing experience in itself. So is the fear of pain or dying as a result of the operation. You long desperately for a life with more freedom and fewer symptoms, but at the same time, the regime of dialysis might become a habit and a kind of security you are afraid of leaving for the uncertainty of the operation, which is, certainly, a dramatic event:

> "Breathe, breathe." An English voice penetrates the darkness in which I'm floating. . . . Terrified I try to suck in air, catch it with my open mouth, but something is inside, something is inside. It is smothering me, I have to retch it out. They are pulling out a long tube with a sudden jerk from my throat, tearing the membranes. A deep sigh. Then a sharp pain under my stomach cuts me in half. "Your kidney is functioning." (Drakulić 1993: 42)

Only slowly does Drakulić recover after the operation; it takes hard exercise and a lot of time to be able to sit up, stand, walk, eat, etc. Even the routine of going to the toilet is an effort and, in the specific case of kidney transplants, also a new and remarkable experience for the patient, since the kidneys have not been producing any urine for a long time.

Even in the successful cases, when the new kidney works properly and is not rejected by the immune system, life after a transplant is not like life before the onset of disease. To suffer from a disease that destroys your kidneys and to get a new kidney means that life becomes prolonged and normalized, but it does not mean that life becomes the way it was before the onset of the disease, since you are at constant risk of renewed kidney failure. To live with a foreign kidney in your body means to lead a life that is extremely self-controlling as regards the relationship to your body. It often means a more anxious life, in the sense that the basic trust in the body is gone, but it could also mean a more self-reflected life, in the sense that the finitude of your life and the question of what is of real importance in it have come to the surface (Frank 1995). Finally, it will lead to thoughts about the life of others and how they are connected to you, particularly the person whose death (in the case of cadaveric transplant) and generous gift means life for you:

> "Her kidney came from a woman," the doctor said to someone. He was leaving the room. He thought I was asleep. … I don't care who it belonged to, I am not curious. I think of it as an organ, not as part of a person. I must not be sentimental. My life is on the line. But the picture reappears. Her smiling face, gone forever. A lot of time will pass, then in a subway somewhere, a tall man will stop me. . . . "Excuse me, I couldn't help myself, but you look so much like my late wife." I'll stare at him, indifferent at first. I'll pretend that I have no idea what he is talking about. Perhaps I'll say I don't know any English. But something will force me to change my mind and I'll say: "Yes. Yes, I probably do look like her. We are sisters, almost twins — you didn't know that she had a sister? You see this thin scar? It has almost disappeared, but this is where she moved in. We live well together, the two of us. Sometimes she gets a little obstinate. I can't keep her from spreading. Sometimes she chooses a smile, other times a gesture, or a walk — to

> show that she is here, that I am in her power. I think perhaps she wants to make me feel grateful. It's not my fault that she was killed." (Drakulić 1993: 73-74)

To sum up: already the kidney *disease* leads to experiences of bodily alienation – the body behaving in painful ways that I cannot control – which have implications for the way I think about myself and my life in relationship to others. However, the otherness displayed by my own body in severe disease has repercussions for my entire life, making it hard, sometimes impossible, to be at home in the world in carrying out everyday activities. It also affects my relationship to other persons and sometimes the way I think about my entire life and its purpose. Why did this happen to me? What kind of a person am I and who do I want to be? After having the transplant this reflection in many cases leads to feelings and thoughts about the origin of the new kidney I now bear in my body (Sharp 2006). The scientific attitude to my new organ as a thing among other things, an attitude that will be encouraged by the doctors, can easily be conquered by an attitude in which the kidney of the other person harbors his or her identity in some way that has now been transposed to me. It might also lead to a thankfulness that becomes transformed into guilt (How have I earned this life that was made possible by the other person's death?).

The Heart Transplant

In the case of the heart, things are slightly different, not only when it comes to the symbolic character of the heart (life, love, goodness) in comparison to the kidney (what, really, is a kidney symbolic of?) but also regarding the extent to which the heart *shows up* to me, in illness, and also in health. In contrast to the case of the kidney, it is possible to direct one's attention to the activity of one's heart at any time, and in situations that make us react strongly emotionally it is almost impossible *not* to notice one's heart pounding in association with other bodily processes, such as blushing or sweating. In exercise, the heart (together with the rest of the body, of course) sets the limit for what we are able to accomplish, and these limits are clearly *felt* on the embodied level as intense heart and lung activity or pain and weakness of muscles when, for example, I run fast for a long time.

Heart disease does not always make itself known through the experience of pain in the heart itself; a heart attack is experienced as a chest pain radiating out through chest and arms, for example. But the possible irregularity in the rhythm of the heart's beating, which can be a very powerful and frightening experience, nevertheless marks out the heart as something that appears in a more singular manner than the kidney does, in at least some cases of heart disease.

Human hearts have been transplanted since the late 1960s while the history of kidney transplantation dates back to the 1950s. A heart transplant is an even more dramatic and difficult operation than a kidney transplant, and it was not until the 1980s that surgical techniques and new immunosuppressive medications made it possible for patients to survive a heart transplant for a longer time (Tilney 2003). To find a new heart for a dying patient is even harder than finding a new kidney, for two simple reasons. Each person only has one heart, which makes living donation impossible (as long as we do not allow killing one person to let another live). Furthermore, hearts deteriorate much faster than kidneys outside the body, which means that we have only a very limited time in which to carry out the transplant (kidneys last much longer if they are kept the right way). Hearts for donation will most often come from patients who have been put on respirators as the result of accidents or sudden occurrences of disease (stroke) and have then been declared brain dead while they are still connected to the machine that assists the breathing and the circulation of the blood that keep the organs of the deceased person fresh.

In the early 1990s, the French philosopher Jean-Luc Nancy underwent a heart transplant after a period of severe illness. He wrote about this event and the cancer that he was subsequently taken with — probably as a result of the heavy doses of immunosuppressive medicines that post-transplantation patients have to take to prevent rejection of their grafts — in the essay “The Intruder,” which I will make use of in what follows (Nancy 2008). Nancy’s main figure for understanding the process he is undergoing is found in the title of his essay:

> The intruder introduces himself forcefully, by surprise or ruse, not, in any case, by right or by being admitted beforehand. Something of the stranger has to intrude, or else he loses his strangeness. If he already has the right to enter and stay, if he is awaited and received, no part of him being unexpected or unwelcome, then he is not an intruder any more, but neither is he any longer a stranger . . . To welcome a stranger, moreover, is necessarily to experience his intrusion. (Nancy 2008: 161)

This way of conceptualizing the *intruder* (as a person, but also, as we will see, as a thing that intrudes in me, such as an organ) is very similar in structure to the analysis of bodily *alienation* I have developed above. When Nancy’s analysis is coupled to the experience of illness and transplantation, the overlap becomes almost total:

> If my own heart was failing me, to what degree was it “mine,” my “own” organ? Was it even an organ? For some years I had already felt a fluttering, some breaks

> in the rhythm, really not much of anything: not an organ, not the dark red muscular mass loaded with tubes that I now had to suddenly imagine. Not “my heart” beating endlessly, hitherto as absent as the soles of my feet while walking. It became strange to me, intruding by defection: almost by rejection, if not by dejection. I had this heart at the tip of my tongue, like improper food. Rather like heartburn, but gently. A gentle sliding separated me from myself. (Nancy 2008: 162-63)

In comparison with the kidney failure experienced by Drakulić we can see that the failing heart penetrates the experiences of Nancy to a far greater extent, as regards the perception of the organ itself. But the alienation is also driven by the unique symbolic quality of the heart as the essence of life, goodness, and personal identity (Lakoff and Johnson 2003). Despite living in a scientific age, it is almost impossible to view the heart as a pure biological entity among others, a “pump” only, rather than the center of our emotional life. The heart is loaded with meaning and identity; therefore the intruding heart (still his old one) separates him from himself.

A new heart (the transplanted heart) is certainly also an intruder, but it is an intruder that we would like to welcome. This is possible, however, only by “experiencing his intrusion,” as Nancy writes (2008: 161). This means the pains and plagues following the procedure of having the sternum cracked and the chest cut wide open in an operation that lasts for several hours and during which the blood is circulated and oxygenated by way of an external device, a heart-lung machine. It also means suppressing the body’s immune system to prevent it from attacking and rejecting the graft, something that will otherwise happen immediately after the operation or in due time. The graft is foreign, an “intruder” in the body, which we have difficulties welcoming. But the immunosuppressive actions taken mean that other intruders (bacteria, viruses), lying dormant in the body or entering from outside, become a major threat. It also means that the regular outbreaks of uncontrolled cell division in the body, which otherwise are dealt with by the immune system before they grow and spread, can now lead to cancer diseases. Nancy describes this multiple intrusion by organs, viruses, and cancerous cells, but also by medical technology and therapies. The latter make him *objectify* his own body, and in this way he becomes alienated from it in a way that aggravates the physical suffering (Nancy 2008: 169).

To sum up: the heart is “mine” in a way that the kidney is not, despite their both being hidden under the skin, rarely visible, except in the extreme situations of accidents, operations, and autopsies. This is probably due to the heart’s being an organ that can be *felt* to a greater extent than the kidney can, and, also, due to the symbolic connotations of the heart in comparison with the kidney. Heart transplants may therefore evoke questions of identity in an even stronger way than kidney transplants will sometimes do (as in the case of Drakulić). Two good illustrations of how such questions of identity surface and lead to new bonds being formed between people as the result of heart transplants are the movies *All About My Mother* by Pedro Almodovar, from 1999, and *21 Grams* by Alejandro Gonzales Innarritu, from 2003. In both movies, stories are told about heart transplants and the attempts made by patients and family members of donors to find out more about the identity of donors and recipients of hearts, respectively. In these interactions new connections and relationships between persons are formed as a result of the transplant.

Embodied Selfhood and Transplant Ethics

Getting a new organ – a kidney, a heart, a lung, a liver, a pancreas, a hand, a face, or some other part of the body that the doctors are able to transplant – will help a patient to a better life in most cases, at least when the new body part is installed in the patterns of the lived body in a successful way. It follows from the phenomenology of organ transplantation, unsurprisingly, that donating organs is a good thing to do because it will help other persons to be more at home with their bodies, enabling them to live a richer life (and survive). To donate posthumously may even be an obligatory thing to do, at least in situations when the transfer of organs can be brought about without violating the dignity of the embodied self (Campbell 2009). To what extent a body with an irreversibly damaged brain, kept "alive" through artificial measures, can be violated depends on the cultural practices of caring for and taking leave of the dying (Lock 2002). Dignity is a tricky concept (The President's Council on Bioethics 2008), but in the situations of organ transplantation, to violate dignity would primarily mean to treat brain dead bodies as entities that are first and foremost useful things – or collections of things – instead of bodily traces of persons that are connected to family members and friends by histories of life-long interaction. Dead bodies, however, have been treated in various ways in different cultures throughout human history, all found respectful in their particular contexts, and it should not be impossible to successively install practices that can be combined with donation of organs. Indeed, this is already happening in many parts of the world, but the issue of how and why the dead body is more than an organ bank needs to be addressed in bioethics rather than being hidden or dismissed as bad metaphysics or religious superstition (Svenaeus 2010).

The phenomenological idea that we in a fundamental way belong to our own bodies, rather than the other way around, can work as an antidote to the influential organ-commodity paradigm in contemporary bioethics. The phenomenological account can deliver an argument explaining why body parts are not just yet another type of things to be traded, but rather fundamental parts of our self-being. We are born *as* a body coming from *another* body. The body makes our existence and appearance as persons possible and it does so in a way that is related to how we depend on each other as finite human beings having to die. This explains why organs are not things that belong to us in the same way as outer things in the world do. Organs are identity bearing in the sense that they belong to the *processes* of selfhood – the lived body – rather than being things that the self (the brain) controls and makes decisions about. Therefore, according to an embodied, phenomenological view, organs should not be traded in, even though they can and should be shared by way of transplants. "Giving life", as the slogan for encouraging organ donation goes, is a *sharing* of life, not an offer of a valuable commodity. Rather than fearing that a view upon grafts as anything but useful biological material will create confusion and feelings of guilt in patients who receive new organs, health care professionals should perhaps to a greater extent acknowledge the bonds that are created between people and families by organ transplantation, also in cases of posthumous transplantation (Sharp 2006).

My attempt above to develop a phenomenological framework in which to place the ethics of organ transplantation is far from complete and the theses put forward here may not be directly applicable to the writing of ethical codes or guidelines. Many questions about the implications of a phenomenology of the embodied, interconnected self for bioethics in the case of organ transplantation have been left unanswered in this chapter. They concern the exact responsibilities embodied bonds put on individuals in different situations. Do I have the same obligations to all human beings in need? Are the obligations stronger in cases of people I connect to in my everyday life and meet face to face, than in cases of people far away whom I hear of or watch on television? The phenomenological ethics to guide organ transplantation certainly remains to be worked out in more detail. Nevertheless, I hope to have shown that phenomenology is a viable way to go in searching for theories in bioethics to complement autonomy, welfare and virtue-based approaches in an interesting way.

Related topics:

Chapter X, "Medical Tourism," I. Glenn Cohen

Chapter X, "Autonomy," Catriona Mackenzie

Chapter X, "Brain death," Winston Chiong

Chapter X, "BIID and the Question of Ethics," Nikki Sullivan

References:

Agar, N. (2010) *Humanity's End: Why We Should Reject Radical Enhancement*, Cambridge Mass.: MIT Press.

Campbell, A. V. (2009) *The Body in Bioethics*, London: Routledge.

Damasio, A. R. (1999) *The Feeling of What Happens: Body and Emotion in the Making of Consciousness*, New York: Harcourt Brace.

Diprose, R. (2002) *Corporeal Generosity: On Giving with Nietzsche, Merleau-Ponty, and Levinas*, Albany: State University of New York Press.

Drakulić, S. (1993) *Holograms of Fear*, London: The Women's Press.

Fabre, C. (2006) *Whose Body is it Anyway? Justice and the Integrity of the Person*, Oxford: Oxford University Press.

Frank, A. W. (1995) *The Wounded Storyteller: Body, Illness and Ethics*, Chicago: University of Chicago Press.

Gallagher, S. (2005) *How the Body Shapes the Mind*, Oxford: Oxford University Press.

Heidegger, M. (1996) *Being and Time*, trans, J. Stambaugh, Albany: State University of New York Press (original work published 1927).

Lakoff, G. and Johnson, M. (2003) *Metaphors We Live By*, 2d edition with a new afterword, Chicago: University of Chicago Press.

Leder, D. (1990) *The Absent Body*, Chicago: Chicago University Press.

Leder, D. (1999) ”Whose Body? What Body? The Metaphysics of Organ Transplantation,” in M. J. Cherry (ed), *Persons and Their Bodies: Rights, Responsibilities, Relationships*, Dordrecht: Kluwer Academic Publishers, pp. 233-264.

Lock, M. (2002) *Twice Dead: Organ Transplants and the Reinvention of Death*, Berkeley: University of California Press.

Mackenzie, C. (2010) "Conceptions of Autonomy and Conceptions of the Body in Bioethics," in J. L. Scully, L. E. Baldwin-Ragaven, and P. Fitzpatrick (eds), *Feminist*

Bioethics: At the Center, on the Margins, Baltimore: Johns Hopkins University Press, pp. 71-90.

Merleau-Ponty, M. (1962) *Phenomenology of Perception,* trans. C. Smith, London: Routledge (original work published 1945).

Munson, R. (2002) *Raising the Dead: Organ Transplants, Ethics and Society*, Oxford: Oxford University Press.

Nancy, J-L. (2008) "The Intruder," in: *Corpus*, trans. R. Rand, New York: Fordham University Press (original work published 2000), pp. 161-170.

Radcliffe-Richards, J. et al. (1998) "The Case for Allowing Kidney Sales," *The Lancet* 351: 1950-2.

Russell, T. (2000) *Brain Death: Philosophical Concepts and Problems*, Aldershot: Ashgate Publishing.

Sharp, L. (2006) *Strange Harvest: Organ Transplants, Denatured Bodies, and the Transformed Self*, Berkeley: University of California Press.

Singer, P. (1995) "Is the Sanctity of Life Ethic Terminally Ill?" *Bioethics* 9: 307-43.

Svenaeus, F. (2000) *The Hermeneutics of Medicine and the Phenomenology of Health: Steps Towards a Philosophy of Medical Practice*, Dordrecht: Kluwer Academic Publishers.

Svenaeus, F. (2010) ”The Body as Gift, Resource, or Commodity: Heidegger and the Ethics of Organ Transplantation," *Journal of Bioethical Inquiry* 7: 163-72.

Tilney, N. L. (2003) *Transplant: From Myth to Reality*, New Haven: Yale University Press.

The President's Council on Bioethics (2008) *Human Dignity and Bioethics*, Washington D. C.: Essays Commissioned by the President's Council on Bioethics.

Waldby, C. and Mitchell, R. (2006) *Tissue Economics: Blood, Organs and Cell Lines in Late Capitalism*, Durham: Duke University Press.

Wilkinson, S. (2003) *Bodies for Sale: Ethics and Exploitation in the Human Body Trade*, London: Routledge.

Zahavi, D. (2005) *Subjectivity and Selfhood: Investigating the First-Person Perspective*, Cambridge, Mass.: MIT Press.

Zaner, R. M. (1981) *The Context of Self: A Phenomenological Inquiry Using Medicine as a Clue,* Athens, Ohio: Ohio University Press.