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Feature
Direct to consumer advertising of prescription medicines
IN THIS ISSUE

3 Feature
Direct to consumer advertising of prescription medicines: What you don’t say counts
Paul Biegler, MBBS, FACEM, PhD

5 Ask the ethicist
Should a nursing home refuse to honor a written advance directive?
Muriel R. Gillick, MD

6 The legal column
Pregnancy exclusions, posthumous pregnancy and the Constitution
Michelle N. Meyer, JD, PhD

8 Ethics and the humanities
A Loss for Words
A review of the memoir by Lou Ann Walker
Jenny Blair, MD

9 Dialogue
What was wrong with eugenics
Robert Sparrow, PhD
Nicholas Agar, Reader in Philosophy

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Direct to consumer advertising of prescription medicines: What you don’t say counts

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A fir-studded slope plunges down to a bay as the afternoon sun conjures jewel-like ripples on the water. A man with umber skin musses his dog’s coat as they set off through a needle-strewn pine forest. They spot a landing jutting into a secluded cove and race to it before diving into the cool depths.

An extract from a “Boy’s Own” adventure? In fact, these invigorating images are part of something so dangerous that it is banned in nearly every country of the world. They are an example of a phenomenon called direct to consumer advertising (DTCA) of prescription medicines — in this case a television commercial for the cholesterol-lowering drug Lipitor. Lipitor is one of the so-called prescription medicines — drugs with such serious side effects that only a doctor can authorize their use by writing a “prescription.” Globally, the only two countries that permit DTCA are the U.S. and New Zealand. Why is everyone else so reluctant to allow DTCA?

The main goal of advertisers is to persuade consumers, not to educate them. So critics are concerned that advertisements will accentuate the benefits of drugs and minimize the risks, which could unduly tempt sick people to try them. The U.S. tries to mitigate that concern with regulation. The U.S. Code of Federal Regulations, for example, demands “a true statement of information relating to side effects, contraindications, and effectiveness” (21 CFR 202.1, .3). The Code also requires a “fair balance” in the way risks and benefits are presented (21 CFR 202.1(e)(5)(ii)).

The aim of the Code is to ensure that statements about the drug’s properties are both factual and evenly weighted. These statements are “propositions” in the sense that they are capable of being proven true or false. But the focus on “propositional content” distracts from something ethnically very troubling.

Prescription drug ads also have “nonpropositional” content, bits that don’t involve any clear statement about the drug. The Lipitor ad is full of spine-tingling imagery, soaring music, smart logos and the dulcet tones of a voice-over artist. This nonpropositional content mostly escapes regulation for a simple reason: You can’t say a mountain, an aria, a graphic design or a reassuring voice is true or false, so regulations that center on truth don’t cover them. But nonpropositional content is persuasive.

Let’s say a picture of children playing under a waterfall makes you happy. Pair that picture over and over with something that leaves you cold, like a new brand of shampoo, and the good feelings eventually rub off onto your perception of the shampoo. Like Pavlov’s dogs that drooled when they heard the bell, you feel good when you see the shampoo. Skeptical?

For years, psychologists have been using happy pictures to make people like things, from toothpaste to beer and even human faces. It’s called “evaluative conditioning,” and it is a powerful tool in the advertiser’s kit. But drugs are different — let’s face it, they can kill you. So, could pretty pictures really condition you to like a drug?

With funding from the Australian Research Council, I teamed with Patrick Vargas, Associate Professor of Advertising at the University of Illinois at Champaign-Urbana, to find out. We dreamed up a realistic-sounding

Continued on next page
drug to treat the flu and dressed it up in a bright box with a blue, green, and yellow sun logo. Then we devised a public service announcement about the flu and our new drug. We asked study participants to listen to the announcement while a computer screen showed our little drug box in front of a big picture that changed as each sentence was read aloud.

One group saw the drug box with nice background pictures, like a skier doing slalom down a mountain, a Hershey bar and a shiny red sports car. A second group saw ho-hum pictures like rubber bands, barrels and a glass mug. The third group got the unpleasant option. They saw our drug box superimposed on a gruesome backdrop of seals bludgeoned to death on ice floes, the scattered aftermath of a plane crash and a violent carjacking. Then we asked people to tell us what they thought of the drug. What they said left us in little doubt about the power of pictures in drug advertising.

People who saw skiing, cars and Hershey bars felt more positively about the drug, believed it to be safer and more effective, and were more likely to ask their doctor for it than were people who saw the macabre images. The ethical implications for DTCA might seem obvious, but it’s worth spelling them out.

The sun-drenched peaks and sparkling bays in a drug commercial help forge viewers’ beliefs about the drug. But they aren’t there to furnish the truth. Major side effects of Lipitor include liver failure and muscle breakdown, but the ad does not feature a jaundiced person, face contorted in pain. That would ring the death knell on the drug’s commercial success. Imagery in DTCA is overwhelmingly positive and usually shows people reeling in wellness, courtesy of the drug. Negative scenes are reserved for those troubled souls who have yet to try it.

But mountain peaks are like sports cars and Hershey bars; they tell you nothing factual about the drug. They are not a reliable basis for drug beliefs, and so the favorable beliefs they do produce are unjustified and frequently false. The big ethical problem with unjustified beliefs is the damage they do to autonomous choice.

To be autonomous is to think rationally and to make choices that reflect one’s deeply held values. Autonomy is a key value in medical ethics because, all things considered, the more autonomous the choice, the more likely the outcome will be in the person’s best interests. But autonomy hinges on people having a factual understanding of relevant information, something that DTCA appears to work against.

In a survey of 459 physicians, three-quarters said DTCA made patients think “drugs work better than they actually do.” Less than a third thought patients understood the limits of an advertised drug’s effectiveness. In the same study, nearly two-thirds of primary care physicians said DTCA made patients want an advertised drug over any other, no matter how effective it is in reality. Another study found patients in jurisdictions that allowed DTCA were more than twice as likely to ask their doctor for a branded drug than were patients from regions where the practice was banned.

One might think that doctors would rein in all this ad-fueled exuberance with cool logic, but it seems doctors are less-than-perfect gatekeepers. One study found that doctors say yes to more than half of requests for branded drugs even when those drugs aren’t the best choice for the condition.

Evaluation conditioning is but one possible technique in DTCA that leverages nonpropositional content. “Priming” is when a cue in your environment triggers you to think or do something related. Studies have found that if you hear a recording of Edith Piaf in the liquor aisle, you’re more likely to buy French wine; and if you see a picture of a library, you’ll be faster at picking out “quiet” words from a list. Priming works in advertising too. In one study, children who watched snack food ads ate 45 percent more from a bowl of crackers than did kids who saw nonfood ads.

And in a recent article in the Kennedy Institute of Ethics Journal, I argued that drug ads prime people to prefer drug over nondrug treatments for illness. The ethical problem is that primed behavior leaves people with an “explanatory gap”; they are unsure why they do as they do. There is good reason to believe they fill that gap with a convenient fiction to justify their primed choice. It is called “post-priming misattribution,” and it may skew beliefs about advertised drugs, again setting back autonomous drug choices and raising serious questions about the permissibility of DTCA. But it is important to consider objections to the foregoing.

All advertising uses these persuasive techniques, so why subject DTCA to such scrutiny? Few products have the potential to cause illness or death, thus prescription medicines are in a special category. Admittedly, ads for health insurance and financial advice could antagonize autonomy and seriously harm some viewers. But that is an argument in favor of tightening advertising standards for those products rather than relaxing standards for drug advertising.

Perhaps the awful side effects listed in drug ads balance out the positive conditioning? There is likely to be some truth in this because there is evidence that words with a negative valence, like cancer and fear, can condition negative attitudes. But if the advertisers’ aim is justified belief, it is surely better to list side effects next to realistic descriptions of the drug’s benefits, as you would find in a plain-language information leaflet.

A further concern is the difficulty of regulating the images, music and so on that could lead DTCA viewers to
Ask the ethicist
Should a nursing home refuse to honor a written advance directive?

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Question: A 91-year-old woman living in a nursing home had executed a written advance directive 11 years earlier while in robust health, stating that if she ever developed dementia so severe that she no longer recognized family members, she instructed her caregivers to withhold her oral food and drink (as well as artificial hydration and nutrition) to allow her to die naturally. The directive was cosigned by her daughter, a nurse, who was her health care agent.

Several years later, the patient developed dementia that progressed to an advanced stage, and she no longer recognized family members. Her daughter produced the signed directive, which she requested be enforced to respect her mother’s clearly stated wishes. However, the nursing staff and administrators of the institution refused to respect the directive because they said it was unethical not to feed her, and it violated state laws governing nutritional requirements for inpatients in chronic care facilities. The ethics committee of the institution was contacted for advice.

Response: This 91-year-old woman was in the unusual position of having addressed in her advance directive precisely the situation in which she found herself. She had delineated her request — no food and drink — and the situation in which it was to apply — advanced dementia. She had executed a witnessed living will and designated a surrogate to carry out her wishes. Yet the nurses and doctors taking care of her balked at honoring her wishes. Why? Are there some types of requests that we are not obligated to respect? Are there some circumstances in which autonomy is not paramount?

What is well-established in both secular ethics and American law is that patients may demand the withdrawal or withholding of any medical intervention, including artificial nutrition and hydration (ANH), and if they are unable to speak for themselves, a surrogate may act on their behalf. These principles were affirmed by the U.S. Supreme Court in the Cruzan case and are endorsed in leading textbooks of medical ethics. But what about food and fluid — not a bottled solution delivered via a gastrostomy tube or an intravenous line, but food taken by mouth?

To regard food as treatment medicalizes anything that is conducive to human health and well-being. Just because dietary restrictions are sometimes recommended by physicians does not transform food into medication; it merely emphasizes the interconnectedness of health and other aspects of life. What characterizes food and drink, like clothing and bathing, is that they are essential for human dignity. If competent individuals can require caregivers to withhold food, they can also demand that caregivers refrain from keeping them clean or clothed. Societal conventions for respectful care may change over time — bathing was once a rarity — and may vary among cultures. Offering food and drink is currently required because it is a social norm; it is not medical treatment that patients have a right to refuse.

Even if food and drink were construed as medical treatment, there is another problem with implementing our 91-year-old’s directive: It assumes the person who drew up the directive is the same person as the individual to whom the directive is supposed to apply. The philosophical underpinnings of advance-care planning hinge on continuity between previous and current selves. The person who wrote that she was not to be fed if she developed advanced dementia assumed that her views of an acceptable life should govern her future self because the two selves shared a common personhood. But suppose her demented self smiles at the aide who cares for her, cheerfully taps her foot to music and coos when her daughter hugs her. Surely her wish, if she were able to articulate one, would be to continue living in her current state, oblivious to and undisturbed by her limited cognition, precisely that state that her previous self viewed as worse than death. Should the preferences of the earlier version trump current best interests?

Vigorous proponents of autonomy (such as Ronald Dworkin) say yes, according “precedent autonomy” greater weight than mere “experiential interests,” but other equally thoughtful commentators (such as Rebecca Dresser) disagree. Dworkin indicates that people wish to have “narrative coherence” in their lives, and therefore, whatever views about dementia they expressed earlier in life should be honored when they in fact develop dementia. Dresser argues that individuals with dementia live largely “in the present,” and that their loss of memory and associated personality changes have effectively transformed them into a new person.

Surprisingly, there is a way to reconcile these seemingly contradictory perspectives. Consider for a moment a case in which the facts on which the patient relied to make an advance directive have been superseded — perhaps the patient had stated unequivocally that she would want artificial nutrition and hydration in the event she developed advanced dementia, based on the erroneous assumption that ANH would prolong life. Would the physician be obligated to provide ANH, knowing that the request was made based on incorrect information? Surely in that situation it would fail to the health care proxy to interpret the advance directive in light of new evidence. Similarly, when our 91-year-old patient’s previously cognitively intact self said she would want food withheld in the event of dementia, her prior self likely failed to recognize how much satisfaction she would one day derive from life with dementia.

The way to resolve the conflict between precedent autonomy and current best interests is thus to invoke the health care agent. The health care agent is in the best position to assess whether the advance directive was drawn up with full awareness of how
The legal column

Pregnancy exclusions, posthumous pregnancy and the Constitution

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In all 50 states and the District of Columbia, advance directive statutes enable individuals to indicate their treatment wishes in the event that they one day suffer from a terminal illness (or, sometimes, an irreversible condition) and can no longer make treatment decisions. Most of these statutes contain “pregnancy exclusions.” About one-third of advance directive statutes resemble Texas’, which provides that “a person may not withdraw or withhold life-sustaining treatment under this subchapter from a pregnant patient.” Another one-third contain similar exclusions that apply only if “it is probable that the fetus will develop to the point of live birth.” Finally, a handful of statutes create a presumption in favor of continued treatment that is rebuttable if a woman’s advance directive specifically directs that life-sustaining treatment be withdrawn or withheld in the event of pregnancy.1

Understanding the legal effect of these exclusions requires dispelling some myths about the legal implications of advance directives. First, advance directive statutes are intended to guide the treatment of living patients. This was one lesson of the Marlise Munoz case, in which a Texas hospital, citing the state’s pregnancy exclusion, refused to withdraw her ventilator. The court ruled that the law on its face does not apply to dead women, rejecting the hospital’s argument that the exclusion’s reference to “life-sustaining” treatment should be read as applying to living fetuses within dead bodies. Once the hospital acknowledged that the patient met the clinical criteria for brain death, the court ordered doctors to pronounce death and remove the ventilator.2

Second, advance directive statutes generally do not obligate health care providers to comply with patients’ stated wishes. Rather, to incentivize providers to follow patients’ advance directives, they immunize providers who choose to do so from civil and criminal liability and from disciplinary action. The Texas law’s admonition that “a person may not withdraw or withhold life-sustaining treatment under this subchapter [emphasis added] from a pregnant patient,” then, is best read as merely denying providers immunity if they choose to follow a pregnant patient’s directive to withhold life-sustaining treatment.3 It does not mean, as the hospital argued in the Munoz case, that providers are prohibited from following a pregnant woman’s directive.

The constitutionality of pregnancy exclusions

The constitutionality of pregnancy exclusions is unclear, not least because they involve other complex, highly contested areas of law, including refusal of life-sustaining treatment, abortion and maternal-fetal relations. Two potentially illuminating lawsuits challenging these exclusions were dismissed because the plaintiffs were neither pregnant nor suffering from any qualifying condition.

The U.S. Constitution is widely assumed to protect an individual’s right to refuse life-sustaining treatment and to have that right exercised on the individual’s behalf if she is incapacitated.4 However, as we have seen, pregnancy exclusions merely deprive providers of automatic immunity. A provider who chooses to treat a pregnant woman against her previously stated wishes may or may not be guilty of battery, and a court that orders such treatment may or may not thereby violate the woman’s constitutional rights. But it is not obvious that exclusions themselves — which withhold any promise of immunity but leave providers free to honor advance directives — are unlawful.

Similarly, pregnancy exclusions are unlikely to violate the Equal Protection Clause, since the Constitution only requires equal treatment of similarly situated groups. The state’s interest in prenatal life makes pregnant women different from other people.

As for the legality of continuing life-sustaining treatment, the Constitution permits states to require clear and convincing evidence that the patient would have refused the proposed treatment. If pregnant women in a persistent vegetative or similar state have expressed their end-of-life wishes at all, they are unlikely to have specifically considered the possibility that refusing life-sustaining treatment might end a wanted pregnancy.

Even if a woman’s wishes are clear and specific, courts have recognized that the right to refuse life-sustaining treatment may be overridden by any of four state interests, including the preservation of life and the protection of third parties. As a result, some lower courts have ordered competent pregnant women and parents of minors to submit to life-sustaining treatment.5 The Supreme Court has held that the state has a legitimate interest in potential life throughout pregnancy. That interest becomes compelling at viability,6 a point in pregnancy that is determined case by case by a woman’s doctor (in some states, via required tests or certification by additional physicians). Courts faced with choosing between a woman’s right to direct her medical care and fetal welfare have often ordered treatment (frequently, a cesarean section) and might similarly order continued gestation, especially post-viability.

Courts may be even more willing to tip the balance of interests in the direction of a viable fetus when the proposed interventions are not burdensome — for example, maintaining a woman in a persistent vegetative state on a ventilator rather than conducting highly invasive abdominal surgery on a sentient woman. Conversely, courts are much less likely to order continued treatment that shortens a woman’s life or causes her pain against her prior wishes, even if the fetus is viable. Although the Constitution allows states to ban abortion after viability, states must make an exception for terminations that are necessary to protect the woman’s life or health.

Posthumous pregnancy

Because our constitutional rights die with us, the decedent’s prior wishes regarding treatment and procreation have no obvious legal weight. Instead, the primary interests are those of the state in prenatal life and those of the male progenitor in choosing whether or not to procreate. In the abortion context, the woman’s interests trump those of the man. But when the woman is dead, courts might well hold that, pre-viability, the Constitution transfers decision-making power over the pregnancy to the man.

After viability, just as the state may insist that a woman remain pregnant, it presumably may insist that a decedent’s body be maintained for the same purpose, notwithstanding any objection by the biological father that he does not wish to procreate under these circumstances. Nor is the next-of-kin’s common-law right to possess the body for burial, which may yield to state interests in learning the cause of death and procuring transplantable organs, likely to be an obstacle to the state’s compelling interest in viable prenatal life.

As the technology allowing women’s bodies to be artificially maintained improves and, with it, the prognosis for fetuses, these constitutional theories may one day be tested. In the meantime, existing case law suggests that neither pregnancy exclusions themselves nor state imposition of life-sustaining treatment on a woman with a viable fetus is unconstitutional (so long as the treatment does not shorten the woman’s life or compromise her health). By contrast, prior to viability, state imposition of treatment is almost certainly unconstitutional in cases of both living women with clearly expressed contrary wishes and deceased women where the male progenitor opposes continued gestation.

The mission of the FDA’s Office of Prescription Drug Promotion is to ensure that “prescription drug information is truthful, balanced, and accurately communicated.” Should DTCA realize that goal, its proponents’ claims of greater public health through, among other things, enhanced disease awareness and treatment become credible.

But nonpropositional content represents a major challenge to that mission, and so the research community must make a concerted effort to quantify its persuasive force in DTCA. When all the data are in, legislators may be better placed to regulate DTCA. Or perhaps they will, instead, rethink the permissibility of this form of advertising.

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Ethics and the humanities


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“Be good. Be good. Be good.”

The writer Lou Ann Walker grew up hearing that phrase over and over again, and she took it very seriously. Walker was born in northern Indiana in the 1950s. The eldest of three girls, she was raised in a warm and loving working-class family with deep roots and many relatives in the area. She loved and admired her parents and got along with her siblings.

Yet the Walker family was different, and this difference rendered the five of them “immigrants in a strange world ... clinging together for safety,” (p. 1). It made them the object of stares, kept her mother’s and father’s parents from conversing with their own son or daughter and pushed Lou Ann and her sisters into the adult world at an early age. Both of Walker's parents were deaf, while their daughters could hear.

Walker’s childhood was inseparable from her role as a caregiver. Countless times, she interpreted from American Sign Language to spoken English and back again, mediating between her parents and the hearing world’s doctors, mechanics, clerks and bearers of bad news, a world “that really didn’t have much patience” (p. 7). Her 1986 memoir, published a few years after the term CODA (Children of Deaf Adults) was coined, remains a thoughtful and moving portrayal not only of deafness in a family but also of the effects of such a communication barrier on child interpreters who assume aspects of the parental role early in life.

These issues remain current even 30 years after this book’s publication. Although professional and tech-based interpreting services in health care settings for deaf and other non-English-speaking patients are mandated by the Americans with Disabilities Act, these services remain vastly underused. In its “Position Statement On Health Care Access For Deaf Patients,” the National Association of the Deaf has said, “Health care is routinely inaccessible to deaf people due to communication and linguistic barriers.... The health care system has largely failed to both ensure and provide accessible language services and health information for many deaf individuals.” Cultural differences, including some deaf individuals’ mistrust of medical professionals who think of deafness as something to be cured, can create barriers, too.²

“At age 5, Walker recalls, she was treated as “head of household” by strangers who ignored her father because they did not care to slow their speech so he could lip-read (p. 57). From age 8, she corrected her parents’ awkward written English, their second language. Over and over, relatives told her to “watch over” her parents, and they disciplined her in front of her parents.

In many ways, then, Walker’s parents were infantilized, while their children were parentified. Walker does not recall minding these duties — “Like all children, I loved feeling important,” she writes. “But in a few instances I was an unfaithful go-between” (p. 21).

She absorbed — and did not translate — countless petty daily cruelties. There was the gas-station attendant’s remark about “mutes” having driver’s licenses. There was the businessman who asked whether her parents were jealous that she could hear. There was question after question about whether her father had a job. (He did.)

These casual ableist microaggressions insulted Walker’s “proud and hard-working and self-sufficient” family (p. 21). As a child, she did not allow herself to dwell on what such questions meant.

Walker’s memories also paint a vivid picture for hearing readers of what it is like to grow up in a deaf household. Her parents used a “cry box” to alert them with lights when the babies cried. The children found it wondrous when they discovered they could shout and converse from separate rooms, without seeing each other. Walker and her siblings learned to talk from nearby relatives and from television, “developing what was for northern Indiana a strange, accentless ’national-speak’” (p. 57).

“The health care system has largely failed to both ensure and provide accessible language services and health information for many deaf individuals.”

The role of language broker remains a common one among the children of both deaf and immigrant adults today, including in health care settings, where providers often find it convenient to rely on such children rather than arrange for an interpreter. (Ableism also remains all too common.) Some positive outcomes for CODAs and other child interpreters can result, including feelings of greater self-efficacy. But these children can also suffer stress, shame and a feeling of being burdened. Walker finally had to reckon with such feelings as a young adult.

Now a writing professor at SUNY Stony Brook and the founder and editor-in-chief of TSR: The Southampton Review, Walker began her career working at magazines in 1970s New York. Outside the office, she freelanced in hospitals, schools and courts all over the city as an interpreter for deaf New Yorkers. What began as a side job became a compulsion, as she began at last to grapple with the effects of her unusual childhood, as well as with the insidious anti-deaf prejudice she had tried to tune out as a child.

Walker writes about interpreting for young men who did not understand questions they were asked in court and who wound up in prison. She recalls a young woman who stabbed an abusive man in self-defense and “didn’t know that the jury would be appalled by the grunts she made trying to talk” (p. 156). And then there was the psychiatrist who concluded that a deaf patient was disturbed after misunderstanding ordinary deaf mannerisms and the

Continued on page 11
What was wrong with eugenics

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Nicholas Agar defends what has come to be known as the “new eugenics” (Lahey Health Journal of Medical Ethics, fall 2015). With Agar, I agree that in the end what matters is whether policies and practices relating to technologies of genetic selection are good or bad rather than whether or not they are eugenic. However, I believe that the history of eugenics has more to teach us about the ethics of genetic selection than Agar allows. A more nuanced account of what was ethically troubling about the eugenics of the past reveals that the new eugenics too should trouble us more than, it seems, it does Agar.

Eugenics is perhaps most closely associated in the public’s mind with the Nazi project of the creation of a superior race by killing those they judged to be “unfit” and encouraging those they identified as being of good “Aryan” stock to have more children. However, ideas about improving the human species through selective breeding were popular around the world in the early decades of the 20th century, including in the United States, Europe and Australia. Agar rightly draws attention to two features of historical eugenics programs that rendered them highly problematic even when they were not murderous — their reliance on bogus science, and their failure to acknowledge the value of reproductive liberty.

I am less sanguine than Agar about the likelihood that dubious claims about the presence of particular genes in particular social groups will not play a role in determining eugenic policy in the future. Claims about “genes for criminality” still appear in the popular and scientific literature; the once-discredited idea that the human species consists of distinct “races” is also being resurrected in medical genetics on the basis of claims about the existence of geographically and historically distinct patterns of gene prevalence.

Nevertheless, Agar is correct that the science of human genetics today has a much better understanding of the role played by genes and environment in producing phenotype than the originators of eugenics did. It’s alsofair to say that there is currently little overt public support for the practices of involuntary sterilization — let alone murder — that were previously justified with reference to eugenic goals.

However, Agar neglects two other features of historical eugenics programs that, I believe, explain why many people find them so troubling.

First, there was the arrogance involved in a self-selected group of experts claiming that they knew what the good of the “race,” nation or species consisted of — not to mention the narrowness of their vision of this good. Philosophers and bioethicists often disparage concerns about arrogance as the “playing God” objection. However, this unjustly maligns the force and origins of an intuition that is often shared by people who are not religious in the slightest. The contribution that different people with different capacities make to the world cannot be assessed without making controversial assumptions about profound questions of value. We should be extremely wary of any attempt by “experts” to settle these questions on our behalf.

Second, the willingness of advocates of eugenics to subjugate the interests of individuals to the good of a collective such as the nation, race or species is troubling. Deciding what sort of people there should be by asking the question, “What would be good for society?” gets the proper relationship between individuals and society the wrong way around.

Many advocates of the new eugenics have tried to distance contemporary practices of genetic selection from these features of the old eugenics by insisting that contemporary policy is concerned entirely with the welfare of the children who might otherwise be born with genes implicated in disease conditions. Preimplantation genetic diagnosis (PGD) allows parents who are willing to conceive via in vitro fertilization (IVF) to be provided with information about the genetics of each of the embryos they create in order to choose which embryo to implant into the mother’s womb. For the most part, this technology is used to prevent the birth of children who might otherwise suffer from serious genetic disorders.

By contrast, Agar is upfront about the idea that we should use PGD to promote the “well-being of a population” and not just individual welfare. Importantly, some things that are good for populations may be bad for individuals. It will often increase aggregate welfare, for instance, to sacrifice the interests of some particular individuals for the greater good.

In Agar’s defense, the more common genetic selection becomes, the more it seems that, in regulating it, we have to consider the welfare of persons other than the future child. Otherwise, the aggregate consequences of individual reproductive decisions may be disastrous. The impact of the availability of sex-selection technologies on sex ratios at birth in India, Bangladesh and China, where these technologies are overwhelmingly used to secure the birth of male children, demonstrates this all too clearly. It is anticipated that many of the men born into these societies over the past several decades will be unable to find life partners, which in turn may result in dangerous social and political consequences in the longer term:¹

However, once we admit that the well-being of a collective must play a role in regulating technologies of genetic selection we have opened the door to a very “brave new world” indeed. It will always be plausible to argue that the interests of the future child are outweighed by the interests of society, the nation or the “species.” This is doubly the case because of a peculiar — but important — feature of the ethics of PGD. As the umbrella term for this and related technologies — “technologies of genetic selection” implies, PGD does not modify the genetics of a particular individual. Rather, it determines who will be born. As a result, PGD arguably neither harms nor benefits the individuals who come into existence at the end of the process. The counterfactual question, “What would their life have been like

Continued on next page
if the technology had not been used?”
fails in such cases because, rather than
that particular individual having higher
or lower welfare, another individual
would have been born in his or her place.
This in turn means that concerns about
harms to the children born as a result
of genetic selection place few, if any,
limits on the pursuit of the collective
interest. While parents do have strong
interests in being able to have children
and in being free to decide what sort
of children they will have, this set of
interests is ultimately only one among
many and may well be outweighed by
the greater good of the population.

Society’s interests in the reproductive
decisions of individuals will only
increase as the potential of genetic
technologies for human enhancement
begins to be realized. In theory, PGD
can be used not just to prevent the
birth of children with genetic disorders
but to select in favor of children
with desirable genes. In practice,
its potential in this regard has been
limited by the small number of ova it is
possible to harvest in each cycle of IVF,
which in turn has limited the number of embryos among which parents
could choose. However, if, as seems
likely, scientists eventually develop
the technology to produce viable ova from
induced pluripotent stem cells derived
from individuals’ somatic cells, this will
greatly increase the power of PGD for
human enhancement.

A new technology of genetic
modification known as CRISPR/Cas9,
which allows scientists to modify
the genetics of organisms with
unprecedented precision, may have
even more potential to produce children
with desired traits. Should this become
possible, individuals’ interests in being
able to make their own decisions about
what sort of children to have may all
too easily be trumped by the increases
in the welfare of populations that might
be achieved by designing future people
to fulfill particular social roles.

For this reason I am cynical that
respect for reproductive liberty can serve
to place firm limits on eugenic policies. Indeed, the extent to which Agar himself
is prepared to respect the reproductive
choice of parents is more limited than
he pretends. He is opposed to requiring
women to abort fetuses bearing the
gene linked with Huntington’s disease
but does not object to the state making
it illegal for women to implant the same
embryos in the course of IVF. I presume
that Agar believes that such restrictions
are defensible because couples are not
being required to terminate a pregnancy
or being denied the opportunity to
reproduce. They are, however, being
denied a reproductive choice. Where
couples are unable to produce any other
embryos genetically related to them, this
custom be a choice they value. Agar already
allows, then, that the public good
provides sufficient reason to override
parents’ reproductive liberty.

Perhaps more importantly, when
it comes to assessing implications of
eugenics for the future of reproductive
liberty — and indeed for human rights
more generally — the extent to which
states will actually respect reproductive
liberty matters as much as the extent to
which they should respect it. Regardless
of their actual success in doing so,
which varied around the globe, the
social democratic parties in Europe,
and the trade union and civil rights
movements in North America, stood
as significant barriers to attempts by
fascist and liberal governments to
violate human rights in the service of
eugenic goals in the first half of the
20th century. Regrettably, the social
and political forces limiting the power
of governments today are much
weaker. While the idea that the state
has the right to limit the reproductive
choices of couples in the public interest
may have limited support at the
moment, should public opinion shift,
there is little that would prevent states
from infringing upon the reproductive
liberty of potential parents.

It is probably too late to try to put
the genie of genetic selection back in
the bottle. Nevertheless, understanding
the extent to which the new eugenics
shares the intellectual and political
heritage of the old eugenics should
make us very nervous about embracing
the use of PGD for a wider range of
conditions for enhancement lest
this lead to unjust restrictions of the
reproductive liberty of parents.

It is hopefully not too late for us to
choose not to unleash the magic of
CRISPR/Cas9 upon the human genome.
While some researchers are touting the
utility of this technology as a means of
correcting genetic disorders in human
embryos, in the vast majority of cases,
PGD offers a much simpler and more
effective way of avoiding the birth of
children with genetic disorders. The
true potential of CRISPR/Cas9 lies in
the pursuit of human enhancement.
Moreover, the concerns about safety
that are currently dominating the
debate about the ethics of genetically
modifying human embryos are unlikely
to rule out its use in the longer term. It
is never possible to know whether new
reproductive technologies will risk the
health of the children born as a result
or their descendants. Our historical
willingness to allow researchers to
proceed with human trials of an
ever-expanding list of reproductive
technologies suggests that concerns
about risks to future generations are
unlikely to constitute a robust barrier
to the use of CRISPR/Cas9. The real
questions raised by CRISPR/Cas9,
then, concern the ethics of human
enhancement. In the debate that is
taking place about the wisdom of this
project, it would be prudent to treat the
argument that technologies of genetic
selection and modification should be
used to enhance the well-being of “a
population” with more caution than
Agar’s discussion suggests.

Response: Robert Sparrow offers
important reminders of eugenics’
horrible history. We should nevertheless
acknowledge that among the flotsam
of bad eugenic ideas was some good
advice. What is distinctive about
eugenics as a branch of medicine is its
focus on the genetic contributors to
population health. Viewed this way,
it complements the focus of public
health on environmental contributors.
A public health campaign that seeks
to reduce the incidence of cancer in a
population might be counted a success
if surveys reveal fewer smokers. A
eugenics campaign would be counted
a success if it reduces the incidence
of genetic variants strongly linked
with cancer. Both measures improve
population health.

Though rarely acknowledged,
the eugenic motive of improving
population health is present in the
current provision of preimplantation
genetic diagnosis (PGD). Rather than
banning reproduction by people with
Continued on next page
serious genetic diseases, techniques like PGD permit them to have children free of identified disease genes. We might think of PGD in terms of the expansion of reproductive liberty — it gives intending parents choices hitherto unavailable to them. But it also improves population health. A practitioner of PGD who refuses to deliberately select embryos with versions of the BRCA1 gene linked with breast and ovarian cancer does not let her skills be used to cause disease. Sparrow finds this intrusion into reproductive choices objectionable. I don’t think it is. When someone asks you for help, you are entitled to set reasonable terms for your assistance. No one forces prospective parents to use PGD. We can insist that, when used, PGD prevents disease rather than knowingly causes it. We celebrate additions to the list of diseases for which PGD can be used chiefly because we expect the technique to reduce the incidence of those diseases.

So why insist on an ugly word for a morally worthy practice? We could instead opt for the comparatively innocuous-sounding “genetic medicine.” I think it’s important to retain the word “eugenics.” Doing so helps prevent a dangerous forgetting. We must remember the crimes of eugenics just as syphilis researchers must not forget the victims of the infamous Tuskegee syphilis experiments in which an interest in studying the progression of the disease meant that patients were denied proven therapies for it. The focuses of public health and eugenics on populations mean that we must try especially hard not to overlook the rights and dignity of individuals. But there is no law of history that compels eugenicists or syphilis researchers to repeat the mistakes of the past.

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patient’s explicable ignorance about certain matters.

As a court interpreter, Walker was bound by an ethical code of the time requiring her not to try to clear things up but only to translate what was said: “I was never allowed to interject a single solitary word. I was a robot” (p. 156). At the same time, the demand for her skills was exhausting and endless; guilt drove her to keep saying yes.

In time, Walker sheds the crushing responsibilities. She stops interpreting, calling it a “crazy addiction … a daily replay of the hurts and the shame and the embarrassment [of childhood]” (pp. 185–186). She begins to recognize the limits of what she is able to do for her beloved parents and other deaf people. She begins to pay attention to her own preferences. There follow several months of anger as she processes feelings of powerlessness, duty and guilt, as she claims “the right to feel” (p. 183). “I realized I had to reconstruct myself,” Walker writes. “I had to start speaking out” (p. 184). At last, she who had for so long been merely a voice for others begins to discover her own.

In conclusion, the nursing home did not need to point to regulatory requirements that it maintain patients’ weight and nutritional status. It could argue that food and drink are not medical interventions and hence do not fall within the proper domain of advance directives. Moreover, when there is uncertainty about the applicability of an advance directive to the current situation, the agent should help resolve the dilemma.

Outcome: Although her daughter continued to advocate withholding her food and water based on her written directive, the patient’s two sons objected and insisted that she be fed. Rather than risk a serious family dispute, the daughter relented. The administrators at the nursing home were relieved. The patient lived another ten months.

4 Regalado A. Engineering the perfect baby. MIT Tech Review (March 5, 2015).
7 http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3704166/
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