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## FROM THE EDITOR

### What Are Ethical Ramifications of a Physician's Power to Name?

Alexandra Charrow, MD, MBE

In 1973, the American Psychiatric Association removed homosexuality from the second edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-II)*.<sup>1</sup> Its removal, spurred by patient and social activism, marked a moment when activists took back a name that marginalized and pathologized them and reclaimed that name as an identity. Today, we physicians, our associations, and our institutions continue to use the power society has granted us to name—to name diseases, medical norms, risk factors, and statistical outliers. And with the label *disease* comes money for research and insurance reimbursement, treatment prioritization by our health care system, and numerous societal associations, both overt and covert. By defining obesity as a body mass index equal to or greater than 30 kg/m<sup>2</sup>, for example, we have given a name to the “obesity epidemic.”<sup>2</sup> By defining hypertension as life threatening, we are suggesting that an asymptomatic but significant risk factor necessitates prevention, treatment, and elimination.<sup>3</sup> By characterizing being without wrinkles as a medically attainable aesthetic,<sup>4</sup> we are driving the medical pursuit of a specific beauty standard.

While the physician's power to name seems *prima facie* beyond the scope of everyday practice, in reality, it is central to much of what a physician does daily—from diagnosing, to fighting insurance companies for coverage, to balancing the risks and benefits of treatment. When a physician examines comedones on a person's face and calls them acne, that physician is designating that person as having a named disease and changing that patient's skin bumps into a medical condition that can be treated with pills or creams. When a patient disagrees with that assessment, when she either feels pigeonholed by a diagnosis or not fully recognized in her illness, tensions can develop between patient and physician.

Beyond individual patient-physician interactions, the public health and social implications of naming are broad. Physician committees and expert groups identify an epidemic, putting a name to a set of symptoms and allowing the media to frame the disease and its demographic. When acquired immunodeficiency syndrome (AIDS) was initially identified, it was referred to as gay-related immunodeficiency disease (GRID) because of its prevalence among homosexual men.<sup>5</sup> That initial name both accurately described a new disease and inaccurately focused broader attention on one affected demographic.

Names also drive society's understanding of normal and deviant in ways that affect nonmedical communities. Some communities have at times embraced a medicalized understanding of their ethnicity, such as the Ashkenazi Jewish community, which invested in genetic disease screening given the high prevalence of specific genetic diseases associated with its ethnic group.<sup>6</sup> Others, such as disability rights groups and the fat positivity movement, have organized politically around rejecting ideas of identity created by physicians that they believe pathologize their illness and measure them against a norm. Central to their arguments is that pathologizing harms them, creates further disparities in health and well-being, and unites them in resistance to being pathologized.

The three cases presented in this issue serve to highlight the bioethical and medical implications of naming a disease and how names can change the counseling and treatment options offered to patients. When a patient feels a need for the legitimacy only the act of naming by a physician can provide, it thrusts certain moral imperatives on a physician, as Jane Bartels and Christopher J. Ryan show in their commentary on a case of a patient with [delusions of infestation](#). They argue that while truth telling is a cornerstone of the physician-patient relationship, temporarily holding back a psychiatric diagnosis can ultimately help some patients achieve psychiatric and physical relief while maintaining the patient-physician relationship. On the other hand, as Stephanie L. Samuels and Wilma C. Rossi argue in responding to a case of [pediatric obesity](#), a health care professional's naming a condition like obesity that stigmatizes a pediatric patient can foster disagreement that impairs the therapeutic alliance. Analyzing a case in which [polypharmacy](#) might be to blame for a patient's symptoms, Christine Wieseler argues that it is possible for a physician to medically intervene in such cases without diagnosing or treating polypharmacy as a disease.

The broad public health implications of naming are explored in several pieces, especially as they relate to aesthetics, deviance, and marginalized populations. Kelsey Walsh examines physicians' authority to name diseases through images of posters and booklets that the American Medical Association used to [promote public health](#) and change public perceptions of those who are ill. Focusing on the public health implications of human trafficking, Stephen P. Wood offers a personal narrative of [caring for a trafficked woman](#) in which he explains that clinicians' naming a patient as someone who is being trafficked can lead to unintentional avoidance and create barriers to understanding. Wendy Macias-Konstantopoulos reviews the limitations of extant abuse codes and argues that the profoundly exploitative nature of human trafficking justifies the new [trafficking-specific codes](#) approved for the 2019 update of the *International Classification of Diseases, 10th Revision, Clinical Modification*, which will facilitate data collection on the incidence of and risk factors for trafficking, among other things. Sander L. Gilman argues that [naming diseases as somatic](#) (eg, sexually transmitted infections)

ignores that dermatologists have historically treated the psyche and social stigma in treating skin conditions.

Naming a disease has especially challenging ramifications when the disease entails morbidity and is strongly associated with identity politics. Marvin J. H. Lee examines the tension between identity politics and medical necessity within the context of the [fat and body positivity movement](#) and an evolving medical-social culture war. Joel M. Reynolds expands on that tension in his review of disability theory and medical professionals' responsibilities to [disability communities](#) and individual patients.

The power to name is especially salient within the domain of reproductive health—from determining a patient's fertility, to selective fertilization, to childbirth, to abortion. Katie Watson discusses how a false distinction between [medical and elective abortions](#) has created a regressive and destructive culture around pregnancy termination and changed society's perceptions of pregnancy itself. And, in the podcast, Watson discusses the term [elective abortion](#)—and why the label might affect patients' experiences and even cause harm—with Meryl Sackeim, a physician who provides abortions. Similarly focusing on a false dichotomy, Jessica Martucci argues that distinguishing [natural and medicalized childbirth](#) impedes improvements in maternal care that can be made through humanizing the birth process. Iris G. Insogna and Elizabeth S. Ginsburg examine how [infertility](#) as a recognized disease exacerbates racial and socioeconomic inequities in access to treatment. Finally, Michelle Bayefsky argues that, in the United States, [preimplantation genetic diagnosis](#) (PGD) should be regulated by physicians on the basis of professional guidelines rather than by (conservative) policymakers, who might view PGD as analogous to abortion.

While the field of medical ethics remains concerned about research, patient autonomy, and death and dying, the underpinning of medicine and ethics hinges on the seemingly banal—on what we name diseased, what we name normal, what we consider aesthetic, and what we consider aberrational. Such notions are fundamental to how we treat people and what we treat. This issue of the *AMA Journal of Ethics* seeks to examine these fundamental notions of naming as they relate to the clinic, the patient, and the physician.

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## CASE AND COMMENTARY

### How Should Physicians Use Their Authority to Name a Stigmatizing Diagnosis and Respond to a Patient's Experience?

Jane Bartels, MBBS and Christopher J. Ryan, MBBS, MHL

#### Abstract

Patients with delusional infestation are unlikely to agree to take the mainstay of treatment—antipsychotic medication. While stressing the general importance of truth telling in medicine, we suggest that, in some cases of delusional infestation, patients' lack of decision-making capacity will—provided a series of criteria are met—justify briefly withholding their diagnosis. We acknowledge this action as a kind of deception with ethical pitfalls and discuss those related to prescribing antipsychotic medication without frank disclosure. We recommend full disclosure of a delusional infestation diagnosis when the patient is recovered, despite this action's potential to exacerbate stigma.

#### Case

Ms M presents to Dr P's family medicine clinic for assessment of severe pruritus (itch) that she has been experiencing for the past 4 years. She first noted the itch in association with small bumps on her ankles and wrists. She was diagnosed with bed bugs and had her apartment cleaned and fumigated. The bumps went away, but the itching persisted. She became concerned that the infestation had returned and ultimately moved out of her apartment and into a new building. She sold all her belongings, including her bed and books, gave away her cat, and bought new furniture 3 years ago. She continues to note severe itching of her arms, legs, and back since that time. She had her new apartment fumigated 3 more times. She discusses with Dr P that, recently, she thinks she has been able to see the bugs—they are hatching eggs and she can pull them out. She brings the "eggs" with her in plastic bags for Dr P to review. She has found topical permethrin to be helpful in the past.

Dr P examines her skin and notes scabbed-over bumps from repeated manipulation of the skin. He sees no signs of an infestation. He reviews the contents of her bag and notes that it is consistent with simple keratin. Dr P suspects the source of Ms M's symptoms and experiences to be delusional infestation, and he wonders how he should respond in a way that is respectful and truthful.

## Commentary

Delusional infestation is a condition in which patients believe themselves to be infected by parasites.<sup>1</sup> It is one subtype of what the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* terms *delusional disorder*, in which patients exhibit few signs of mental illness beyond one unfounded pathological conviction.<sup>2</sup> Like Ms M, patients with delusional infestation commonly present to their physicians with amorphous debris as evidence of parasites or eggs.<sup>3</sup> This clinical feature—the matchbox sign—was named after the vessel patients often used to transport the debris.<sup>4</sup>

Dr P's suspicions that Ms M could be suffering from delusional infestation are entirely justified. However, confirmation of this diagnosis would require ruling out anxiety, depression, or any other possible comorbid mental illness and excluding medical or neurological conditions that cause itching, which could be mistaken for, or lead a patient to develop, delusional infestation.<sup>5</sup>

It is vital that, while establishing a diagnosis, the physician both establish and maintain rapport with the patient. The main task early on is to explore the patient's experience while gently inquiring whether her symptoms could be accounted for by something other than bugs. In doing so, the physician gauges the patient's level of insight and the extent to which she might be willing to consider her symptoms as psychologically based. Prematurely labeling Ms M's experience as delusional infestation could be experienced by Ms M as invalidating and might lead her to abandon further contact not only with Dr P but with all health professionals. A general practitioner or dermatologist might, understandably, feel out of his or her depth in diagnosing and managing cases of delusional infestation but also recognize that these patients might be reluctant to consider seeing a psychiatrist. Even without formal psychiatric referral, however, local psychiatric services might be able to provide useful advice.<sup>5</sup>

In this article, we discuss a physician's ethical predicament when diagnosing and managing a patient with delusional infestation while withholding the name of the disease. Physicians sometimes use *benevolent deception* to justify withholding information from patients. We suggest that withholding a diagnosis is a form of deception and that it is probably ethically objectionable without further justification. Therefore, we propose criteria we believe should be satisfied in order to make withholding a diagnosis ethically acceptable. Lastly, we clarify that when patients regain insight with treatment, they should be informed of their diagnosis, despite the [risk of stigmatization](#) associated with labeling the illness.

## Managing Without Naming

Delusional infestation is a psychotic illness, and hence antipsychotics are the recognized mainstay treatment and, in most circumstances, the only practicable way to assist patients with this disorder.<sup>6</sup> Although formerly the antipsychotic pimozide was preferred

in delusional infestation, evidence of its differential effectiveness is weak and its side effect profile is poor.<sup>6,7</sup> As a result, newer antipsychotics are usually used in contemporary practice.<sup>7</sup>

Prescribing any sort of antipsychotic to patients with delusional infestation presents a challenge. They will typically come to the consultation without insight, certain they are infested and, understandably, will have no interest in taking antipsychotics. In some cases, with cautiously delivered education and decision-making support, it will be possible to enable patients to reach points at which they, first, understand how antipsychotics could help them and, second, consent to treatment. However, in cases of delusional infestation in which patients do not have insight into their conditions, best efforts at support might still fail to secure patients' consent. Recognizing this reality, some have suggested that the best option for motivating adherence to medication is to deceive patients about the nature of their illness or the mechanism of action of the proposed medication.<sup>5,8,9</sup> Several authors too easily justify such actions with terms such as *benevolent deception*.<sup>10,11</sup> For example, Zomer et al. advise the following:

We tell the patients that some people are more sensitive to stimuli on their skin than others, and that the drug (pimozide) increases the threshold to these stimuli. Their belief with regard to infestation is not challenged. It is of no use attempting to convince patients that they are not infested by parasites, because their conviction is unshakeable.<sup>12</sup>

In our opinion, this type of advice models an unreflective use of the term *benevolent deception* that gives too broad a license to physicians to lie to patients based only on their perception of patients' best interests. We reject this approach while acknowledging that it might, in many cases, be reasonable (temporarily) to lie to patients and to prescribe antipsychotics without explicitly acknowledging the condition for which they are prescribed. In this context, lying has broader meaning than simply imparting false information; it means deliberately withholding information that a clinician knows a patient would see as relevant—in this case, the fact that the medication being proposed is used to treat delusions, not itches. If physicians are going to lie, it is important to own this and reflect carefully on their reasons for managing patients' care in a way that is, generally and usually, rightly condemned. We argue that clinicians are justified in (temporarily) lying to patients with delusional infestation only in circumstances in which they believe all of the following apply:

1. As a result of a patient's delusions and associated lack of insight, he or she is incapable of making an informed decision. That is, despite a physician's best efforts to provide decision-making support, the patient cannot understand or cannot use and weigh information that would be relevant to consenting to or refusing antipsychotics.
2. Harm would likely come to a patient for whom antipsychotics are not prescribed.

3. A patient who lacked insight would probably not take an antipsychotic if it were recommended.<sup>13</sup>
4. Typical means of compelling treatment to which a patient has not consented—by using a hold or involuntary commitment justified by statute, for example—are either (a) unavailable because harm from which a patient requires protection is insufficiently severe or immediate or (b) inappropriate because legally sanctioned coercion itself would cause a patient harm that might be avoided by withholding information.

We argue that when these criteria are met, physicians are justified in prescribing antipsychotics while not labeling them as such to a patient. Instead they may say, in truth, that their intention is to relieve a patient's symptoms. Note that physicians are not relieved of an obligation to fully disclose possible side effects, and these must be truthfully conveyed.

Physicians are well advised to avoid blatant lies, such as "This is not an antipsychotic." In our experience—rightly or wrongly—patients usually find blatant lies more morally objectionable than other forms of deceit, and the distinction between a blatant lie and a benevolent deception could become important later on—for example, after a physician reveals a diagnosis and is trying to maintain rapport. Also, of course, some lies are easily uncovered by a simple internet search. With these concerns in mind, we usually declare that the prescribed medication is used as an antipsychotic but that we hope it will relieve the patient's symptoms nevertheless.

If possible, it is important to engage family and friends to reinforce treatment aims and to better understand the effects that delusional infestations can have on people around the patient. If the patient's children are being significantly affected or if there is immediate concern for a patient's safety, using a hold or involuntary commitment could still be necessary.

### **Revealing the Lie**

When a patient like Ms M has been treated, has recovered, and has regained insight and decision-making capacity, she will no longer satisfy the first criterion in the above list. If Ms M is like many patients with delusional infestation, she will need to continue antipsychotics after the psychosis has resolved.<sup>7</sup> At this point, the clinician is obligated to reveal the diagnosis, the rationale for the treatment chosen, and that treatment commenced without the rationale being fully explained. This last revelation is best combined with an apology and an explanation that demonstrates the reasoning outlined in this article. With the resolution of the psychosis, the patient will be competent either to consent to continue the antipsychotic or to refuse to continue it. Competent informed refusals must be respected no matter how foolish they might appear, though, of course,

the clinician should continue to try to persuade the patient to continue with a treatment that *ex hypothesis* has been effective.

Revelation of a diagnosis to a now-recovered patient still risks being perceived by the patient as stigmatizing. Sadly, the public continues to hold stereotypes of people with psychosis as dangerous, unpredictable, incompetent, and responsible for their condition.<sup>14</sup> There is also risk that patients like Ms M might agree with, identify with, and internalize these beliefs, leading to self-stigma, which itself can cause lowered self-esteem and self-efficacy and demoralization.<sup>15,16</sup> To decrease the likelihood of adverse consequences, Dr P should not only reveal Ms M's diagnosis but also explore her understanding and beliefs regarding her diagnosis. As he does so, he should provide Ms M with information about her illness to combat any myths, and, if he identifies any self-stigmatizing beliefs, he should gently but firmly challenge them. Some patients may benefit from referral for further psychological therapy.

### Conclusion

Delusional infestation provides rare examples of cases in which physicians are justified in temporarily withholding a diagnosis from their patients. However, physicians should embark on this kind of deceit only if certain criteria are met. When the patient recovers, the diagnosis should be revealed, as should the physician's understanding of the patient's illness, but these revelations should be approached skilfully and cautiously to avoid damaging the patient-clinician relationship and possibly amplifying stigma.

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#### **Editor's Note**

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*The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

## CASE AND COMMENTARY

### How Forcefully Should Clinicians Encourage Treatment When Disagreement Persists About Obesity Risk?

Stephanie L. Samuels, MD and Wilma C. Rossi, MD, MBE

#### Abstract

Pediatric obesity is a major public health problem, and weight reduction in children and adolescents with obesity is associated with improvement in health outcomes. This case of an adolescent diagnosed with obesity whose mother disagrees with the diagnosis illustrates challenges often encountered in clinical practice, including (1) diagnosing a disease in an asymptomatic patient whose future risk for negative health outcomes is uncertain, (2) addressing ethical implications of naming a stigmatizing disease, and (3) resolving conflicting goals and opinions of a patient, caregiver, and physician. Suggestions for navigating disagreement and implementing courses of action are discussed.

#### Case

Ms D presents with her daughter, Ms W, for an adolescent medicine appointment with Dr N. Ms W is 14 years old and on weigh-in at Dr N's office has a recorded weight of 175 pounds and a height of 5'1". As Dr N reviews Ms W's records, he notes that her body mass index (BMI) is 33 and discusses with Ms D and Ms W that Ms W meets criteria for being labeled *obese*. He reviews with Ms W and Ms D the long-term ramifications of obesity and encourages the patient to enact a diet and exercise routine with a goal of losing 10% of her body weight over the next year. At that same appointment, Dr N obtains a hemoglobin A1c (6.0), a total cholesterol of 310, and verifies that thyroid stimulating hormone levels are within normal limits.

At her next visit 1 year later, Ms W excitedly reports to Dr N that she has joined the track team and has been running 3 miles a day and lifting weights. She notes that she has been eating more protein and has mostly stopped eating candy. Her weight at this visit is 191 pounds and her BMI is 36. Dr N discusses with Ms D and her daughter that her BMI now defines her as *morbidly obese*. Although she is young for bariatric surgery, Dr N notes that she has already made a myriad of lifestyle modifications to no avail and should strongly consider bariatric surgery in an effort to prevent the long-term sequelae of obesity.

Ms D refuses the bariatric surgery referral, stating that her daughter is healthy—she has prediabetes but her blood pressure is excellent. "We are all big in my family—bigger than

my daughter by a lot. My grandmother is 85 years old and 300 pounds, and I'm not going to let a skinny doctor tell me or my family we aren't healthy just the way we are." Ms W isn't sure she wants the surgery but when her mother leaves the room, she does report to Dr N that she wishes she was thinner because she is being made fun of by people in school.

### **Commentary**

Pediatric obesity is a major public health problem currently affecting approximately 17% of US children and adolescents.<sup>1</sup> Weight reduction in children with obesity is associated with improvement in cardiometabolic outcomes, including decreasing risk for development of type 2 diabetes, hypertension, and dyslipidemia.<sup>2</sup> Therefore, it is essential for physicians to counsel patients and families effectively regarding the risks of obesity and the importance of lifestyle changes. Challenges in counseling youth in these situations are compounded when lifestyle modifications prove insufficient and future health risks are uncertain. The patient-clinician relationship is best served by a collaborative approach to weight management strategies, especially when a clinician suggests alternative weight management treatments such as medication or [bariatric surgery](#) that have risks.

### **Should Physicians Have Power to Name Obesity as a Disease?**

In this case, the physician labels the patient as obese based on her BMI,<sup>3</sup> and when her BMI has increased one year later, he notes that she is morbidly obese. In using these labels, the physician classifies the patient as having a disease requiring treatment. This classification serves as the basis for his further recommendations for lifestyle modifications, and, ultimately, for a more extreme intervention—bariatric surgery—when those lifestyle modifications do not result in measurable improvements. The mother responds as many parents would in this situation: she denies that her daughter demonstrates any manifestations of true disease, stating that her daughter is “healthy” overall and has excellent blood pressure. As the mother implies, prediabetes does not inevitably lead to diabetes in all cases.<sup>4</sup>

There has been considerable debate regarding whether obesity should be called a disease. The Obesity Society supported the classification of obesity as a disease in 2008,<sup>3</sup> and the American Medical Association officially recognized obesity as a chronic disease in 2013.<sup>5</sup> But should physicians have the power to diagnose a disease when future morbidity and mortality are not guaranteed? As the patient's mother indicates in her emphatic reaction, it is possible for a person with obesity, such as the patient's grandmother, to “beat the odds” and show no signs of obesity-related complications at 85 years of age.<sup>6</sup> While the patient's laboratory results meet criteria for diagnoses of prediabetes and hyperlipidemia, she remains asymptomatic. Even with prediabetes and hyperlipidemia, it remains unknown whether she will eventually go on to develop overt complications. As the mother implies, BMI alone is not always the best indicator of health status.<sup>7</sup>

### **Ethical Considerations in Diagnosing Obesity in an Adolescent Patient**

Despite the possibility that this patient could “beat the odds,” it is the physician’s responsibility to provide recommendations based on the most probable outcomes. With increasing BMI and prediabetes, this patient is undoubtedly at high risk for adverse health outcomes. By diagnosing her as obese and thus naming a disease, the physician is better able to recommend appropriate, evidence-based treatments. Moreover, by naming obesity as a disease—effectively acknowledging that the patient cannot entirely control her weight through behavioral choices and willpower—the physician might be attempting to reduce the stigma and shame often associated with obesity, as Ms W is being bullied in school regarding her weight. In our society, stereotypes unfortunately persist that persons with obesity are lazy, unmotivated, or lacking in discipline. In naming obesity as a disease, numerous professional societies including the Endocrine Society,<sup>8</sup> the Pediatric Endocrine Society,<sup>9</sup> and the Obesity Society<sup>10</sup> have recognized the complex genetic and environmental factors that contribute to overweight and obesity. Persons with obesity, as with any other chronic disease, should not be blamed for their medical condition. This argument has helped facilitate expansion of research, medical treatments, and insurance coverage for obesity and its complications.

But is it ethical for the physician to use the words *obese* and *morbidly obese* when talking to a patient, particularly when the patient is a child or adolescent? While it is certainly beneficial for the physician to use these labels for the purpose of diagnostic coding in the medical record, he can choose to use different terminology when conversing with the patient and her parent. In studies of patient and parental perceptions of words commonly used to describe excess body weight, the terms *fat*, *obese*, and *extremely obese* were rated as undesirable and stigmatizing compared to terms like *unhealthy weight* or *BMI*.<sup>11,12</sup> The physician in this case referred to Ms W’s elevated BMI, thereby using a term that is less stigmatizing, but then proceeded to explain that her BMI defines her as “morbidly obese,” a more stigmatizing and undesirable term. The Obesity Society recommends using people-first language to reduce the use of potentially stigmatizing words; for example, the physician should say “a child with obesity” rather than “an obese child.”<sup>13</sup> Additional research could help further elucidate how health care practitioners can discuss weight management using sensitive, neutral, and patient-friendly language.

### **Ethical Issues in Acknowledging Obesity as a Problem**

In this case, the physician is recommending bariatric surgery, an invasive procedure that entails known risks with unclear benefit to the patient. While there is some evidence of effectiveness of bariatric surgery for weight loss in the adolescent population,<sup>14</sup> current pediatric obesity guidelines recommend bariatric surgery only in cases in which the patient meets certain developmental and other criteria and “has a BMI of  $> 40 \text{ kg/m}^2$  or has a BMI of  $> 35 \text{ kg/m}^2$  and significant, extreme comorbidities.”<sup>8</sup> This patient currently has a BMI of  $36 \text{ kg/m}^2$  and prediabetes without extreme comorbidities, and it is not possible to predict with precision her future risk for development of complications.

The principle of nonmaleficence—to “first, do no harm”—is one of the pillars of medical ethics and could justify the mother’s preference not to pursue bariatric surgery. In this case, the daughter does not presently have any serious comorbidities, and it cannot be concluded that there is risk for imminent harm if the mother elects for no interventions. Indeed, many well-informed and reasonable caregivers would not choose to follow this physician’s recommendation for bariatric surgery at this time, instead opting for continued efforts at positive lifestyle changes. Although it is unclear from the case description how actively the mother is encouraging her daughter’s efforts to improve her diet and physical activity, the daughter has clearly been able to make several positive changes. Furthermore, the family is appropriately utilizing health care services through regular yearly visits.

By noting that obesity is typical in the patient’s family and not always associated with poor health or reduced lifespan, the mother could be seeking to normalize her daughter’s weight and thus reduce the stigma associated with obesity. She questions the ability of “a skinny doctor” to empathize and provide unbiased care. Her skepticism could be valid, as evidence has suggested that physicians often share society’s negative stereotypes regarding persons with obesity.<sup>15</sup> And research has shown that health care professionals demonstrate both implicit and explicit **biases** when seeing patients with obesity.<sup>16</sup> Although the physician in this case does not show any obvious signs of prejudice, he should constantly strive to be aware of his unconscious biases and the potential subtle ways that they can impact care delivery. The patient and her mother might no longer wish to interact with health care professionals if they experience prejudice. Being **stigmatized by the physician** might precipitate the patient’s feelings of shame and lead to her becoming depressed. The physician, in taking a collaborative approach, would be more likely to lead to an improved relationship with Ms D, as discussed below. He should address Ms D’s concerns regarding bariatric surgery and discuss the risks and benefits. Since there is no medical consensus that bariatric surgery is needed, he should abide by Ms D’s decision.

### **Navigating Parent-Clinician Disagreements About Pediatric Obesity Treatment**

This patient’s case highlights 2 areas of disagreement often encountered by clinicians in pediatric practice: between physician and parent and between parent and child. The recent Endocrine Society clinical practice guidelines on pediatric obesity strongly suggest that a clinician’s obesity prevention efforts “enlist the entire family rather than only the individual patient.”<sup>8</sup> This family-oriented approach, however, can only yield desired outcomes when caregivers and other family members are motivated participants in the treatment plan. The mother in this case does not currently acknowledge the potential risks of her daughter’s obesity, defensively insisting that her daughter is “healthy.”

The physician should start by recognizing his and the mother’s common goals in order to partner with her and keep her as an ally in her daughter’s care. Undoubtedly, both the mother and the physician desire to promote good long-term health and quality of life for

the patient. While praising the patient for joining the track team and selecting healthier foods, the physician should acknowledge the supportive role the mother has likely had in fostering her daughter's behavioral changes. Through continued dialogue over the course of frequent follow-up visits, the physician could eventually help the mother understand that her daughter is at high risk for future comorbidities.

While the patient expresses desire to be thinner, it is unclear whether her primary motivations for weight loss are well aligned with the physician's intentions. In his counseling, the physician emphasizes the potential long-term health consequences of obesity. The patient, however, voices fear of bullying as a significant factor contributing to her desire to lose weight. Particularly when counseling adolescents, physicians must consider how social stigma and poor body image can influence patients' eagerness to engage in treatment.<sup>13</sup> One study found that over half of adolescents seeking weight loss treatment had experienced weight-based victimization, including pervasive teasing and bullying.<sup>16</sup> It is essential for the physician to encourage weight management efforts while addressing concerns about bullying and promoting development of a healthy body image.

The physician should continue to promote the patient's demonstrated efforts at healthy lifestyle changes. Follow-up visits every 3 to 4 months would also give him the opportunity for continued discussion with Ms D regarding her daughter's health and potential interventions to help her with weight reduction. An interdisciplinary approach to management could be helpful, with a team including a nutritionist, physical activity specialist, and social worker or psychologist. Counseling services could also be particularly beneficial in addressing the bullying that the patient has experienced. However, community resources, if they exist, might be more acceptable to Ms. D and easier to access than services offered in a health care setting.

In summary, ethical challenges arise in caring for a teenager with obesity. Prejudices regarding obesity might incline some health care professionals to be overly zealous in recommending treatments that are controversial, such as bariatric surgery. However, [medicalization of obesity](#) can reduce the stigma associated with it within the medical community. By clinicians' naming obesity as a disease, a patient with obesity might no longer feel guilt or shame regarding her weight, and societal imposition of blame for obesity might be reduced. It is essential for health care professionals to approach patients with obesity with compassion and to avoid using terminology that is stigmatizing or offensive. A collaborative approach is needed when there are conflicting goals and opinions among the physician, patient, and parent.

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## CASE AND COMMENTARY

### When Should Iatrogenic Polypharmacy Be Considered a Disease?

Christine Wieseler, PhD

#### Abstract

This case of an elderly patient taking 17 medications, who presents with new neurological symptoms, raises multiple philosophy of medicine questions, including, What is a disease? And what would it mean to treat iatrogenic polypharmacy? Polypharmacy can obscure whether a patient like the one in this case has a neurological disease. I argue that, insofar as polypharmacy is likely to have caused, or at least contributed to, this patient's symptoms, her physician should treat it as a disease.

#### Case

Ms M and her daughter, Ms J, present to Dr R's neurology office for an initial evaluation. Ms J is concerned that her 83-year-old mother might be developing Parkinson's or another neurodegenerative disease and has sought out Dr R's expertise.

Ms J has noticed that her mother has been moving much more slowly recently, has had numerous falls, and looks depressed. Her mother, who had always been full of energy, now spends the day watching TV and sleeping. Her mother has been slurring some of her words lately and has even developed a tremor. Dr R reviews Ms M's exam. She has no cogwheel rigidity, but her gait is wide based and she wobbles as she turns. She has mild ataxia and an intention tremor. Her concentration is poor, as is her 3-object recall. She agrees that she is not herself and is worried she is developing Parkinson's disease, a condition from which her uncle suffered before his death.

Dr R reviews her history and notes that her symptoms have worsened in the setting of a few recent hospitalizations for heart failure, chronic obstructive pulmonary disease (COPD) exacerbations, and a gastrointestinal bleed. During her most recent hospitalization, she was initiated on amiodarone and a beta blocker, a selective serotonin reuptake inhibitor (SSRI) and trazodone for sleep, as well as albuterol nebulizers every 4 to 6 hours. During a previous hospitalization, she was placed on 2 new medications for gastroparesis and initiated on a more intensive, insulin-based diabetes regimen. Prior to that, she was placed on 2 diuretics for severe volume overload. In discussing her regimen with Ms J, Dr R notes that Ms M is currently taking 17 medications for her numerous medical conditions including heart failure, atrial fibrillation, COPD, diabetes complicated by gastroparesis, and hypertension. While Ms M has difficulty remembering which

medications she takes, her daughter has been very diligent about ensuring that she takes her medications as prescribed.

Dr R reviews Ms M's illness history. Ms M was hospitalized 10 times last year for heart failure or COPD exacerbations, but, looking at her long medication list, she realizes she is not sure what is making her sick—her illnesses or the medications to treat them.

### **Commentary**

Rather than making a broad pronouncement on whether iatrogenesis—defined literally by its Greek roots as *physician generated* or as inadvertent harm induced by medical care—should always be classified as a disease, the scope of this commentary will be limited to the question of whether Dr R should consider effects of polypharmacy to be a disease in this case. Before responding to this question and arguing that polypharmacy should be *treated* as a disease in this case, this essay begins with a brief overview of some philosophical considerations related to judgments about disease and concepts relevant to the case. This essay will conclude by calling for further critical examination of polypharmacy as a clinical practice that can generate iatrogenesis.

### **Philosophy of Medicine Considerations**

The first question concerns how *disease* should be characterized. Naturalist and normative accounts of this concept provide the main philosophical responses to this question. Naturalist positions contend that disease exists in nature and that it is possible to make objective judgments regarding what counts as a disease entity without reference to social or personal values. Importantly, naturalists are not necessarily tied to the claim that applications of disease concepts are independent of values. For example, philosopher Christopher Boorse, an advocate of naturalism regarding disease, notes that an oncologist's assessment that a cancer is inoperable "involves the value judgment that the results of operating will be worse than leaving the disease alone."<sup>1</sup> Normativists, on the other hand, maintain that we make decisions about which sorts of somatic or mental states are considered diseases and that these choices inevitably involve value judgments, even at the theoretical level.<sup>2</sup>

There are at least 2 types of normativists with regard to disease: weak and strong normativists.<sup>1</sup> The former hold that judgments about health and disease are simultaneously descriptive and normative, while the latter view them as solely normative.<sup>1</sup> In other words, strong normativists suggest that judgments about what constitutes a disease are indicative of our social values without describing anything about the objects to which they are applied. Some weak normativists claim that naturalism and normativism are compatible under the umbrella concept of social constructivism.<sup>3</sup> Although there are numerous iterations of social constructivism, the central claim is that social processes play an important role in shaping concepts or entities. Philosopher Rachel Cooper maintains that the phenomena we refer to as

diseases exist in nature, independently of our judgments about them (a naturalist position), but that the concept of disease itself involves social values (a normative position).<sup>3</sup> There are additional approaches to characterizing disease, but they will not be discussed here. While naturalist, normativist, and social constructivist accounts present useful considerations to keep in mind, the purpose here is not to advocate for one of these theoretical approaches. Rather, this essay prioritizes one of the key points of the preceding discussion: personal and social values expressed in clinical practice can and do influence judgments about disease.

In practice, clinicians must go beyond theoretical concerns related to disease in order to determine when and what types of medical interventions are appropriate. Boorse distinguishes between “theoretical and practical uses of the health vocabulary.”<sup>1</sup> He implores the reader to “always remember that a dual commitment to theory and practice is one of the features that distinguish [sic] a clinical discipline.”<sup>1</sup> Thus, even if a given condition can theoretically be considered a disease, a clinical assessment must be made with regard to whether it is appropriate to *treat* the condition as a disease, ie, to offer an intervention for the condition. Philosopher H. Tristram Engelhardt makes the stronger claim that calling a condition a disease is equivalent to being committed to providing medical intervention for that condition.<sup>4</sup> Cooper advances a similar but more nuanced position, asserting that a condition must at least have the potential to be medically treated in order to count as a disease.<sup>5</sup> Rather than assuming that disease diagnosis entails commitment to or availability of medical intervention, this discussion will use the phrase *treating a condition as a disease* to refer to a disease in need of medical intervention, leaving open the possibility that there are diseases without treatments or that are best left untreated. The remainder of this commentary will focus primarily on the question of whether adverse effects of polypharmacy should be considered a disease and whether medical intervention is appropriate.

### **Polypharmacy and iatrogenesis**

A few working definitions follow to launch this inquiry. Recall that physician-generated illness or injury is called *iatrogenesis*. Medical errors and adverse effects not resulting from errors are examples of iatrogenesis.<sup>6</sup> Polypharmacy has been variously defined as the use of multiple drugs, prescription of more drugs than are medically necessary,<sup>7</sup> or “concomitant ingestion of four or more” medications in the last 3 months.<sup>8</sup> Some authors distinguish between polypharmacy and polyprescription, with the former referring to patients ingesting multiple medications and the latter referring to clinicians prescribing multiple medications to a patient.<sup>9</sup> When polyprescription leads to illness or injury, it would be considered iatrogenesis. Potential for [drug interactions](#) arises with as few as 2 concurrent medications, and risk of iatrogenic harm increases with the number of medications.<sup>10</sup> Whether such interactions will occur and their severity is often unknowable in advance.<sup>11</sup>

This brings us to the case of Ms M. She has reduced energy level and reports that she “is not herself.” In addition to previously being diagnosed with heart failure, atrial fibrillation, COPD, diabetes, and hypertension, Ms M exhibits numerous new symptoms including but not limited to flat affect, poor concentration, slurred speech, ataxia, and a tremor. Both the patient and her daughter are distressed by these new symptoms and worried that Parkinson’s disease could be the cause. While many of Ms M’s symptoms seem to fall clearly into the aforementioned disease categories, whether her recent symptoms should be collectively treated as a disease remains an open question.

Ancillary questions follow from this central question. First, should Dr R consider Ms M’s new symptoms—which are likely caused or at least exacerbated by the number of prescriptions she is taking—to be symptoms of Parkinson’s or another neurodegenerative disease? Second, what should she do—is (further) medical intervention warranted? Given that the patient is currently taking 17 medications, it is not possible for Dr R to get a clear picture of whether her new symptoms are caused by individual medications, interactions among medications, or a neurodegenerative disease. Even in an otherwise healthy patient, diagnosis of Parkinson’s disease, in particular, can be challenging given the lack of a definitive diagnostic test.<sup>7</sup> In order to gain clarity, some physicians proceed by prescribing medications such as carbidopa and levodopa in order to observe whether and how a patient’s symptoms respond to treatment.<sup>12</sup> If they do, then a physician might diagnose the patient with Parkinson’s disease. In the case of Ms M, it seems inadvisable for Dr R to attempt making a diagnosis of a neurodegenerative disease, especially if doing so would involve introducing new medications. Since prescribing additional medications could do more harm than good due to the potential for drug interactions, a [different type of medical intervention](#) is warranted instead: in consultation with physicians in relevant specialties—and, ideally, Ms M’s primary care physician—Dr R ought to determine which medications are necessary and beneficial for her and discontinue the others. In this way, her new symptoms would be collectively treated as a disease, but she would not be given a definitive diagnosis such as Parkinson’s or another neurodegenerative disease. By taking a smaller number of medications, Ms M’s symptoms might be ameliorated, as it stands to reason that the risk and severity of drug interactions would likely decrease. Dr R also would stand a better chance of being able to make an accurate diagnosis, and, hopefully, she would be able to help Ms M to feel like herself again.

### **Polypharmacogenic iatrogenesis**

It is important to consider the plight of Ms M and Dr R within the broader context of prescribing practices and the clinical research that informs them. Polypharmacy is a practice involving individuals and social institutions. There are a few factors that make it a clinically and ethically troubling phenomenon worthy of further attention by bioethicists and philosophers of medicine.

One of the ways that polypharmacy occurs is that some patients receive prescriptions solely from specialists practicing in isolation from a patients' other clinicians, perhaps during hospitalizations. In addition, while clinicians might be aware of common interactions among medications, little research has been done to date that considers the large numbers of prescriptions elderly patients take on a daily basis.<sup>11,13</sup> More research needs to be done that is responsive to actual prescribing practices so that, in turn, clinicians can make more informed decisions when weighing potential benefits and risks of adding medications to a patient's existing drug regimen. While it seems inevitable that clinicians will need to prescribe multiple medications to some patients in order to manage their conditions, better health outcomes are likely when polyprescribing involves careful coordination among clinicians, avoids unnecessary medications, and is informed by an evidence base that takes into consideration the reality that many patients take multiple medications.

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## AMA CODE SAYS

### **AMA Code of Medical Ethics' Opinions Related to a Physician's Power to Name**

Scott J. Schweikart, JD, MBE

#### **Abstract**

The AMA *Code of Medical Ethics* offers guidance on ethical issues related to naming a condition via diagnosis. This article discusses 3 case examples that consider how the AMA *Code* can be applied.

#### **Three Cases of Clinicians Exercising Authority in Labeling or Naming Patients' Conditions**

Labeling or naming a patient's condition can profoundly influence how diseases are treated, social stigmas, insurance reimbursement, and the scope of empathy towards patients. The 3 cases below examine how the American Medical Association (AMA) *Code of Medical Ethics* can be applied and possibly interpreted with regard to naming a patient's condition.

*Case 1.* In the first case, a patient visits a dermatologist and complains of severe pruritus. Due to a prior bed bug infestation, she has taken extreme measures to fumigate and eliminate all possible affected belongings, but she still believes she suffers from pruritus and that she can see bed bugs hatching from her skin and provides the dermatologist samples. The dermatologist examines the samples, which contain keratin, not insect eggs. He suspects that the patient is suffering from a psychosomatic disorder, not pruritus caused by bed bugs. In this case, the AMA *Code* suggests that how the physician responds to the patient and labels her condition is an **exercise of authority** that requires attention to how the label "psychosomatic disorder" will influence the patient's life and the patient-physician relationship. For example, the physician's capacity to express respect for the patient is vital. The AMA *Code* addresses respect in Opinion 1.1.3, "Patient Rights," which states, "The health and well-being of patients depends on a collaborative effort between patient and physician in a mutually respectful alliance."<sup>1</sup> Immediately relaying to the patient that her condition is psychosomatic could be construed by the patient as dismissive and thus as an expression of disrespect. Hasty labeling, in particular, risks undermining trust and harming the patient-physician relationship. Based on Opinion 1.1.3, the physician may have an ethical obligation to thoughtfully devise a way to impart this diagnosis that expresses respect for the patient and her experience of illness, regardless of what the illness is called or how it is labeled clinically.

*Case 2.* In the second case, a mother and her 14-year-old daughter visit a physician for a routine physical examination. The girl's height and weight measurements yield a body mass index (BMI) of 30, which meets the criterion for a diagnosis of obesity. The physician recommends diet changes and regular exercise with an aim of the patient losing 10% of her body weight over the next year. A year later, the mother and daughter arrive at the physician's office for the daughter's yearly medical checkup. The daughter is now 15 years old and has since taken up a healthier lifestyle, including running 3 miles a day and lifting weights. However, her BMI has increased to 36, which, the physician explains, now meets the diagnostic criterion for morbid obesity and means that she is at risk for other health problems. The physician recommends bariatric surgery treatment for the girl. The mother adamantly refuses a surgery referral, insisting that her daughter is healthy. The daughter is unsure about surgery but expresses a desire to be thinner.

In this case, the patient's mother strongly disagrees with the physician's assessment of the patient's health status and the physician's recommended course of action. Opinion 2.2.1, "Pediatric Decision Making," states:

Decisions for pediatric patients should be based on the child's best interest, which is determined by weighing many factors, including effectiveness of appropriate medical therapies and the needs and interests of the patient and the family as the source of support and care for the patient. When there is legitimate inability to reach consensus about what is in the best interest of the child, the wishes of the parents/guardian should generally receive preference.<sup>2</sup>

This opinion suggests that the physician should consider engaging in serious discussion with the mother and daughter in order to reach consensus about which treatment is in the [best interest of the minor patient](#). The physician should consider how labeling a patient as morbidly obese could influence her life and experiences, especially in light of recent criticisms that BMI might be an inadequate tool for assessing morbidity risks of obesity.<sup>3</sup> It also might be counterproductive, since the label "obese" generated a defensive response from the patient's mother. Both the patient's physician and the patient's parent are committed to serving the child's best interest, but it's the physician, not the parent, who has a professional obligation to try to recruit other stakeholders as allies. Opinion 2.2.1 states that, when consensus can't be reached "about what is in the best interest of the child, the wishes of the parents/guardian should generally receive preference."

*Case 3.* In the third case, an 83-year-old woman is concerned she's developing a neurodegenerative disorder, such as Parkinson's disease, and sees a neurologist for an evaluation. The patient's history reveals worsening symptoms after recent hospitalizations, during which numerous medications were administered and prescribed. She now takes 17 medications for heart failure, atrial fibrillation, chronic obstructive pulmonary disease, diabetes, high blood pressure, and hypertension. The neurologist is not sure whether her ailments are being caused by an undiagnosed neurodegenerative

disease, her current illnesses, polypharmacy,<sup>4</sup> or some combination of these. Opinion 1.2.3, “Consultation, Referral and Second Opinions,” states that “physicians’ fiduciary obligation to promote patients’ best interests and welfare can include consulting other physicians for advice in the care of the patient or referring patients to other professionals to provide care.”<sup>5</sup> In cases in which causes of a patient’s symptoms are unknown and there exist numerous sources of uncertainty about their origins, Opinion 1.2.3 could be interpreted as ethically obligating the physician to seek advice and consult other clinicians. In this case, consultation with other specialists before naming the patient’s condition might ultimately enable the development and implementation of a treatment plan more likely to be responsive to her specific needs and vulnerabilities.

### Conclusion

How a physician defines or labels diseases when caring for patients can have significant clinical, ethical, social, and cultural consequences. The cases considered above suggest ways in which the *AMA Code* might be interpreted and applied in scenarios in which labeling a disease can affect not only a diagnosis, but also clinical encounters and thus the quality of patient-physician relationships.

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## **POLICY FORUM: PEER-REVIEWED ARTICLE**

### **Diagnosis Codes for Human Trafficking Can Help Assess Incidence, Risk Factors, and Comorbid Illness and Injury**

Wendy L. Macias-Konstantopoulos, MD, MPH

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#### **Abstract**

The *International Classification of Diseases, 10th Revision, Clinical Modification (ICD-10-CM)* is the system used by clinicians and medical coders to document diseases, symptoms, social circumstances, and external causes of illness and injury. *ICD-10-CM* codes for various forms of abuse and violence perpetrated against children and adults exist and facilitate the study of incidence, social context, and comorbid illness and injury. Extant abuse codes, however, fail to capture the profoundly exploitative nature of trafficking and adequately distinguish trafficking patients from other types of abuse patients. As a result, the first trafficking-specific codes have been approved for the 2019 *ICD-10-CM* update and are expected to strengthen data collection on incidence of and risk factors for trafficking, the burden of comorbid illness and injury, and resources needed to effectively care for trafficked persons.

#### **The Power of Naming and Coding Abuse and Violence**

The *International Classification of Diseases, 10th Revision, Clinical Modification (ICD-10-CM)* is a diagnostic classification system used in health care to code all diseases, symptoms, abnormal findings, social circumstances, and external causes of illness and injury recognized in patient encounters.<sup>1</sup> This coding system enables entities like the National Center for Health Statistics at the Centers for Disease Control and Prevention to aggregate epidemiological data directly relevant to population health management and clinical treatments.

The *ICD-10-CM* classification system in medicine serves a purpose analogous to that of the penal code in criminal jurisprudence. The use of penal codes to classify and record crimes facilitates the tracking of criminal activity patterns in order to inform new legislation and resource allocation decisions meant to enforce the law more effectively.

Similarly, the use of *ICD-10-CM* codes facilitates the tracking of health and risk trends in order to inform health policy and resource allocation decisions.<sup>2</sup> Although other data collection and tracking tools exist, the *ICD-10-CM* is the coding system required under US legislation and represents a comprehensive classification system that lends itself to epidemiological and population health data analyses.<sup>2</sup>

The *ICD-10-CM* includes diagnosis codes for experiences such as child sexual abuse, spouse or partner violence, and elder physical abuse.<sup>1</sup> Given the many physical and mental health problems associated with experiencing abuse and violence, naming the dimensions of abuse and violence experiences that can be addressed clinically is key to improving overall health and well-being. As with disease *ICD-10-CM* codes, the ability to track specific diagnosis codes for the spectrum of abuse that patients experience is critical to understanding, for any given type of abuse, its epidemiology, the burden of comorbid illness and injury, and the resources needed to effectively address it. The use of abuse codes as primary diagnoses is essential to amassing evidence in support of new prevention strategies, treatment best practices, services, reimbursement mechanisms, and new areas of research funding to specifically address the abuse and violence.

The various forms of abuse and violence cannot be understood in isolation, however, and the undergirding forces must be taken into account. The experience of abuse and violence is best understood as a complex interplay of the physical environment (residential placement, educational and employment opportunities), social circumstances (gender roles, family traditions, cultural and social norms, religious beliefs), and individual vulnerabilities and risks (truancy, substance use, gang involvement). Assessing whether abuse and violence play a role in presenting medical conditions, psychiatric symptoms, and traumatic injuries is essential to a more effective health care response to illness and injury. The assessment, medical documentation, and coding of the physical, social, and individual factors influencing the situation (*ICD-10-CM Z* codes), however, allow for a more comprehensive health care response that addresses underlying health-related social needs. If comprehensive medical documentation and coding is achieved and sustained over time, these data can also serve as the basis for health policy and resource allocation advocacy. Similarly, *ICD-10-CM* codes for external causes of morbidity (*S, T, V, W, X, Y* codes), including injury and poisoning, categorize the type, intent, and mechanism of injury, providing additional dimensions of information regarding the perpetration of abuse and violence that could inform primary, secondary, and tertiary prevention strategies.

In short, coding of the salient external causes of injury and morbidity and of any influencing factors can furnish the medical and public health community with the information needed to identify the risk factors that fuel and exacerbate abuse and violence and potentially the protective factors that could be leveraged to decrease incidence and minimize negative outcomes. It should be stressed, however, that coding

is not possible without adequate assessment and medical documentation by the clinician during a patient encounter.<sup>3</sup> The table offers a side-by-side comparison of the potential impact of focused vs comprehensive medical assessment and documentation on diagnostic coding, the health care response, and the understanding of long-term resources needed.

**Table.** Potential Impacts of Focused vs Comprehensive Medical Assessment and Documentation of a Left Arm Infection

Factors	Focused Medical Assessment and Documentation	Comprehensive Medical Assessment and Documentation
Diagnostic coding	In order of presumed causation: L02.414: Left arm abscess L03.114: Left arm cellulitis	In order of presumed causation: Y07.0: Spouse or partner abuse and violence Z59.0: Homelessness F32.9: Depression F19.10: IV drug use L02.414: Left arm abscess L03.114: Left arm cellulitis
Health care response and treatment offered	<ul style="list-style-type: none"> <li>• Incision and drainage</li> <li>• Antibiotics</li> </ul>	<ul style="list-style-type: none"> <li>• Incision and drainage</li> <li>• Antibiotics</li> <li>• HIV counseling and testing +/- treatment</li> <li>• Hepatitis testing +/- treatment</li> <li>• Addiction counseling and referral to treatment</li> <li>• Suicide screening</li> <li>• Psychiatry consultation +/- treatment</li> <li>• Social work consultation for danger assessment, safety planning, housing/shelter assistance, and referral to domestic/partner violence services</li> </ul>
Long-term resources needed	No additional resources needed	Policy and resource allocation needed for: <ul style="list-style-type: none"> <li>• Resources and reimbursement for screening, brief intervention, referral, and treatment efforts for substance use and suicide</li> <li>• Funding for prevention strategies, treatment programs, and community services</li> </ul>

## Human Trafficking: An Egregious Form of Interpersonal Abuse and Violence

Not only is human trafficking (HT) a crime under the US federal law, it is also a human rights violation and, by all accounts, a particularly egregious form of interpersonal abuse. The Trafficking Victims Protection Act (TVPA) of 2000,<sup>4</sup> as amended (22 USC § 7102),<sup>5</sup> defines “severe forms of trafficking in persons” as:

- (a) sex trafficking in which a commercial sex act is induced by force, fraud, or coercion, or in which the person induced to perform such act has not attained 18 years of age; or
- (b) the recruitment, harboring, transportation, provision, or obtaining of a person for labor or services, through the use of force, fraud, or coercion for the purpose of subjection to involuntary servitude, peonage, debt bondage, or slavery.

To be defined as human trafficking under federal law, the commercial exploitation of an adult must be achieved by *provable* force, fraud, or coercion. On the other hand, the commercial sexual exploitation of a child is always human trafficking under the TVPA, regardless of the means used to achieve the child’s exploitation. The law recognizes that children (ie, those younger than 18 years of age) lack the intellectual capacity and developmental maturity to consent to their own exploitation and therefore assumes that a child engaging in a commercial sex act has been “*induced to perform such act*”—be it by force, fraud, coercion, threat, blackmail, intimidation, deception, psychological manipulation, suggestion, or other calculated means—and that the crime of sex trafficking has been committed against the child.<sup>4,5</sup>

In the United States, HT for manual or domestic labor and sexual labor<sup>6</sup> are known as labor trafficking and sex trafficking, respectively. The commercial exploitation of trafficked persons essentially results in their commodification or, in other words, their dehumanization as property that can be bought, used, sold, and discarded and whose sole value is commercial and based on their ability to generate profits. Motivated by strong financial incentives, traffickers often operate at the extremes of abuse and violence to gain and maintain **power and control** over those who perform the labor and generate the profits.<sup>7-9</sup> In addition to suffering abuse and violence inflicted by their traffickers, sex-trafficked children and adults also suffer physical and sexual violence at the hands of those who pay their traffickers to violate them with impunity.<sup>10-12</sup>

From violence-related injuries and sexually transmitted infections to communicable diseases and untreated chronic diseases, HT has devastating implications for the physical health of those affected.<sup>13,14</sup> In addition, trafficking can result in a wide range of industry-specific occupational injuries, such as falls from heights (construction), exposure to respiratory and skin irritants (agriculture), and joint or back strains from repetitive motions (domestic work).<sup>14</sup> Due to trafficking victims’ high rates of physical, sexual, and emotional abuse and violence, HT is further associated with severe

psychological and emotional distress. Indeed, the [mental health effects of HT](#) have been described as tantamount to those observed among survivors of torture.<sup>15</sup>

Health care professionals have the unique opportunity to [identify and assist](#) victims of human trafficking. Studies confirm that trafficked persons are accessing care.<sup>12,16-19</sup> One study found that 88% of trafficking survivors reported having been cared for by a health care professional while being trafficked yet none were assisted in escaping their captors.<sup>12</sup> As a result of increasing calls to action, efforts to educate health care professionals about HT and to provide training on the identification and proper care of trafficked patients have been escalating in recent years.<sup>14,20,21</sup>

### **The Case for ICD Diagnosis Codes for Human Trafficking**

Until implementation of the 2019 *ICD-10-CM* update on October 1, 2018, the ICD-10-CM trafficking-specific abuse codes did not exist. Prior to this date, abuse codes available for documenting child, partner, and elder abuse failed to capture the exploitative nature of human trafficking and thus the varying degrees of physical, sexual, psychological, and emotional trauma experienced by trafficked persons during their exploitation.<sup>9</sup> Indeed, although child sex trafficking is legally recognized as a form of child abuse,<sup>4,22</sup> the additional component of commercial exploitation that is involved in human trafficking places trafficking and its sequelae into a category of its own. While commercial exploitation falls along the same continuum of interpersonal abuse and violence, it is unique in that it entails stripping individuals of their autonomy and inherent human rights and thus can lead to the extreme level of psychological trauma seen in torture survivors.<sup>15</sup>

Given HT's profound health sequelae for survivors, the needs of this patient population are quite extensive and the experience of trafficking merited an *ICD-10-CM* code structure of its own for more robust data collection on its two forms—forced labor and sexual exploitation. Responding to survivors' broad spectrum of health needs, both medical and psychiatric, as well as their social and economic needs will require abundant resources. Understanding the extent and the types of resources needed to effectively address HT is critical to developing coordinated interdisciplinary care strategies and their mechanisms for funding. The ability to track this diagnosis is key to furthering our epidemiological understanding of the incidence of trafficking in the United States as well as to expanding our knowledge base, through research, of (1) risk factors that could facilitate early screening and identification of adults and children at risk, (2) comorbid illnesses and injuries that may require dedicated diagnostic and treatment efforts, and (3) potential prevention strategies.

While extensive efforts and notable advances have been made within specific institutions and health systems, the overall low level of victim identification and medical documentation in the US health care system and the lack of human trafficking codes

until now unfortunately have reinforced each other and could have thwarted development of an effective response protocol in the clinical setting beyond involving the National Human Trafficking Hotline or law enforcement (LE). Although well intended, LE involvement, unless required by state [mandatory reporting laws](#) (eg, as in cases involving minors), can lead to increased harm to trafficked patients and their loved ones and should only be pursued after engaging patients in discussion and obtaining explicit consent to do so with a clear understanding that LE involvement does not guarantee safety.<sup>23</sup> As the training of health care professionals continues to expand, victim identification and medical documentation can be expected to increase, and the new trafficking-specific codes can be expected to facilitate relevant health data tracking that may improve the health sector's effectiveness.

Although medical documentation and coding of human trafficking must be thoughtful and measured so as to minimize the potential harms and stigma associated with the diagnosis, the use of *ICD-10-CM* codes for secondary data purposes (eg, identifying opportunities and gaps in comprehensive care, informing policy and resource allocation) can better equip the health care system to assist persons suffering exploitation without access to services and resources. Furthermore, more robust health data collection may also be useful in determining reimbursement payment methods that account for, and thus encourage, antitrafficking efforts in the clinical setting such as victim identification, intervention, and referral that may otherwise be considered nonbillable, time-consuming activities. Ultimately, medical documentation and coding of human trafficking are critical in developing an infrastructure of services and resources capable of addressing the profound and wide-ranging needs of this patient population.

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## POLICY FORUM

### Infertility, Inequality, and How Lack of Insurance Coverage Compromises Reproductive Autonomy

Iris G. Insogna, MD, MBE and Elizabeth S. Ginsburg, MD

#### Abstract

Disparities in access to infertility care and insurance coverage of infertility treatment represent marked injustices in US health care. The World Health Organization defines infertility as a disease. Infertility has multiple associated billing codes in use, as determined by the *International Statistical Classification of Diseases and Related Health Problems*. However, the often-prohibitive costs associated with infertility treatment, coupled with the lack of universal insurance coverage mandates, contribute to health care inequity, particularly along racial and socioeconomic lines.

#### The Problem of Infertility

Infertility has been unequivocally defined as a disease state by the World Health Organization (WHO).<sup>1</sup> The WHO recognizes that infertility confers a disability, and it is now fifth on the international list of serious disabilities in women.<sup>1</sup> Moreover, it is a disease with billable codes that physicians can use when charging patients and their insurance companies, as determined by the *International Statistical Classification of Diseases and Related Health Problems*.<sup>2</sup> Despite the expense associated with infertility treatment, the lack of [mandated insurance coverage](#) for this disease implies that infertility is a condition undeserving of financial assistance and minimizes its importance to patients.

Infertility, a broad disease state that encompasses the inability to achieve a viable pregnancy within 1 year of attempting to conceive,<sup>3</sup> is a condition affecting millions of patients in the United States. A recent survey found that, in the United States, 12% of women aged 15 to 44, or 7.3 million women, have used infertility services.<sup>4</sup> The same survey reported that 12.1% of women have impaired fecundity (the ability to conceive biologic offspring), and 6.7% of married women are infertile.<sup>4,5</sup> Among men in that age group, the rate of infertility is 9.4%, with 15.8% of married men aged 25 to 44 classified as infertile or subfertile.<sup>6</sup>

There are myriad causes of infertility. In women, these causes include tubal abnormalities, ovulatory dysfunction, premature ovarian insufficiency, and uterine

factors such as fibroids or congenital uterine anomalies.<sup>7</sup> In men, they include factors such as decreased sperm count or motility and abnormal morphology.<sup>8</sup> And, in both sexes, idiopathic infertility and impaired fertility are the result of treatment of malignancies.<sup>7,8</sup>

Infertility affects people in a wide variety of ways and can have significant detrimental effects on quality of life. For example, approximately 40% of infertile women suffer from anxiety and depression, about twice the rate seen in fertile women.<sup>9</sup> One study of 488 American women found that infertile women had rates of anxiety or depression equivalent to those of patients diagnosed with cancer, hypertension, myocardial infarction, or HIV.<sup>10</sup>

The Universal Declaration of Human Rights of 1948, proclaimed by the United Nations General Assembly, states that all people have a right to found a family.<sup>11</sup> The 2015 American Society of Reproductive Medicine (ASRM) Ethics Committee states that “reproduction is a fundamental interest and human right.”<sup>12</sup> However, reproductive autonomy is being threatened by the exorbitant costs associated with infertility treatment. In 2015, as part of the Access to Care Summit, the ASRM reported that the average cost of one IVF cycle was \$12 400.<sup>13</sup> There are additional fees for genetic or chromosomal testing of embryos, ranging from \$2000 to \$5000, and yearly fees for egg and embryo storage are around \$1000.<sup>14</sup> Many patients may require multiple treatment cycles in order to achieve a pregnancy.<sup>15</sup>

In this essay, we aim to illustrate how the lack of broad insurance coverage for infertility further propagates health care disparities for marginalized populations in the United States.

### **The State of Insurance Coverage**

*Private insurance.* Currently, there are 16 states that have infertility coverage mandates for private insurers, with requirements developed on a state-by-state basis (Arkansas, California, Connecticut, Delaware, Hawaii, Illinois, Louisiana, Maryland, Massachusetts, Montana, New Jersey, New York, Ohio, Rhode Island, Texas, and West Virginia).<sup>16</sup> Only 6 states have what is considered comprehensive coverage that includes all or most of the costs associated with IVF (Connecticut, Illinois, Maryland, Massachusetts, New Jersey, and Rhode Island).<sup>16</sup>

Data from 1998 shows that, overall, the use of infertility services increased nearly 3-fold in states where there is an insurance mandate.<sup>17,18</sup> In the most recent data available from 2015, there were 2832 assisted reproductive technology (ART) procedures performed per 1 million women of reproductive age.<sup>19</sup> Of the 13 states and federal districts with rates of ART utilization that exceeded the national rate (California, Connecticut, Delaware, the District of Columbia, Hawaii, Illinois, Maryland, Massachusetts, New

Hampshire, New Jersey, New York, Rhode Island, and Virginia), 9 had insurance mandates as of 2015 (California, Connecticut, Hawaii, Illinois, Maryland, Massachusetts, New Jersey, New York, and Rhode Island), although California and New York exclude IVF.<sup>19</sup> Today, 10 of the 13 states on this list (including Delaware) have insurance mandates.<sup>20</sup> Data from the United States stand in contrast to many European countries where ART is much more affordable and corresponding rates of ART utilization are much higher. In Denmark and Belgium, for example, there are more than 12 500 ART cycles per 1 million women ages 15 to 45.<sup>21</sup>

*Government insurance.* There is no coverage for infertility treatment for patients with public or federal insurance. Federal civil service employees working for the US government, for example, have no insurance coverage for infertility treatment.<sup>22</sup> As of March 2018, there were 34.7 million adults enrolled in Medicaid, none of whom have insurance coverage for infertility.<sup>23</sup> For those on public assistance requiring government aid, mandating coverage for infertility treatment is a controversial topic, one that falls outside the scope of this brief essay. However, financial limitations alone should not be paramount in determining which citizens are appropriate parents. For most people, paying for ART out of pocket is impossible, leaving many without a financially feasible way to manage their disease or achieve their reproductive goals.

### **Disparities in Access to Care**

Minority patients face substantial [barriers in seeking treatment for infertility](#). There is evidence that African American, Chinese, and Hispanic patients are much less likely to seek care than white patients and that African American and Hispanic women, despite having higher rates of infertility, are underrepresented in the infertility clinic population.<sup>17,18,24-26</sup> After failing to conceive spontaneously, it takes an average of 4.3 years for African American women to present to infertility care centers compared to 3.3 years for their white counterparts.<sup>18</sup> When cost barriers are reduced and access is equalized, as demonstrated in a study of patients with at least partial insurance coverage provided through the Department of Defense, there is a 4-fold increase in utilization of assisted reproduction services among African Americans relative to the US ART population.<sup>24</sup>

Once patients present for care and begin treatment, however, poorer outcomes have been observed in minority patients compared to white patients. A large single-site study demonstrated that, compared to white patients, African Americans had significantly higher spontaneous abortion rates (28.9% vs 14.6%) and lower clinical pregnancy rates (24.4% vs 36.2%) and live birth rates (16.9% vs 30.7%) following IVF.<sup>25</sup> A recent systematic review of 24 studies, including 5 US registry-based studies, confirmed these findings.<sup>26</sup> Moreover, the review concluded that lower clinical pregnancy rates and live birth rates are also observed in Hispanic and Asian women compared to their white counterparts.<sup>26</sup>

It has been hypothesized that increased rates of obesity, tubal factor infertility, and uterine factor infertility secondary to fibroids might explain the poorer outcomes following infertility treatment in these populations.<sup>24,26</sup> However, sociocultural and financial barriers encountered by many minority patients are very likely contributing to the disparities in ART outcomes manifested, and they may partially explain why minority patients are underrepresented in infertility clinics and present later for care.<sup>18,26</sup> The ASRM has stated that “the access, treatment, and outcome disparities that are associated with ART are a form of stratified reproduction that warrants correction.”<sup>12</sup>

### **Disparities in Treatment**

*Tubal factor infertility.* Tubal factor infertility typically affects 25% to 35% of IVF patients and provides a good example of how insurance status can dictate care.<sup>27</sup> Tubal dilation or damage can be incurred from a variety of insults such as ectopic pregnancy or gonorrhea or chlamydia infections. The presence of a hydrosalpinx, or dilation of the fallopian tube, directly impacts the success of ART, with pregnancy rates essentially doubling for patients who have undergone either laparoscopic salpingectomy (removal of the affected tube) or proximal tubal occlusion (34% vs 17%) prior to starting IVF. Thus, it is now a formal recommendation of the ASRM to surgically treat hydrosalpinges, if present, prior to starting ART.<sup>27</sup>

In a survey including over 400 infertility specialists, physicians practicing in states without an insurance mandate were more likely not to perform salpingectomy or proximal tubal occlusion before providing ART due to lack of infertility insurance coverage.<sup>28</sup> This finding suggests that patients without insurance coverage with tubal factor infertility secondary to hydrosalpinges are likely to receive substandard care and are likely to have worse outcomes if they do pursue self-pay IVF without the appropriate surgery. Because chlamydia infection, a common cause of tubal factor infertility, is 6 times more common in black women and 2 times more common in Hispanic women than in white women, the practice of bypassing surgical treatment prior to ART represents a disparity in treatment that falls along both economic and racial lines.<sup>29</sup>

*Oncofertility.* Fertility preservation for patients with a new diagnosis of malignancy provides another example in which socioeconomic barriers prevent appropriate care. Women who face losing their fertility secondary to surgery, chemotherapy, or radiation may be strongly motivated to pursue oocyte or embryo cryopreservation. The cost of ovarian stimulation, oocyte retrieval, and cryopreservation ranges from \$10 000 to \$13 000, and the cost of ovarian stimulation, oocyte retrieval, fertilization of eggs, and embryo cryopreservation ranges from \$13 000 to \$16 000, both with substantial associated yearly storage fees beyond the first year.<sup>14</sup> However, most states do not mandate insurance coverage for fertility preservation, and only 4 states mandate coverage for iatrogenic infertility related to treatment for malignancy.<sup>16</sup> Although patients with breast cancer commonly report significant concerns about fertility, it has

been shown that wealthier patients are more likely to pursue fertility preservation.<sup>30,31</sup> The financial burden associated with cryopreservation of oocytes or embryos is prohibitive for many patients and thus poses a direct threat to their reproductive autonomy.

### Conclusion

Infertility is a disease with a substantial psychosocial burden, and the lack of affordable options may have significant detrimental effects on the quality of life of millions of Americans. Because of the current lack of universal insurance coverage mandates for ART, infertility is implicitly designated as a disease undeserving of financial support, leaving many patients unable to fulfill their reproductive goals. Improving access to care via broader insurance mandates and coverage plans would help rectify these disparities. The fundamental right to reproduce is currently under threat, and these disparities will only intensify if the financial barriers to infertility care are not directly and promptly addressed.

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## POLICY FORUM

### Who Should Regulate Preimplantation Genetic Diagnosis in the United States?

Michelle Bayefsky

#### Abstract

Unlike in many European countries, preimplantation genetic diagnosis (PGD) is not regulated in the United States. As a result, PGD may be used for any condition for which genetic testing is available, at the discretion of fertility specialists and their patients. This essay explores the question of who should be responsible for regulating PGD in the United States. Federal or state regulation of PGD in the United States is likely to be challenging and problematic for several reasons, including the proximity of PGD to the abortion debate. I propose that PGD regulation in the United States can be most appropriately performed by health professionals using professional society guidelines that set standards for clinical practice.

#### Regulatory Lacuna for Preimplantation Genetic Diagnosis in the United States

Preimplantation genetic diagnosis (PGD) is a technique that can be used during in vitro fertilization (IVF) to test an embryo for genetic abnormalities associated with specific disorders before deciding which embryo(s) to transfer to a woman's uterus. PGD is primarily used to help people have children who will not be affected by heritable disorders, such as Tay-Sachs or cystic fibrosis. While these applications of PGD might seem clearly beneficial, the technique has also been used for more controversial purposes. In the United States, a small number of clinics offer PGD to select for a [disability](#), such as deafness or achondroplasia.<sup>1</sup> PGD is also widely offered for [sex selection](#); a 2017 study showed that 72.7% of US fertility clinics offer sex selection, and 83.5% of those clinics offer sex selection for couples without infertility,<sup>2</sup> meaning that a couple would only undergo IVF in order to select their child's sex. Furthermore, some worry that PGD could be used to select for traits such as hair color, height, and athletic ability, although these are unlikely to be single-gene traits for which we can easily select in the near term.

PGD can be employed for these "nonmedical" purposes in the United States because there are no legal limitations on the technique's use. It can be used for any condition for which genetic testing is available at the discretion of fertility treatment clinicians and their patients. By contrast, many European countries have rigid legal structures that determine for what indications PGD is permissible.<sup>3</sup>

This article explores the question of who should be responsible for regulating PGD in the United States. I will argue that federal or state regulation of PGD is likely to be difficult and problematic for a number of reasons, including proximity of PGD to the abortion debate. (For those who believe life begins at conception, there are important similarities between a decision to abort a fetus and a decision to transfer or discard an embryo.) I propose that PGD should be regulated by health professionals using society guidelines that delineate standards for clinical practice. For the purposes of this essay, I take as my starting point that PGD should indeed be regulated, an issue I explore and defend elsewhere in depth.<sup>4</sup> Given the wide range of potential uses of PGD, the regulatory lacuna in the United States will soon become untenable, regardless of which current uses of PGD one finds acceptable. For sake of comparison, I briefly outline British and French approaches to PGD regulation and policy making.

### **British and French Regulation of PGD**

In the United Kingdom (UK), PGD is regulated by a statutory body called the Human Fertilisation and Embryology Authority (HFEA). The organization maintains a list of conditions for which PGD has been approved, which now includes almost 400 conditions, including BRCA1 and 2, sickle cell anemia, and certain forms of deafness.<sup>5</sup> For conditions not already on the list, the HFEA considers a number of factors, including “how serious the condition is, the likelihood of it being inherited and the testimony of people affected by the condition before deciding whether to approve it for PGD testing.”<sup>6</sup> In order for a new condition to be considered for PGD testing approval, a couple must have a licensed PGD clinic apply to the HFEA on their behalf.

In France, PGD is explicitly authorized in the public health code and is permitted only when a couple has a high probability of giving birth to a child with an incurable heritable disease,<sup>7</sup> as evidenced by the couple already having a child or immediate relative with such an illness.<sup>8</sup> Before the couple can undergo PGD, their case must be evaluated by a team of experts, who determine whether there is sufficient risk of that couple having a child with a sufficiently serious condition.<sup>9</sup> An organization called the Agence de la Biomédecine has the power to increase the number of uses of PGD, and, in 2012, the Agence recommended that PGD be allowed for selecting children who can serve as tissue donors for sick siblings.<sup>10</sup>

Both France and the UK have robust systems for regulating PGD and determining when PGD can ethically be used. Both France and the UK have also designated agencies responsible for maintaining regulations’ adaptability to changing scientific realities, patient needs, and social views.

## **US Government Role in Regulating PGD**

In the US, there are a number of challenges to federal or state regulation of PGD. First, unlike France and the UK, the US does not have a government-funded national health care system. French and British lawmakers already make determinations about which applications of assisted reproductive technology (ART) should be publicly accessible because they decide which, and for whom, procedures should be funded. For example, in the UK, the National Institute for Health and Care Excellence (NICE) recommends covering 3 cycles of IVF for women under 40 years who have been trying to get pregnant for 2 years and have failed 12 cycles of artificial insemination.<sup>11</sup> Women aged 40 to 42 should be offered 1 cycle of IVF if they meet criteria demonstrating their potential fertility.<sup>11</sup> (In practice, however, the number of cycles a woman will be offered in the UK depends on her National Health Services locality.)

In the United States, IVF is not covered by federal programs (ie, Medicare, Medicaid, or Veterans Affairs [VA] health benefits), with the exception of VA coverage of IVF for patients who have lost fertility due to a service-related injury.<sup>12,13</sup> Although 15 US states have passed laws requiring private insurance companies to offer coverage of some form for fertility treatment, only 8 explicitly require IVF coverage,<sup>14</sup> which is necessary to carry out PGD. While it is possible for the US government to regulate IVF and PGD without funding their use, lack of government funding means a state is not required to provide recommendations for the just and prudent utilization of public resources for PGD. Furthermore, there is resistance to regulation among some physicians who argue that, given the lack of funding for ART, the government should not intervene in clinical practice.<sup>15</sup>

Another obstacle to federal PGD policy making is the absence of a clear federal actor or agency responsible for regulating clinical practice. The Food and Drug Administration is responsible for ensuring safety and efficacy of drugs and devices but not when and how they should be used.<sup>16</sup> The Centers for Disease Control and Prevention gathers data nationally and annually on fertility treatments, but its purview is limited to data collection and reporting. The Centers for Medicare and Medicaid Services regulates performance of genetic testing, including specimen processing and results reporting, but not the circumstances under which tests can be ordered.<sup>17</sup> Congress could pass a law establishing appropriate uses of PGD, but it would be highly atypical for Congress to legislate when a particular medical treatment can be offered.<sup>18</sup> Federal oversight of PGD would require Congress to assign regulatory authority to an existing agency or create a new agency.

Creating a new federal system for regulating PGD would be challenging due to the proximity of PGD to the abortion debate, which is particularly contentious in the United States.<sup>19,20</sup> PGD, which is carried out in sequence with IVF, involves creating a batch of embryos and selecting certain embryos from that batch, while the rest are stored,

discarded, or donated to research, depending on patient preferences. Regulating PGD would require accounting for the fate of the embryos that are not selected. Federal legislators have been hesitant to regulate IVF because of the incendiary politics surrounding the creation and destruction of embryos<sup>21</sup> and would likely be similarly reluctant to address PGD. If PGD legislation were proposed in Congress, there is concern among some that such legislation may be aimed at limiting destruction of embryos rather than maximizing benefits PGD can bring to families.

Historically, government regulation of clinical practice has been left to states. Although there are no laws pertaining directly to PGD, some states have proposed or passed laws related to abortion of fetuses with genetic or congenital anomalies. North Dakota prohibits abortions in cases of any fetal abnormality.<sup>22</sup> Indiana and Louisiana passed laws banning abortions for genetic abnormalities, but Indiana's law has been permanently blocked and Louisiana's law has been temporarily blocked by court orders; neither are currently in effect as of the writing of this article.<sup>22</sup> In February 2018, the Utah House passed a bill that would prohibit physicians from performing abortions solely on the basis of fetal Down syndrome.<sup>23</sup> If some legislators are attempting to restrict abortions intended to prevent the births of children with genetic abnormalities, they might well oppose employing PGD for the same purpose. While some might distinguish between embryos in vitro and fetuses, and thus view PGD as a means of avoiding abortion, those who believe that life begins at conception might find creating and then rejecting (not selecting) affected embryos to be as ethically unacceptable as abortion.

It is possible to write a law requiring unused embryos to be stored indefinitely so that no embryos would be destroyed. For those who view life as beginning at conception, ensuring that no embryos' lives are ended might be sufficient. For others, the concept of embryos remaining forever frozen is still objectionable; in fact, there is a movement for "[snowflakes embryo adoption](#),"<sup>24</sup> the name given to the practice of adopting and carrying to term frozen embryos that genetic parents chose not to gestate. Nonetheless, even for people who object to keeping embryos frozen indefinitely, freezing embryos is preferable to destroying them, since freezing maintains an embryo's potential for growing into a child. A law requiring embryos to remain frozen could be seen as a compromise between those concerned with the embryo's life and those seeking to ensure access to PGD. However, lawmakers primarily concerned with limiting destruction of embryos might attempt to ban PGD outright, which would constitute a serious violation of reproductive autonomy for families who need PGD to have healthy children. Given the inflammatory nature of the abortion debate in the United States, state regulation of PGD could result in laws that are not sufficiently nuanced to both respect the views of pro-life constituents and allow the use of PGD to select for embryos without serious heritable conditions.

### **Professional “Self-Regulation” of PGD**

“Self-regulation” of PGD by professionals applying society guidelines is a viable alternative to government regulation that avoids the potential pitfalls described above. Health professionals, including infertility specialists, OB/GYNs, geneticists, and genetic counselors, are more likely to prioritize the needs of patients when deciding which uses of PGD are ethically permissible. They are also apt to have a keen understanding of the current limitations of PGD, genetic testing, and new developments on the horizon. Allowing medical professionals to decide when PGD should be used is, in some sense, giving them authority to determine which diseases are sufficiently serious to warrant PGD. These decisions are ethically fraught and would be best made by multidisciplinary committees in order to avoid clinicians offering PGD too liberally due to bias or self-interest. Although professional guidelines are not legally binding, physicians face pressure to conform their practices to standards of care, and physicians who choose not to follow guidelines leave themselves vulnerable to criticism, litigation, and possible action against their licenses.

At present, self-regulation of PGD is inadequate because current guidelines effectively allow individual clinicians to decide when and for which conditions to use PGD. This kind of discretion results in an essentially limitless use of PGD, which is precisely what regulation of any kind seeks to avoid. For example, the American Society for Reproductive Medicine (ASRM) guideline on transferring embryos with known genetic anomalies concludes that the decision to use PGD should be left to individual clinicians unless an anomaly would result in extremely severe disability, in which case physician assistance with selecting such an embryo is discouraged.<sup>25</sup> In the ASRM guideline on the use of ART for sex selection, decisions are also specified as being within individual clinicians’ purview.<sup>26</sup> The American College of Obstetricians and Gynecologists (ACOG) and the American College of Medical Genetics and Genomics do not have committee opinions pertaining directly to PGD, but guidelines on related topics are likewise open-ended.<sup>27,28</sup> ACOG has historically opposed sex selection, but its guidance on sex selection has been withdrawn and has not been replaced.<sup>29</sup> Without more definitive statements to guide future practice, some clinicians could offer PGD for reasons others would find unethical, including to select for superficial traits. Furthermore, if some clinicians offer PGD for any reason requested by the patient, others could feel pressured to follow suit in order not to lose patients to colleagues with more liberal practices on the use of PGD. The decision of when to perform PGD could then fall to the lowest common denominator of the profession rather than being referred to a thoughtful multidisciplinary team of health professionals who are particularly knowledgeable about the technology.

### **Conclusion**

Due to a dearth of PGD regulation in the United States, clinicians and patients are currently able to carry out PGD for any reason. As PGD is offered for more and increasingly controversial conditions, lack of regulation will ultimately become untenable.

However, due to proximity of PGD to the abortion debate, attempts to regulate PGD at state or federal levels would most likely provoke controversy and could even result in outright bans. Professional self-regulation is preferable, but health professions' societies must provide more definitive guidelines in order for regulation to be effective.

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## MEDICINE AND SOCIETY

### Beyond the Nature/Medicine Divide in Maternity Care

Jessica Martucci, PhD, MBE

#### Abstract

Much has been made of distinguishing natural from medical in childbirth in both popular and professional contexts. But what do we really mean by *natural childbirth*? This essay examines the history behind the natural childbirth movement and suggests that distinguishing natural from medical childbirth is no longer productive in ongoing efforts to improve maternal health care.

#### What Do We Mean by *Natural Childbirth*?

The word *natural* figures prominently in contemporary health care discussions on everything from foods and supplements to breastfeeding. But what exactly do we mean when we use the word *natural*? There simply is no fixed definition for the term that fully captures its many meanings or interpretations. What seems natural can vary from person to person and is context dependent.<sup>1</sup> The slipperiness of the term *natural*, in fact, was the subject of an entire 2015 report by the Nuffield Council on Bioethics.<sup>2</sup> The term has also inspired heated debates at the Food and Drug Administration (FDA) about regulating its use in the food industry.<sup>3</sup>

More specifically, what does it mean to talk about a *natural childbirth*? When it comes to data on childbirth, there are no measures of natural childbirth as a category, but there are certain terms that serve as corollaries: *unassisted vaginal delivery*, *out-of-hospital birth*, or *midwife-assisted birth*.<sup>4-6</sup> Each of these can be understood as existing under the larger umbrella of natural childbirth alongside other qualifiers including, but not limited to, having a vaginal birth, avoiding an episiotomy, foregoing pain medication, or maintaining freedom of movement. As we dig more deeply into what we mean by *natural childbirth*, its distinction from medical childbirth becomes less and less clear.

The reality is that there are dozens of ways a mother might experience her labor and delivery as natural even as specific aspects of the process might intersect and overlap with the knowledge, tools, and interventions associated with a more medicalized birth. Furthermore, as any woman who has gone through a labor and delivery experience can tell you, what one thinks of as natural in the context of childbirth can change during the course of a birth experience. Despite these ambiguities, the fact that it is necessary to distinguish a natural birth from simply birth suggests that there are some practices that

we generally agree are *not* natural. If you do an internet search for “natural childbirth,” for example, you are unlikely to find the term affiliated with procedures like Cesarean sections, episiotomies, and epidurals.

Here, I will discuss the emergence of natural childbirth as a response to the early 20th-century medicalization of birth. I argue that there is a need to move beyond the natural/medicalized childbirth dichotomy for the purpose of framing maternity care decisions more productively.

### **The Emergence of Medicalized Birth**

Prior to the 20th century, the idea that childbirth was natural would have been an unnecessary and meaningless distinction for most people. The concept of a natural birth only arose as a response to the widespread medicalization of birth in Europe and the United States that took place over the course of the late 19th and early 20th centuries.<sup>7</sup> The transition away from the traditions of lay midwives and social childbirth in the home towards university-trained male midwives and, later, obstetricians was one that proceeded gradually during the 17th through the 19th centuries as the medical profession grew along with its knowledge base and its cultural authority and prestige.<sup>7</sup> By the late 1800s, [advances in pain relief](#), antiseptic and aseptic surgical practices, and surgical techniques and outcomes—alongside a rapid rise in people’s faith in scientific medicine—helped accelerate a transition to hospital childbirth.<sup>7</sup>

By the end of the 1930s, the number of women in the United States who gave birth in hospitals under the direction of a physician surpassed the number giving birth at home.<sup>8</sup> Although midwife-attended home births persisted as the norm for many who lived in rural areas, particularly for black women in southern states, medically supervised hospital birth became the new ideal of modern childbirth to which most women aspired.<sup>9</sup> Yet while many poor, rural women of color still struggled to access medical assistance during childbirth, white middle-class American women began reacting against what they experienced as disempowering and dehumanizing medical practices.<sup>10</sup> It was within this context that some women began articulating an interest in what they called *natural childbirth* as early as the 1930s.

### **The Origins of Natural Childbirth**

Grantly Dick-Read is often credited with inaugurating the era of natural childbirth, but as is often the case, the story is a bit more complicated.<sup>11</sup> While it’s true that the British obstetrician’s 1942 classic, *Childbirth Without Fear*,<sup>12</sup> helped launch an international movement of women seeking physicians who would agree to fewer interventions during childbirth,<sup>13</sup> he was not the first to consider, or even describe, natural birth. If anyone ought to be looked to as an early popularizer of natural birth, it would be more appropriate to single out the anthropologist Margaret Mead. Mead spent years studying the ways in which different non-Western cultures approached practices concerning

sexuality, reproduction, and childrearing. These experiences inspired her to seek out a more natural birth experience for herself in 1939, as she prepared for the arrival of her daughter, Mary Catherine Bateson.<sup>14</sup> Having witnessed and even filmed numerous deliveries among women in New Guinea and Bali where she conducted her research, Mead had seen women give birth without medical intervention or pain medication, often outdoors and surrounded by supportive friends and family.<sup>15-17</sup>

Despite her enthusiasm and a cadre of high-profile physicians who supported her, however, she was unable to escape the institutional pressures of the medicalized birth experience that had become the American norm for professional and middle-class women like herself. Mead found a physician (Claude Heaton) who was willing to refrain from medication, to a point, and she convinced the hospital and nursing staff to acquiesce to her desire to breastfeed her child.<sup>18</sup> However, she could not convince them to let her keep her child with her in the room overnight and ultimately even her request to go unmedicated was overruled. As she recalled, "They were convinced that as a primipara I could not be so ready for birth and I was given medication to slow things down."<sup>18</sup> Nevertheless, Mead helped lay important groundwork for knowledge about and interest in natural birth through her work as a public intellectual and mother and as a mentor to a generation of natural childbirth and breastfeeding advocates.<sup>19,20</sup>

### **Humanizing Maternity Care**

Although slow to start, interest in natural birth simmered throughout the post-World War II decades. During the late 1950s and 1960s, the popular breathing methods introduced by the French obstetrician Fernand Lamaze gained momentum alongside a more general interest in natural motherhood practices, like breastfeeding.<sup>21</sup> A small but growing breastfeeding movement helped nurture a belief among some that women's bodies had a natural flow, rhythm, and connectivity to them that united mothers across time and place.<sup>22</sup> This perspective gained its most successful advocate in the work of birth reformer Ina May Gaskin. With its roots in observations of indigenous cultures obscured, Gaskin's vision of natural childbirth that emerged in the 1970s was imbued with the era's sense of cosmic mysticism and self-discovery.<sup>23</sup> Giving birth naturally in the era of the women's movement became seen by some as an opportunity for consciousness raising, spiritual fulfillment, and female empowerment. Through the work of birth reformers like Gaskin, the idea of natural childbirth increasingly became associated with the feminist belief that women ought to be able to experience birth as something other than a medical event.<sup>24</sup>

Although Gaskin's work on natural childbirth has had a broad impact on how American women approach childbirth today, the struggle to bring a sense of female autonomy and empowerment to bear on the birth process has been a laborious and incomplete one. The modern movement in the United States to [re-establish midwifery](#) and natural childbirth methods has hewn closely to the medical model. Midwifery in many places

exists today as part of a larger hospital or birth center (often attached or right next to a hospital, like the Birthing Suite at Pennsylvania Hospital in Philadelphia.<sup>25</sup>) Although birth reform efforts have been successful in humanizing many aspects of women's experience in these institutions (allowing family, friends, and doulas into the labor and delivery rooms and supporting women who want to breastfeed, for example), women's autonomy during childbirth remains highly circumscribed.<sup>26</sup> This loss of autonomy and control over what is done to their bodies in the medical context continues to remain a significant source of women's fear and anxiety leading up to labor and delivery.<sup>27</sup>

### **Shifting to the Good Birth**

Although the ideas behind natural childbirth have helped bring about important reforms in maternal health care, it's time we move beyond the natural/medicalized childbirth dichotomy. The natural/medicalized distinction simply fails to adequately or accurately capture the desires, needs, expectations, and experiences of most mothers who give birth in America today. One 2002 survey of women who gave birth in the United States found that 45% of respondents believed "birth is a natural process that should not be interfered with unless medically necessary."<sup>28</sup> Yet 61% of women living in 27 states who had vaginal delivery for a single birth ultimately chose to get an epidural or spinal anesthesia in 2008,<sup>29</sup> and 32% of women living in the United States received Cesarean sections in 2016.<sup>30</sup> I suggest a more productive reframing of this discourse is one in which we simply seek to support women in their pursuit of a *good birth*, a concept physician and bioethicist Anne Drapkin Lyerly has explored at length.<sup>31,32</sup> Lyerly's work engages with women's birth stories to highlight a simple truth: treating women with dignity and respect throughout the entire birthing process matters far more than whether or not the birth is able to proceed "naturally" or not. Lyerly, too, takes issue with the natural/medicalized childbirth dichotomy. What she has found in over 100 interviews with mothers about their birth experiences is that regardless of whether women had a more natural or medical birth, 5 important values emerged as part of a good birth. These included having feelings of personal agency, personal security, connectedness, respect, and knowledge.<sup>32</sup> Her work suggests that discrete options about specific interventions (and whether they are natural or not) matter far less to a woman's overall birth experience than how she is treated as a person throughout the process.

Rather than continuing to focus on framing birth as a choice between medicalized and natural (a choice that is neither fixed in meaning nor always optional in the case of a real medical concern), maternity care practitioners should look to Lyerly's work. Although women's voices are routinely marginalized in their encounters with the medical system,<sup>33,34</sup> Lyerly's birth narratives, along with other more quantitative studies on maternal experiences, call attention to how this marginalization manifests itself in the labor and delivery room.<sup>35</sup> Maternal health care practitioners should work with expectant mothers to develop meaningful perspectives on, and to attain, a good birth. The shift

beyond the historical natural/medical divide in discussions of maternal health care is long overdue.

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## MEDICINE AND SOCIETY

### Why We Should Stop Using the Term “Elective Abortion”

Katie Watson, JD

#### Abstract

In abortion care, the term “elective” is often used as a moral judgment that determines which patients are entitled to care. Secular health care organizations that attempt to avoid controversy by allowing “therapeutic” but not “elective” abortions are using medical terminology to reinforce regressive social norms concerning motherhood and women’s sexuality because what distinguishes pregnant women with medical indications for abortion is that they originally wanted to become mothers or, in cases of rape, that they did not consent to sex. Secular health care organizations should stop denying the moral agency of patients and physicians who conclude abortion is morally acceptable and should only use the word *elective* when billing codes require it. Regardless of reason, the proper label for all abortion is health care.

#### The Term “Elective” as a Label

My stepfather recently had elective surgery—a classic case of knee replacement on demand. Tom wanted to reverse the perfectly natural physical change of eroded cartilage (exacerbated by his choice to play squash for pleasure), so he went to a physician who agreed with his value-laden rejection of how using a wheelchair would change his life. Insurance paid for this elective procedure because his physician recommended it, but that recommendation was simply confirmation that a safe medical procedure could return Tom’s body and life to what he previously experienced as his baseline state.

The phrase “knee surgery on demand” is as silly as the phrase “abortion on demand,” yet the latter phrase appears in political rhetoric and judicial opinions.<sup>1</sup> Medicine designates all but the most emergent procedures as elective, which means they are all done on request of the patient. Yet the categorization of a procedure as elective or medically indicated is quite different for abortion than for other medical procedures, and it both reflects and feeds the politics of abortion. This nomenclature has bad consequences for patients, which should motivate serious examination of how clinicians, health care organizations, and insurers have used—and misused—the term elective abortion.

*Williams Obstetrics*, a classic textbook in the field, provides one example of how the term elective abortion is defined in medicine. The content of its chapter on abortion suggests that the authors support legality and access, but the 2018 edition of the chapter contains a subsection called “Classification” that’s dedicated to distinguishing “elective” and “therapeutic” abortions:

Therapeutic abortion refers to termination of pregnancy for medical indications. Inclusive medical and surgical disorders are diverse and discussed throughout this text. In cases of rape or incest, many consider termination. The most frequent indication currently is to prevent birth of a fetus with a significant anatomical, metabolic, or mental deformity. The term elective abortion or voluntary abortion describes the interruption of pregnancy before viability at the request of the woman, but not for medical reasons. Most abortions done today are elective, and thus, it is one of the most frequently performed medical procedures.<sup>2</sup>

Yet *Williams Obstetrics* does not explain why abortions are classified. What purpose does this classification serve? What goal does it accomplish?

Some private and public [insurance plans](#) will not pay for “elective” abortions, and one could argue that clinicians and health care facilities are simply using terminology that reflects this coding issue. But whether the patient or her insurer will be billed for the procedure is not the primary significance of the term. Many secular hospitals and private practice groups attempt to avoid internal and external controversy by prohibiting their physicians from performing elective abortions.<sup>3,4</sup> As a result, women with medical indications can often receive therapeutic abortions within their current health care delivery systems, and those whose abortions are labeled elective must go elsewhere. For some patients, getting to a clinic requires significant travel, added expense, and braving a picket line. For all patients, being rejected by the organization that provides all their other health care sends a stigmatizing message: “We won’t perform this simple, safe, life-altering procedure for you because of your reasons.”

### **The Term “Elective Abortion” Is Moral Judgment Masquerading as Medical Terminology**

Every abortion is elective. No pregnant woman with health problems is required to terminate her pregnancy—she can choose to deliver a baby with a disability or a terminal condition, risk her own health to deliver a baby, or decide the risks outweigh the benefits and choose abortion.<sup>5</sup> But like women considering nonmedical risks and benefits of pregnancy and parenthood, every woman analyzing medical indications for abortion also has a choice.

Alternatively, perhaps no abortion is elective. Pregnancy is a radical bodily change, and the risk of death from childbirth is 14 times higher than from abortion.<sup>6</sup> Deciding whether to bring a new child into the world is a serious moral commitment, and doing so can cause some women economic or interpersonal harm that could result in deeper or more sustained suffering than many medical conditions. Several physicians who perform abortions have told me that many of their patients do not perceive themselves as having

any choice at all—dire social circumstances lead them to see abortion as their only option.

*Social abortion* is another term that is occasionally used to describe abortions that are not chosen in response to disease or anomaly.<sup>7</sup> However, the decision to become a parent and the decision to not become a parent are equally “social.” Both are lifestyle choices that revolve around women’s or couples’ visions of their most happy and meaningful lives, yet women with planned pregnancies are never described as pursuing social childbearing.

The term *medical indication* can falsely suggest the kind of medical complexity that typically justifies hospital care, implying a logic to some hospitals’ willingness to do therapeutic abortions while referring elective abortions to clinics. Yet abortion for the medical reason of an embryonic genetic anomaly discovered at 8 weeks does not require hospital-level abortion care, and abortion for the social reason of a partner’s abandonment at 20 weeks might be more safely done at a hospital in some communities. With the exception of some maternal health conditions, the reason for the abortion rarely changes the procedure. Instead, it is advancing gestational age that increases the procedure’s complexity and risks. Labeling an abortion therapeutic usually signifies whether it will be done, not how.

Ultimately, the term *elective abortion* is moral judgment dressed up as medical judgment. Medical versus elective is code for morally justified and morally unjustified,<sup>8</sup> as decided by someone other than the patient and her physician. Yet the patients’ rights and medical ethics revolutions of the 1970s were premised on the idea that ordinary people were serious moral thinkers entitled to request or refuse medical care according to their own values, and patients’ expressions of values and priorities in this area of medicine are as worthy of respect as in any other. When you learn a woman’s or a couple’s reason for an abortion, you also learn what moral status that woman or couple assigned to their embryo or fetus. When a woman does not want to have a child, and she has concluded that her embryo or fetus does not have moral status that outweighs her own, she is entitled to decide the risk of childbirth is not outweighed by its benefits. However, instead of treating a patient who has decided she needs an abortion as a moral decision maker and allowing her physician to respond to her as a medical professional, secular hospitals and practice groups that prohibit their willing physicians from performing “elective” abortions are using their institutional power to unjustly impose the judgment of strangers on her instead. As a result, this misappropriated medical terminology allows politics to rob patients of access to legal medical care.

### **The Term “Elective Abortion” Reflects and Reinforces Institutionalized Sexism**

The distinction between elective and medically indicated abortions is a regressive, destructive conceit. What really distinguishes abortion patients with medical indications

is that these pregnant women are presumed to have initially wanted a child—they would not have asked for an abortion if it weren't for this health problem—or, in cases of rape and incest, that they did not consent to sex. The allowance hospitals, private practice groups, and insurers make for medically necessary abortions is not a medical line, it is a sex-discriminatory social line: *We will only care for women who accept the social norms that women are meant to be mothers and that women cannot have sex solely for pleasure instead of for procreation. Mainstream medicine will cast out all others.*

Women's ability to control their fertility, which medicine can now safely and effectively provide, is a prerequisite to their full citizenship. By labeling the vast majority of abortions women request as elective, the medical profession labels women's equality optional. In 2014, abortion rates were the lowest they'd been since abortion became legal nationwide in 1973.<sup>9</sup> Still, 2.8 million US women confronted unintended pregnancy in 2011, and 42% of them chose to terminate those pregnancies.<sup>10</sup> If the low 2014 abortion rate holds steady, 1 in 4 American women will have an abortion before menopause.<sup>11</sup> Calling the vast majority of these procedures elective is a cavalier way to dismiss the aspirations and disparage the judgment of the almost 1 million American women who ask for this procedure every year.<sup>9</sup>

Who is a candidate for care? If my stepfather had only sprained his knee and had requested knee replacement surgery, his request would have been refused—his physician would have told him that was not the appropriate medical solution for his condition, and therefore he would not have been a candidate for surgery. The way the term "elective" is used in abortion means this is what the vast majority of women confronting unwanted pregnancies are told by their health care practitioners—pregnancy termination is not the appropriate medical solution for your condition. That is a moral judgment, in many cases colored by a gender judgment, not a medical judgment.

### **Electing to Drop the Term "Elective Abortion"**

For these reasons, I've discarded the term "elective abortion." Instead, my scholarship focuses on what I think of as ordinary abortion. I use this term to describe the vast majority of abortions, which are done at early gestational ages for the most common reasons—eg, "Not ready for another child/timing is wrong," "Can't afford a baby now," or "Have completed my childbearing/have other people depending on me/children are grown."<sup>12</sup> Ordinary abortion is in contrast to extraordinary abortion, which describes the minority of abortion cases that have a variety of distinctive features but often include increased medical complexity and later gestational age.<sup>4</sup> For the same reasons, secular health care organizations should stop discriminating among pregnant patients who want to end their pregnancy. Only use the word "elective" when billing codes require it, and otherwise resist the urge to categorize abortions when it's not relevant to the medicine.

Most people can't exercise their right to abortion without the help of a medical professional. As a result, regardless of reason, the proper label for all abortion is health care. The term "elective abortion" obscures the fact that abortion restrictions and bans are government policies of forced childbearing. Instead of categorizing abortions, the medical profession should continue working to make the word "elective" an accurate descriptor of every woman's childbearing.

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## MEDICINE AND SOCIETY

### Three Things Clinicians Should Know About Disability

Joel Michael Reynolds, PhD

#### Abstract

The historical relationship between health care professionals and people with disabilities is fraught, a fact all the more troubling in light of the distinctive roles clinicians play in both establishing and responding to that which is considered normal or abnormal by society at large. Those who wish to improve their clinical practice might struggle, however, to keep up with developments across numerous disability communities as well as the ever-growing body of disability studies scholarship. To assist with this goal, I offer an overview of recent disability theory, outline a set of responsibilities clinicians have to disability communities, and provide recommendations for clinicians who hope to justly treat patients with disabilities and improve their care and health outcomes.

#### Clinicians' Power to Name Disabilities

While medical practice has always involved people with disabilities, it is only in recent decades that sustained disability activism, increased legal protections and social awareness, and new forms of communication have afforded various communities of people with disabilities larger platforms and increased political leverage to voice their experiences. Historically, these voices have by and large been silenced, a truth that sadly still reverberates today and one which requires significant effort to counter.<sup>1</sup> Through the creation, maintenance, and revision of diagnostic categories, health care in general and the practice of physicians in particular play distinctive roles in both establishing and responding to that which is named a *disability* or as *disabling*. Clinician misunderstanding concerning the meaning of disability and the resultant miscommunication between clinicians and people with disabilities can lead not only to negative health outcomes but also to much larger social consequences, ranging from ill-conceived state and federal policies that result in systemic oppression to various forms of interpersonal discrimination and stigmatization.<sup>2</sup>

Clinicians also wield enormous power over the care and treatment of people with disabilities, a group every human will become part of over the life course. Those who wish to advance their knowledge and improve health outcomes would thus benefit from reflecting upon the meaning of disability and the moral obligations and responsibilities owed to communities of people with disabilities. Throughout, I will use the phrase

*disability communities* to highlight the profound diversity of experiences of disability and also the way entire communities, cultures, histories, and political movements can form around certain types or sets of experiences of disability.

With this aim in mind, I first offer 3 central takeaways from the fields of disability studies and philosophy of disability. These takeaways demonstrate how mistaken assumptions about disability can lead to poor treatment and negative health outcomes. They show, in other words, that when used without care and caution, the power to name and respond to disability in clinical contexts can *hurt* people; it is a power used unethically if clinicians do not actively learn about disability communities and practice disability humility. Second, I formulate these responsibilities in terms of recommendations that clinicians can integrate into their practice across specialties.

### **Three Things Clinicians Should Know About Disability**

Disability activists as well as scholars working in the academic fields of disability studies and philosophy of disability have produced a large body of research over the last 40 years. For shorthand, I refer to this body of knowledge as *disability theory*. There are 3 core insights from disability theory I highlight here: assumptions about quality of life, the problem of ableism, and the distinction between disability, disease, and illness.

*Quality of life.* Numerous studies demonstrate that able-bodied people assume the quality of life experienced by people with disabilities to be lower than they themselves report.<sup>3</sup> Given that the vast majority of clinicians are able bodied, this means that many, if not most, clinicians mischaracterize the quality of life of people with disabilities.<sup>4</sup> For example, a patient diagnosed with multiple sclerosis (MS) might be told by her primary practitioner or a specialist that she should expect significant loss, pain, and the dissolution of her current social supports. Of course there is truth to that claim, but it poisons the prognostic well by only focusing on the difficulty of ability transitions—which can indeed come with pain, suffering, and loss—and ignoring or downplaying the establishment of new and different abilities and ability expectations, which can result in new forms of flourishing and community.<sup>5</sup>

As philosopher S. Kay Toombs has argued—and as her life itself testifies, as a successful, tenured emeritus professor of philosophy at Baylor University who was diagnosed with multiple sclerosis (MS) at the age of 29—such catastrophizing and partial assessments do not reflect evidence based upon the reports of people living with conditions such as MS.<sup>6,7</sup> They are, instead, empirically uninformed *assumptions* made by clinicians who have not studied social scientific evidence concerning the conditions in question that are then extrapolated to other forms of disability.

As [disability activists](#) and disability scholars have argued for decades, people with disabilities, on the whole, flourish in all sorts of bodies and in all sorts of ways.<sup>8</sup> What

many people with disabilities do report as diminishing quality of life is often less the direct effect of their physical or psychological impairments than the effects of living in a society that is designed for and supportive of abled-bodied people alone.<sup>9</sup> From inaccessible buildings and modes of communication to pervasive employment discrimination—often despite the protections of the Americans with Disabilities Act (ADA) of 1990—modern societies have been built in ways that often systematically oppress, discriminate against, and stigmatize those who are not able bodied.<sup>10-12</sup> There is a word for this: *ableism*.

*The problem of ableism.* Ableism refers to the assumption that the “normal” able body is better than abnormal bodily forms and to the social ramifications of that assumption. Ableism leads to a world where we actively shape bodies to be normal and shape our environments for those bodies alone. As this definition should make clear, ableism has unfortunately been a central and unquestioned part of medicine across its history. If the idea that “[being normal is best](#)” is taken as common sense, evidence to the contrary will be judged as suspect, including the evidence that people with disabilities are often as happy as people without disabilities.<sup>13</sup> Ableism is especially problematic for clinicians because insofar as it operates in the background of their knowledge and expertise, it can actively undermine best practices and negatively impact health outcomes without clinicians even realizing it.

For example, the ableist underpinnings of the idea that hearing is normal—that everyone wants to hear, should hear, and would suffer if they could not hear—is made obvious once one learns about deaf culture and history, wherein using sign language to communicate opens up a rich cultural history and set of communities.<sup>14</sup> The ableism behind the idea that people using wheelchairs wish above all else to walk is revealed once one learns that they typically want better, cheaper, and more reliable wheelchairs.<sup>9,15,16</sup> The ableism behind the idea that living with [Down syndrome](#) is bad or undesirable is exposed by the fact that people with Down syndrome typically live happy and flourishing lives.<sup>17</sup> Ableist intuitions such as these negatively impact patient-clinician communication, the assessment of treatment and rehabilitation programs, and priority setting for research, among other areas. Ableism undermines clinicians’ ability to engage with patients with disabilities as they in fact live their lives; it distorts communication with all patients regarding transitions into and experiences of various states of disability, whether due to age, injury, or other factors; and it misaligns the ultimate priorities of medical care insofar as it fosters an unreflective support of normalcy. In all these ways, ableism leads to worse care and increases the chances of harm.

*Disability vs disease/illness.* Ableism also contributes to a specific and persistent issue dogging medical communication: the ableist conflation of disability with disease, illness, pain, suffering, and disadvantage.<sup>5</sup> To be disabled is not automatically or necessarily to suffer or be in pain or to have an illness or disease. Many people with disabilities do not

experience pain and suffering, and many are not ill or diseased. It is not a contradiction in terms to be disabled and healthy. Some express pride in their disabilities, and some would not choose to become comparatively normal or “able” if given the option. These varied experiences point to the social dimensions of disability and the way that disability is far more multifaceted than being a “fact” of a person’s body. Disability is in many respects as complex and contextual as any other significant facet of human identity such as race, ethnicity, sexuality, gender, and so on.

### **Three Responsibilities of Clinicians to Disability Communities**

Given that the demands on clinicians’ time and knowledge are already immense, I offer the following 3 responsibilities and corresponding recommendations in the hope of deepening clinicians’ existing knowledge base and skill set, enriching patient-centered care, and increasing overall health outcomes.

- *Clinicians have a responsibility to develop disability humility.*<sup>13,18,19</sup> Disability education and the history of medicine more generally are essential for basic and continuing medical education because they are essential for effective and just medical practice. *Disability humility* refers to learning about experiences, cultures, histories, and politics of disability, recognizing that one’s knowledge and understanding of disability will always be partial, and acting and judging in light of that fact. Disability is a phenomenon with *both* medical and social components, and clinicians must work to successfully don what philosopher and bioethicist Erik Parens calls a “binocular” view of disability: a view that thoughtfully fuses both medical and social understandings of disability.<sup>20</sup> Without this binocular vision, clinicians will not have the reflective depth necessary to best diagnose, treat, care for, communicate with, and otherwise interact with patients of abilities of all sorts. Without this binocular vision, clinicians will not achieve optimal health outcomes.
- *Clinicians have responsibilities to communicate better with and about patients with disabilities.* Poor patient-clinician communication can have significant negative health outcomes.<sup>21,22</sup> Developing the virtue of disability humility will assist in improving such communication, for [successful communication](#) is as much a question of what one knows as it is the recognition of what one does not know. Disability humility would improve patient-clinician communication and should be practiced across all health care settings.<sup>21</sup>
- *Clinicians have responsibilities to recognize the authority of people with disabilities as experts about their own lives and communities and to elevate their voices.* The claims made by people with disabilities as well as entire disability communities are regularly diminished or not taken seriously.<sup>21</sup> This marginalization is exacerbated in cases in which professionally trained people are positioned as experts about forms of life of which they may have no lived experience, such as many able-bodied clinicians with

respect to experiences of disability. By practicing disability humility, clinicians will be in a position to actively combat the tendency to undermine patients' epistemic authority and, in so doing, improve care and overall health outcomes.

Since the passage of the ADA in 1990, people with disabilities make up the largest legally protected group in the country.<sup>11</sup> In 2013, approximately 1 in every 5 adults reported a disability.<sup>23</sup> Disability has always been and always will be a part of human life. Better care for the great diversity of people with disabilities—and, by extension, all people—requires better engagement with and reflection upon the rich and complex meaning of disability. Insofar as the institution of medicine aims for just and equal care across individuals and groups, clinicians and members of society at large have a responsibility to educate themselves about disability and actively work against the effects of ableism that have too long undermined the justice and effectiveness of health care delivery.

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## MEDICINE AND SOCIETY

### Historical Situatedness of Categories' Meanings in Medicine

Sander L. Gilman, PhD

#### Abstract

Dichotomies in medicine are real, and the boundaries that define them are constantly shifting. Radical antitheses such as healthy versus ill, reconstructive versus aesthetic, or medical dermatology versus cosmetic dermatology can be more clearly understood by considering the cultural context of medicine. This essay examines the latter two antitheses and asks whether medical dermatology should be a category limited to somatic illness. It also examines how the tendency to create and endorse dichotomies distorts the meaning and delivery of surgical procedures as well as reimbursement practices in contemporary medicine.

#### Shifting Boundaries Between Aesthetic and Reconstructive Surgery

In 1992, US Food and Drug Administration (FDA) Commissioner David Kessler, later a distinguished dean of the Yale Medical School, facilitated the FDA's decision to limit access to [silicone breast implants](#).<sup>1</sup> The implants had been allegedly silently leaking their contents and causing a wide range of autoimmune illnesses, including scleroderma, lupus, rheumatoid arthritis, and fibromyalgia, and, it was argued, increasing the risk of breast cancer.<sup>2</sup> Introduced in 1962 by Dow Corning,<sup>3</sup> but not subject to safety testing by the FDA until 1976,<sup>1</sup> the implants replaced a range of substances, from autogenous body fat to paraffin, which had been employed in breast enhancement from the mid-1890s.<sup>3</sup> Kessler, relying on a scientific committee report, halted their general use, but allowed—and here was a critical point of contention—“access to silicone breast implants for patients ... who undergo reconstructive surgery at the time of mastectomy.”<sup>1</sup>

A number of scholars studying reconstructive and aesthetic surgery pointed out the FDA's odd rationale: if silicone breast implants caused pathological reactions (a claim eventually disproven<sup>4</sup>), why would their use be permissible, even under close supervision, in patients who had been diagnosed with breast cancer?<sup>5</sup> Did this not exacerbate cancer recurrence risk among patients who had already survived a severe health crisis? The rationale seemed clear at the time: women—and indeed the word *patient* here meant only women, ignoring the consistent if low percentage of males who present with breast cancer<sup>6</sup>—needed these implants to help ameliorate the psychological trauma of mastectomies. This rationale ignored the simultaneous public appearance of articulate women who had had mastectomies, such as the poet Audre

Lorde, who saw their scars as signs of survival rather than badges of shame,<sup>7</sup> a view depicted on the *New York Times Magazine* cover in 1993 in a photograph titled *Beauty out of Damage*.<sup>8,9</sup> This is one historical example of how personal, social, and cultural meanings of mastectomies continue to be debated.<sup>10</sup>

Breast implants were quietly suggested as an intervention for a psychological side effect of breast cancer surgery, the loss of self-esteem.<sup>1</sup> It seemed that Kessler recognized psychic pain as a treatable symptom, although how to balance the potential benefits of implants in ameliorating psychological trauma against the potential health risks of silicone leakage was never articulated. Kessler noted that insurance companies' payments for implants following mastectomies signaled their social value, while mere augmentation could mask breast cancer during mammograms.<sup>1</sup> This all became moot by May 2000 when the FDA approved saline implants, which replaced silicone ones.<sup>11</sup> Silicone implants never actually vanished from the marketplace, however: implants employing more cohesive silicone gel were approved for broad use in spring 2013 after discussions of health risks posed by silicone leakage finally abated.<sup>12</sup>

### **A Lesson**

What should we glean from the FDA's approach to implants? Be careful when assuming that categories of pathology are universally accepted and unchanging; the categories are, indeed, socially, culturally, and historically contingent and must be contextualized as such. The patients that the FDA imagined having mastectomies were women, who, by World War I, were labeled by society as vain for undertaking aesthetic procedures—even when those procedures, developed by and for men, such as nasal reduction, had been earlier understood as reconstructive.<sup>9</sup> Some religious organizations that had opposed many aesthetic alterations of the body from the early modern period came to advocate, in the 20th century, for procedures such as the “nose job” when men's employability was at stake.<sup>9</sup> This debate pitted those who saw the psychological impact of bodily appearance as trivial against those who saw it as essential for human functioning. Aesthetic surgery became “vanity” surgery and was thus distinguished from “real” surgery—now labeled reconstructive—even when identical procedures were done, as with breast implant procedures. Women trying to look younger or more attractive, Jews trying to pass as gentiles, and blacks trying to pass as white were seen by some as vain or duplicitous if they underwent such procedures. White World War I veterans who underwent procedures to reconstruct their appearance because of their need to be employed or to have a more socially acceptable visage were, however, not viewed in the same light.<sup>9,13</sup>

There are similarly shifting boundaries in the realm of dermatology, where some program directors have questioned whether dermatology residents should use their limited training time to learn cosmetic dermatology,<sup>14</sup> with its implied contrast to the diagnosis and treatment of real dermatological diseases. In other words, there is a

perceived dichotomy between treating real illnesses, such as acne, and pandering to the vanity of members of the upper middle class through Botox® skin tightening. Should funding and training time be devoted to such frivolity? A response to this ethical question, based on what we learn from the FDA's response to silicone breast implants, would do well to emphasize the importance of resisting the temptation to distinguish among categories of treatment based on assumptions about patients' motives for undergoing clinical procedures (surgical, dermatological, or other). Historically contextualizing ethical questions about funding of and training in such procedures enables us to discern that the boundaries between reconstructive and cosmetic procedures are contingent and always shifting.

### **The Contingency of Distinctions Between “Medical” and “Nonmedical” Procedures**

Should we be uncomfortable with aesthetic interventions and applaud reconstructive ones? Why are aesthetic procedures always self-pay and rarely seen as necessary, especially by programs such as Medicare? Should aesthetic surgeons volunteer in programs that provide free cleft lip and palate surgeries to children in resource poor areas but not offer free blepharoplasties to their parents? How can physicians address the dichotomy between treatment of real diseases and treatment that merely satisfies human vanity—that is, between medical and cosmetic dermatology?

Responses to these questions might well come from a considering what a physician's calling is: Is it to “help the sick according to my ability and judgment,”<sup>15</sup> according to the ancients who saw themselves as bound by the religious and moral practices of their age? Let me stress the role of *judgment*, for learning professional judgment is a goal of training. Should amelioration of pain and discomfort be limited to that which we define as somatic only? Should we deal with the body as if it is not intimately connected to and influenced by mind, psyche, and emotions? I suggest not, since physical pain is simultaneously psychic pain, and psychic pain is often experienced in the body. This duality is evident in dermatology, for the surface of the body is the immediate social space we occupy as persons and as patients.

There is, of course, the omnipresent problem of whether and to what extent physicians should be held responsible for responding to patients' psychological as well physical reasons for requesting clinical interventions to modify a stigmatized bodily feature, regardless of whether the source of stigma is breast cancer, deformity from war, or social and cultural privileging of youthful skin texture. Since any stigmatized bodily feature can cause psychic pain, I suggest that it's ethically questionable to perform an intervention that reifies problematic views of the body. If a physician refuses to undertake requested interventions, such as a nose job or liposuction, because doing those procedures does not confront the underlying cause of stigma in unfounded prejudice against nonconforming bodies, should we applaud that physician? Perhaps we should, particularly if such interventions exacerbate stigma and contribute to a kind of

moral damage called *infiltrated consciousness*.<sup>16</sup> Given that a physician's immediate duty is to the patient, not to general society, a physician should try to ameliorate the patient's psychic pain while being aware of its sources—in the social, cultural, and historically entrenched practices and messages in greater society—and while also being aware that [providing an intervention can exacerbate stigma](#) from those sources though it might ameliorate the suffering of an individual patient. Physicians can play important roles in helping to shift meanings associated with being different; this can be good for society (by undermining stigmatizing messages) and good for patients (by strengthening clinician-patient relationships).

### **Implications for Meaning in Medicine**

Diseases of the skin took on social and ideological meanings in the mid-nineteenth century. *Plica polonica* was the dermatological disease ascribed to poor Jews that marked them as certainly as the convex shape of their nose and the prominent form of their ears (“Morris’ ears”).<sup>17</sup> The 19th-century dermatologist dealt with the former; the aesthetic surgeon dealt with the latter. That none of these were real “racial” markers made no difference. Their treatment was seen as nonmedical, allowing Jews to “pass” in gentile society, and was therefore merely aesthetic and sufficiently culturally situated to qualify as vain.<sup>9</sup> Perhaps the trickiest diseases to diagnose in the 19th century, as dermatology developed into a medical specialty, were sexually transmitted infections (STIs). That they are infectious diseases no one doubted, even well before Noguchi and Moore isolated the *syphilis* spirochaete in 1913.<sup>18</sup> But the treatment of STIs, like ear tucks and nose jobs, also treats the serious social stigma that accompanies them. The orthopedic surgeon Jacques Joseph, who helped develop modern *cosmetic* rhinoplasty and breast surgery, recognized as early as 1898 that social stigma caused psychic pain that inhibited normal (healthy) human interaction.<sup>19</sup> He operated on the psyche, not on the body. Ever since, however, aesthetic surgeons bear the stigma of treating vanity diseases, just as early dermatologists were seen as treating STIs and therefore abetting immorality even though they were treating stigma.

What, then, is treated and [who pays for it](#)? Today, we tend to separate out medical interventions based on idiosyncratic decisions of funding agencies, as indeed Kessler did. In a health care system that is heavily reliant on private insurance, the question of what should be reimbursed rests on the profit motive. The rationale for these decisions relies on social conventions of what is medical and what is not at any given moment. In the Weimar republic, the government funded a wide range of free clinics—including one for cosmetic interventions—as many people in prison desired such interventions, which were seen to ameliorate recidivism.<sup>20</sup> (This view has also been espoused more recently.<sup>21,22</sup>) That people would better be able to function in society without the stigma and resulting psychic pain was a given. Now it is also clear that what causes psychic pain differs from time to time and place to place. In societies that are oriented around a culture of youth, Botox interventions have a higher demand than in those that praise

“aging gracefully” (France, for example).<sup>23</sup> These trends reflect ever-changing boundaries between the healthy and the ill that are part of all clinical practice and training.

Thus, to put less curricular emphasis on medical dermatology and more on cosmetic dermatology is to make a real but momentary distinction between the two that will shift over time as social changes shift the boundary between the medical and the cosmetic and, indeed, as this distinction is shown to be only socially defined. I am not arguing that residents should have more freedom to determine what constitutes medical interventions but rather that the shifts in what is considered medical are frequent and often contradictory. Resident physicians do not make those determinations, but they are bound by their seeming inflexibility. One of the central demands on training physicians is to be aware that while the training they are providing is the best possible at any given moment, it might well quickly turn out to be the worst possible as the boundary between the medical and the aesthetic changes. Treating each patient means examining the disjuncture between that patient’s sense of discomfort and the means available to constitute or reconstitute his or her sense of health and wholeness within the parameters of what is considered to be best practice at any given moment. Indeed, that could well be a working definition of medicine in our time.

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## HISTORY OF MEDICINE

### Why Naming Disease Differs From Naming Illness

Marvin J. H. Lee, PhD, MDiv

#### Abstract

Addressing the question of how medicine should engage with people who consider their clinical disease condition to be importantly constitutive of their identity, this article focuses on one group—advocates for the fat acceptance (FA) or body positivity movement in American society. Drawing on philosophical analysis, I try to show that FA and physician communities represent different traditions within the larger culture and that whether obesity should be considered a disease is a culture battle. I argue that diseases (medical) and illnesses (cultural) are 2 different designations of clinical symptoms and that both disease and illness designations can change over time or be uncertain.

#### When Conditions Constitute Identity

How should medicine engage with people who consider their clinical disease condition to be importantly constitutive of their identity? To answer this question, I focus on a group whose claim to not having a disease strikes many physicians as odd: advocates for the “fat acceptance” or “body positivity” movement. Fat acceptance (FA) and body positivity describe characteristic features of the same movement, and, for this reason, I use these terms interchangeably here. Nevertheless, a technical distinction can be made; the former is “more of a reaction to fat shaming” while the latter is “a more commercial self-esteem movement, [which] came later.”<sup>1</sup>

Based on my philosophical diagnosis that the issue of whether obesity is a disease involves a culture battle, I present the physicians and the FA activists as having agendas derived from 2 different traditions cohabiting the greater culture. Physicians, by training, tend to subscribe to the [medical tradition](#) with its primary agenda of furthering excellence in physical functioning and longevity. Because obesity is an adverse condition that impairs functioning and decreases life expectancy,<sup>2</sup> it is reasonable to call it a *disease*. On the other hand, the FA movement represents one creative adaptation of the secular liberal individualist (SLI) tradition, which has as its agenda the protection of individual autonomy and social tolerance,<sup>3</sup> which are regarded as the most important socioethical values. FA advocates creatively adapt this agenda to obesity, arguing that being fat is an individual’s autonomous lifestyle choice that deserves social tolerance and respect.<sup>4</sup> The FA movement is a relatively new development, so it is too early to call it a

new independent tradition or an established branch of the SLI tradition. Thus, it is better to understand it as a social movement.

Some physicians might be members of the SLI tradition if they openly or clandestinely avow that individual autonomy and social tolerance are the supreme socioethical values. Nevertheless, physicians would distance themselves from a group that creatively uses the SLI moral agenda to claim that being fat is a personal lifestyle choice and that the obese lifestyle can be healthy. That is, physicians can accept obesity as a lifestyle to be socially respected. But what the physicians find impossible to accept is the activists' extended claim that the obese lifestyle can be healthy, which is contradictory to the traditional medical view. Therefore, the physician community and the FA movement are in a sharp disagreement with each other on the particular issue of whether obesity is a disease.

I maintain that the disagreement is a culture battle. It is *cultural* in that the dispute will be resolved by the verdict of the culture within which this tradition and movement coexist, each vying for its own survival. It is a *battle* rather than a war because the conflict here occurs between one tradition and one social movement within the culture to which they both belong, not a clash between different cultures.

### **Tradition and Culture**

In current scholarly literature, there are various definitions of *culture*, *tradition*, *heritage*, *custom*, and so on, which are largely equivocal; the meanings of the terms overlap without clear explanations about how they are conceptually related to one another. According to Stephen Mulhall and Adam Swift, a tradition can be "primarily religious or moral (for example Catholicism or humanism) ... economic (for example a particular craft or profession, trade union or manufacturer), aesthetic (for example modes of literature or painting) or geographical (for example crystallizing around the history and culture of a particular house, village or region)."<sup>5</sup> Following Mulhall and Swift, I define *tradition* as "a medium by which a set of practices are shaped and transmitted across generations."<sup>5</sup> In other words, tradition is formed under a particular teleological agenda (which I shall call a *telos* henceforth) and is in turn the means by which practices socially or intellectually worthy of preserving are shaped and transmitted, with the ultimate vision that the practices will survive, be reproduced, and thrive. I consider culture to have the same meaning as tradition. Thus, culture, just like tradition, derives from a *telos* and is a medium by which a set of practices are shaped and transmitted across generations. However, tradition and culture, I argue, are distinct from each other in that the former is considered to participate in the latter. Various participating traditions get woven together to yield the final product called a culture.

### **The Secular Liberal Individualist Tradition and the Fat Acceptance Movement**

The SLI community thriving in the United States preserves a distinct tradition that carries a few-centuries-old ethical ideology, namely, secular humanism.<sup>6-9</sup> The SLI community in the United States is one of the existing contemporary heirs of the secular humanist tradition that is sustained by a telos of social harmony and order via the power of human agency.<sup>6-9</sup> But situated in the American democratic sociocultural context where no single custom, belief system, or ideology can be considered culturally superior, members of this community have naturally come to stress respect for voluntary, individual adult agency and social tolerance as the quintessential virtues to achieve the prized social harmony and order. In other words, in their effort to find common ground, members of the SLI community emphasize respect for individual adult autonomy and social tolerance over respect for the customs and values of certain racial, religious, or political communities.

In the 1970s, some activists within the American SLI tradition pushed the agenda—in advance of the culture’s readiness to change—that homosexuality was a personal identity (inborn or acquired) expressed through an individual’s sexual lifestyle. Nevertheless, they were able to convince the psychiatric community, as the American Psychiatric Association removed the diagnostic category of homosexuality from the second edition of *Diagnostic and Statistical Manual of Mental Disorders* in 1973.<sup>10</sup> Given hindsight, medicalization of homosexuality was an ethical issue the psychiatric community needed to resolve.

Now, FA advocates have arisen, creatively adapting the SLI’s telos to body appearance while demanding recognition and visibility for the new body-proud people. For FA activists, everyone should feel proud of their own body shape, regardless of whether they have obesity (but, interestingly, not anorexia).<sup>11</sup> Thus, FA advocacy is essentially for nondiscrimination in society, which FA advocates regard as an ethical fight.<sup>4</sup> As a result, their controversial medical claim of being fat but fit should be considered not as its core agenda.<sup>1,11</sup>

### **The Tradition of the Physician Community**

The medical community, whose primary members include clinicians and medical scientists, is also a community of tradition. But I will use the term *physician community* due to my focus on physician members. Originating presumably in the ancient Hippocratic tradition, the community’s telos, as mentioned previously, is supporting or restoring excellence of physical functionality and longevity.<sup>12,13</sup> However, while the super-healthy body is the ideal, the desired functional excellence and optimal lifespan have become troubling questions physicians need to answer. Is it medically normal for elderly people to suffer from knee problems? Are some couples naturally infertile? Is it clinically OK to feel depressed or sad? Is dying a pathological symptom we can find a cure for in the near future? The answers to these questions depend on whether there is a consensus among physicians about whether to define them as *diseases*.

### **Is Obesity a Disease or an Illness?**

Physicians or researchers have power to name diseases, not illnesses. The distinction between disease and illness has been well explored already by quite a few scholars; we understand the former to be medical and the latter to be cultural.<sup>14</sup> To be more accurate, the 2 concepts have 2 different designating authorities. The physician community decides if a certain condition is a disease while the general culture determines whether it is an illness. In the case of homosexuality, the Western medical community and the public eventually converged on naming it neither a disease nor an illness. But note that homosexuality is still considered an illness by some Muslims and by some conservative Christians.

Schistosomiasis also illustrates that disease classification is not always clear cut. It was not seen as an illness in 20th-century Egyptian culture since it was named the “male menstruation.”<sup>14</sup> Today Egyptian physicians seem to call it a disease, but the disease designation arguably does not have a great deal of appeal to the Egyptian public for it is difficult to adduce whether, or how many, people die of schistosomiasis because death certificates rarely identify schistosomiasis as the primary cause of death.<sup>15</sup> Obesity in the United States seems similar. The physician community, represented by American Medical Association, calls obesity a disease state.<sup>16</sup> But we do not identify obesity as the primary cause of death, which allows FA advocates to have leeway to say, in effect, “It is all right to be obese. You don’t die of it,” or “You can be fat but fit (whatever ‘fit’ means).”

### **Winning a Culture Battle**

It is important to understand that whether the public accepts the physician community’s disease designation of obesity as an illness is not a problem to solve but a conflict to resolve, for we can solve a problem only when stakeholders share the same paradigm and telos, which is not the case here. This is a conflict between the physician community and the FA community, as the 2 groups are fighting for cultural endorsement by the general public. Accordingly, it would be a mistake to think that the physician community could or should find a way of treating a disease that the FA community, in its view, erroneously or delusionally refuses to accept. It can be argued that the FA and physician communities hold the “truths” of 2 different realms, the ethical and the medical, respectively. If so, then the primary question that physicians should struggle to answer is this: What would the physician community do to win the heart of the general public to resolve the conflict?

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## HISTORY OF MEDICINE

### Naming and the Public Health Roles of Physicians

Kelsey Walsh, MA

#### Abstract

Resources from the American Medical Association (AMA) Archives facilitate historical consideration of how physicians' authority has been exercised in naming diseases, epidemics, and other health-related issues of national importance. Selected images emphasize physicians' roles in motivating public health initiatives through public service posters, advertisements, and minutes of the AMA House of Delegates meetings.

**Figure 1.** *Centennial Meeting*



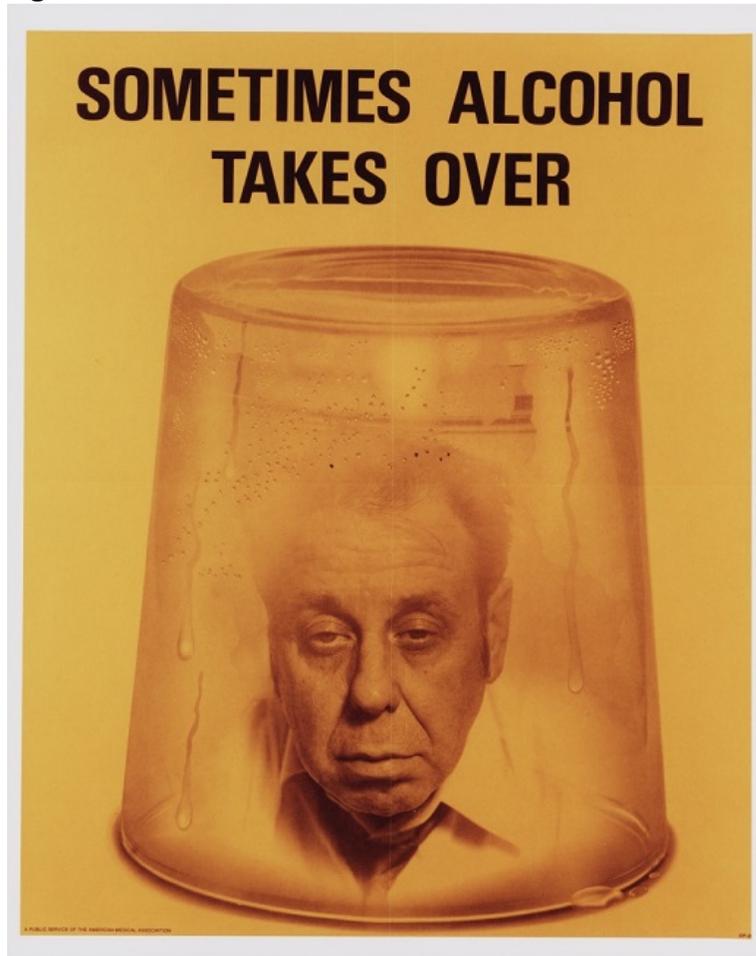
Courtesy of the American Medical Association Archives.<sup>1</sup>

American Medical Association (AMA) president Harrison H. Shoulders, MD addressed the assembled membership at the Centennial Annual Meeting in 1947:

The problems which face medical practitioners today are different in character from those which our predecessors encountered. Yet the fundamental principles they used still apply. It is important for us to remember that environments, technics [sic] and tools may change but that fundamental principles do not change. They are eternal.<sup>2</sup>

Fundamental principles include maintaining focus on patients, public health, and the art and science of medicine.<sup>3</sup> Throughout the history of the profession, physicians have recognized the inexact nature of medicine and ways in which social and cultural trends can influence clinical and public health practice. The AMA Archives offers an abundance of resolutions presented to the House of Delegates that expressed the need for the profession of medicine to respond to social, cultural, and technological changes.

**Figure 2.** *Sometimes Alcohol Takes Over*



Courtesy of the American Medical Association Archives.<sup>4</sup>

This AMA public service poster, published in the 1970s, reframes the idea of alcoholism. Naming addiction—specifically alcoholism—as a disease enables recognition of alcoholism as an illness and facilitates development of resources to help physicians respond to affected patients and populations. At several points in AMA history, medically treating [alcohol addiction](#) has been reaffirmed as a way to help affected individuals, families, and their communities. The AMA also urged Congress to increase funding for alcoholism treatment and for clinical research into better understanding of physical, social, and cultural causes of alcoholism. Although the AMA passed a resolution urging equality in hospital admissions for patients with alcoholism in 1956,<sup>5</sup> it had to urge Congress to fund treatment programs as late as the 1990s. This funding lag suggests how deeply entrenched was the notion of drinking as a moral failing. In naming alcoholism as an illness worthy of treatment, physicians have helped change public perceptions of alcoholism, which has generated not only economic structures of reimbursement for treatment but also social, cultural, and moral empathy for individuals, families, and communities who suffer alcohol-related harms.

**Figure 3.** Heroin PSA

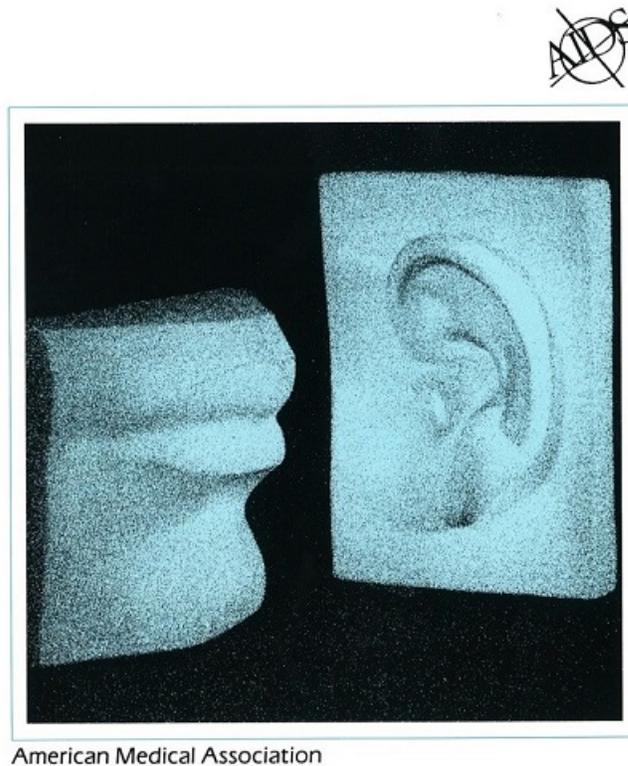


Courtesy of the American Medical Association Archives.<sup>6</sup>

This poster—produced by the AMA in the 1970s—identifies death as a potential consequence of drug use. This image conveys the AMA’s message that responding to addiction is within medicine’s purview. At a time when the War on Drugs had gained momentum and harsh policies prioritized punishment over treatment, the AMA publicly emphasized addiction as an illness and treatment as a job of medicine. The AMA urged health professionals and the government to become more informed about drug dependency and to **create responsive policy**. In the cultural and political environment of the 1980s, physicians used their training and education to serve the public by facilitating a shift in focus from criminalizing “addicts” to treating patients suffering from the illness of addiction. Indeed, the AMA increased its outreach to remind the public of treatment options in response to the predominantly punitive government and police responses to illicit drug use.<sup>7</sup>

**Figure 4.** *HIV Blood Test Counseling: AMA Physician Guidelines*

HIV Blood Test Counseling: AMA Physician Guidelines



Courtesy of the American Medical Association Archives.<sup>8</sup>

This 1988 booklet is one of several HIV- or AIDS-focused publications attempting to bridge gaps between a public without much knowledge about a sensitive topic and clinicians charged with talking to patients about a newly prevalent disease with no known cure. In naming the AIDS crisis of the 1980s an epidemic and a public health issue, the AMA advocated for nondiscrimination in workplaces, schools, and hospitals; public education; and more research. The AMA worked to help prepare physicians by offering conferences and training on how to care for patients with HIV or AIDS, the importance of confidentiality, and the critical public health role of testing. Developing policies and guidelines for HIV-infected health care personnel, confidential testing, maternal screening, contact tracing, and partner notification were also AMA priorities during this time. The AMA fought stigma against HIV, AIDS, and AIDS-related illnesses by [educating the public](#) on facts about virus transmission. The AMA also modeled expressions of empathy for those suffering from HIV, AIDS, and AIDS-related illnesses.

**Figure 5.** *Where's Your Seatbelt?*



Courtesy of the American Medical Association Archives.<sup>9</sup>

Posters like this one produced in the 1960s took aim at diseases and injuries resulting from a person's choices rather than by chance. In 1954, the AMA passed a resolution recommending that all manufacturers equip automobiles with seatbelts and emphasize safety in their design. This commitment to car safety increased through the years, and, by 1977, AMA policy asserted that seatbelt use was an important expression of preventative medicine. Noting that injuries were the most frequent cause of death among Americans aged 1 to 44 and that motor vehicle accidents (MVA) were involved in half of all deaths due to injury, the AMA encouraged physicians to assume leadership roles in MVA-related injury prevention. This effort resulted in a public campaign on behalf of the AMA and America's physicians to re-emphasize the need for all vehicle occupants to use seatbelts. By naming preventable motor vehicle injuries as a public health issue, the AMA extended the influence and social power of physicians from clinical encounters to public health.

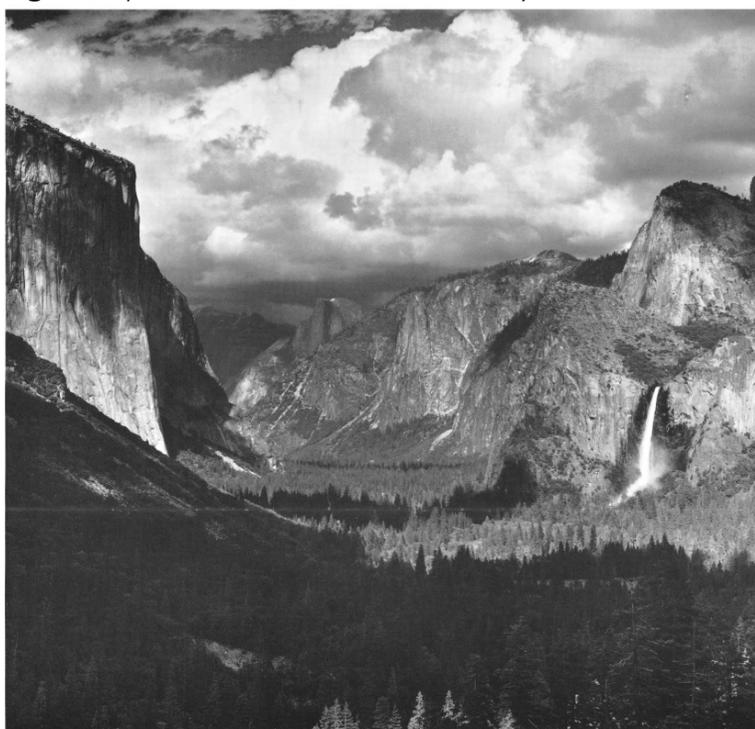
**Figure 6.** *The Best Time to Stop Smoking*



Courtesy of the American Medical Association Archives.<sup>10</sup>

This public service poster was one of many the AMA produced in the 1970s targeting lifestyle choices that adversely affect public health. The AMA officially took a stand against cigarette smoking as early as 1964, encouraging physicians to lead by personal example and to advise patients about the health hazards of smoking. In 1972, the AMA launched a campaign to ban [cigarette advertising](#) from all public media, which marked the beginning of a major social, cultural, and political push to reduce—with the goal of eliminating—tobacco's place in public life. Previous AMA efforts to combat tobacco use focused specifically on the harms of tobacco use from a clinical standpoint. Naming a "best time to stop smoking" was one strategy for focusing on tobacco advertising, especially advertising that might appeal to children. This strategy broadened the AMA's approach to tobacco-related health risk from a clinical to a public health point of view.

**Figure 7.** *If America Dies, Where Will We Bury It?*



### **If America dies, where will we bury it?**

We are doctors of medicine. Naturally, we care about the health of your body. But we care, too, about the health of the body of land you live on. America's body is not well. Its condition is critical. Suddenly the words "ecology" and "pollution" are in the air. People seem worried. But we hope their worry isn't just another passing fad. A sick environment can make people sick. It can undo everything a doctor works for.

Polluted air can damage the eyes, aggravate lung diseases, actually cause death during long episodes of heavy pollution. Polluted water can infect plant, animal, marine and human life. Noise pollution can cause deafness, may produce ulcers and hypertension. The list of depressing entries on our environment's health chart goes on and on. In fact, disease induced by the environment now costs us \$38 billion a year. That bill will go up. If we don't nurse our environment back to health.

How to do the job? We at the American Medical Association worry about it. But we want *everyone* to worry. Because *everyone* is going to have to help get the job done. There's no use our trying to keep people well in a dead land. For a free booklet on environment and health, write: American Medical Association, Box E, 535 N. Dearborn St., Chicago, Ill. 60610.

#### **America's Doctors of Medicine**

Courtesy of the American Medical Association Archives.<sup>11</sup>

The AMA's Committee on Environmental Health focused on issues related to public health and environmental conditions, reviewing scientific evidence on topics such as climate change, pollution, fossil fuel combustion, and deforestation. This advertisement from the 1970s displays one of the AMA's messages to the public and names environmental health as public health, stating, "A sick environment can make people sick. It can undo everything a doctor works for." The AMA produced a free booklet discussing interactions between the environment and health. At the time, the AMA estimated that \$38 billion was spent on environment-related health costs. According to the AMA, preserving a clean environment was a key preventative medicine strategy for curtailing the predicted skyrocketing costs of health care. AMA policy continues to support ongoing efforts to address environmental pollution and its corresponding health hazards.<sup>12</sup>

**Figure 8.** *Are You a Candidate for Creeping Obesity?*



Courtesy of the American Medical Association Archives.<sup>13</sup>

Communicable diseases were supplanted as the leading causes of death in the United States in the 1970s, when accidents, heart disease, cancer, cirrhosis of the liver, and other conditions due to lifestyle and environmental conditions became more prominent causes of death.<sup>14</sup> Advertisements like this one illustrate physicians' frustrations navigating a shifting health care environment. The AMA saw a lack of ingenuity in public health education and forcefully stepped into this role by publishing public service announcements and advertisements naming [preventative care's importance](#) in medicine and illuminating obesity as one kind of health condition that is both environmentally influenced and a product of individual choice. A symposium titled "Obesity: The Cause and Management" was presented at the AMA's 1974 Clinical Convention. The Department of Foods and Nutrition—then an arm of the AMA's Scientific Activities Division—planned this symposium, which took place alongside presentations on alcohol toxicity and total parenteral nutrition within hospital settings.

**Figure 9.** *Take Your Sun Time in Small Doses*



Courtesy of the American Medical Association Archives.<sup>15</sup>

This public service poster from the 1960s is one product of the AMA Committee on Cosmetics' charge to educate physicians and the public about the sun's potential harm to skin. In 1961, the Committee displayed exhibits titled "Sunlight and the Skin" and "The Aging Skin" during AMA meetings and distributed comprehensive pamphlets on these topics. By naming "excessive exposure" of skin to sunlight as a health risk, the AMA illuminated the importance of prevention as a feature of public health. The AMA supports educating physicians and their patients about health risks of ultraviolet light from the sun and from commercial tanning.<sup>16</sup>

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## PERSONAL NARRATIVE

### Trafficked

Stephen P. Wood, MS, ACNP

#### Abstract

This first-person narrative describes some of the barriers to caring well for patients at the intersection of human trafficking and substance use disorder. I canvass some of the ethical considerations regarding these patients' autonomy and call for establishing and using evidence-based practice to manage these complex scenarios.

#### One Trafficked Patient

Her phone sat in a plastic evidence bag on the counter where we stand to do our clinical notes. It had been dropped off by an area drug detective for me to return to the young woman in the room across the hall from me. She had been brought to the emergency department after she had been offered help by the same detective during a sting to arrest pimps, people who traffic women in the sex trade for profit and drugs. This woman was 23. She told the detective that she had been living out of a car and motels for 2 weeks, travelling between New York and Maine, kept under control by her traffickers with threats of violence and drugs. She was being trafficked with another woman and would have sometimes upwards of 10 "dates" a day. She saw none of the money; it was all handed over in exchange for transportation, boarding, and drugs. She had a 5-year history of opioid abuse, starting with oxycodone supplied by a boyfriend and now intravenous fentanyl, cocaine, and benzodiazepines. She has a daughter who lives with her grandmother and very little else—no friends, no other family, no job, and no place to live.

The phone buzzed on the counter every 30 to 45 seconds. "You Raw Dog?" "Can we do fitty? I'll bring party favors." "How much for a double?" These were messages from men, responding to an ad, looking for sex. It was endless. The area codes ranged from Maine, to New Hampshire, to Rhode Island, to New York. The constancy of these messages was shocking. Even more distressing was the display underlying the phone's cracked glass of this patient holding her daughter, no more than 2 years old, wearing a pink dress and matching ribbons in her hair, a "Happy Birthday" banner in the background.

I went in to examine Alyssa (not her real name). She was rail thin, her eyes sunken, her hair knotted and in disarray. She had a peripherally inserted central catheter (PICC) in her right forearm, placed a week ago at an outside hospital. She was being treated for

osteomyelitis but had left against medical advice and had been off antibiotics since then. She said the PICC line hurt and admitted she had been using it to inject drugs. The bandage around the site was tattered and dirty, and I had asked the nurse to clean the site and change the bandage. I ordered a replacement line, although admittedly with some reluctance wondering whether she would stay for treatment this time. We drew labs, treated her for gonorrhea and chlamydia and offered an HIV test, which she refused. After a long discussion, she agreed to stay to get medical treatment for her infection in the hope for transfer to a facility that could manage her medical issues and her [mental health issues](#), which included depression, anxiety, and bipolar disorder. This was a tall order as few beds—called *dual diagnosis beds*—exist and the ones that do are rarely empty. The emergency department (ED) social worker and I had a plan, though, and it was put into action. Alyssa left the ED to go to interventional radiology for a new PICC line and, from there, to her bed on the medical floor for management of her medical issues before we could address her mental health concerns.

I went to check on her the following day and she was gone. A “man” had come to visit and then she was gone. We were certain that the man was her pimp; he came to get his property. Any time she spent in a hospital bed was money lost. He couldn’t have that.

### **Reflections on Caring for a “Captive” Patient**

I think about this case a lot. We aren’t particularly well equipped as a profession to deal with these cases, which was apparent from the start of this case. No one was really all that comfortable in addressing that this person was and remains a victim of human trafficking, a modern-day slave, and that she is being sold online, subjugated through violence and drugs. We offered comfort and treatment, but could we have done more to protect her? Can she make autonomous decisions? Does she possess this value we all hold so dearly when she is enslaved, not just to drugs but to another person through coercion and violence? When offered the choice of treatment or returning to the street, can she make this decision in an informed way? There was very little we had to offer except encouragement, comfort, and empathy. There were no legal grounds to hold her against her will or to deny her decision to leave, despite her circumstances.

Her care might also have been impacted by defining her as a person who is being trafficked. Saying someone is being trafficked labels him or her less as a person and more as a commodity. There is a loss of identity in that label, a loss of being seen as a patient and, more so, as a person. This is a label that carries significant stigma and can have an impact on how a patient is viewed and treated. Unknowingly, nurses, physicians, and other health care practitioners might avoid this patient, not because they lack compassion but because they are simply ill equipped to deal with a patient who is being controlled, manipulated, and restrained. I struggled with this as well. Clinician-patient interactions can be uncomfortable when clinicians are dealing with someone they struggle to understand and who might even seem impossible to understand. I worried

about how this patient would be viewed and would be treated. Terms such as *prostitute* or *sex worker* are often used for these persons, not likely with any wrongful intent but because they are the terms we know. Did we unknowingly harm this patient by labeling her as trafficked?

There was another issue that caused me some apprehension. What did I learn from this patient? Has my experience made me better equipped for the next time we have a patient in a similar situation? Will I do better by the patient, protect him or her in a way that I feel we failed with Alyssa? Can we use the label *trafficked* as an excuse, a way to alleviate responsibility since it is widely understood that trafficked patients are often trapped, have lost autonomy, and are very difficult to get into treatment? Does it offer the convenience of an excuse to say, “Well, we tried our best”?

### **The Intersection of Human Trafficking and Health Care**

Although human trafficking is happening all across the United States, providers and clinicians are mostly unequipped to address it. While some professional organizations have pushed for educational efforts, there are still deficiencies in the use of evidence-based screening tools as well as clinician knowledge on the topic.<sup>1,2</sup> There is a National Human Trafficking Hotline and law enforcement can be an excellent resource as well.<sup>3</sup> State [mandated reporting](#) in the case of a minor being trafficked provides a mechanism by which clinicians can try to help children they suspect are being trafficked, and the Health Insurance Portability and Accountability Act (HIPAA) does allow release of some patient information to law enforcement if a patient is deemed at significant risk or in imminent danger.<sup>4</sup>

There is very little in the way of an evidence-based approach for how best to address patient autonomy and barriers to treatment in in this patient population. In the setting of human trafficking, the mind and the person are enslaved. It is difficult to say whether that person still possesses the ability to make autonomous decisions.<sup>5</sup> While many states have mandated treatment for acute psychiatric issues and some for substance abuse,<sup>6,7</sup> there are no states that have mandated treatment for adult victims of human trafficking.<sup>8</sup> If a patient who is—or who is suspected of being—involved in human trafficking wants to leave, to sign out against medical advice, she or he is typically free to do so.

### **An Opportunity for Improvement**

The phone number Alyssa had provided us was a dead end—an out-of-order phone. Her contact phone number yielded similar results. The detective who brought her in lost track of her, too. This is the reality of these cases. I think of that child, that “Happy Birthday” banner, and wonder if that banner will be the only one Alyssa ever hangs, if she will see her child again, and just how powerful addiction can be to take her away from that.

I think about how we need to be better prepared as a profession to deal with victims of human trafficking and how we need to do anything and everything we can to protect them. As health care practitioners, we need to think about the ethical implications of how we manage patients who are victims of trafficking and how we can ethically protect them. These efforts should start with clinicians learning how to identify potential victims, how to provide [trauma-informed care](#), and how to access resources to provide the best possible care to these patients. There are several resources, including the HEAL toolkit,<sup>9</sup> which can help clinicians and hospitals develop protocols for responding to potential trafficking victims from an interdisciplinary perspective.

In addition, we as health care practitioners need to stimulate public discussions so that legislators are aware and consider special, ethically balanced protections for trafficked persons. Either a component of or separate from the opioid epidemic, human trafficking is a major public health issue that we need to be better equipped to manage.

I fear I know when the cycle of trafficking and substance abuse will stop Alyssa. I can only hope that “Happy Birthday” banner serves as a beacon for Alyssa to find her way home.

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