PATIENT COMPLAINS OF . . . :
HOW MEDICALIZATION MEDIATES POWER AND JUSTICE
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Abstract
The process of medicalization has been analyzed in the medical humanities with disapprobation, with much emphasis placed on its ability to reinforce existing social power structures to ill effect. While true, this is an incomplete picture of medicalization. I argue that medicalization can both reinforce and disrupt existing social hierarchies within the clinic and outside of it, to ill or good effect. We must attend to how this takes place locally and globally lest we misunderstand how medicalization mediates power and justice. I provide concrete examples of how this occurs by considering dyesthesia ethiopsia, autism, chronic fatigue syndrome, depression, and HIV/AIDS.

Cancer would be better, I shouldn't say that, because I don't think it would be better. But it would be easier to share with somebody. I think I could tell somebody I had cancer, that I was dealing with cancer, I can't tell people about this, because, first of all, I don't know what to call it. I don't know how to describe it. Chronic fatigue syndrome? People have never heard of such a thing! It doesn't mean anything to them! It doesn't sound real.

—PATIENT WITH CHRONIC FATIGUE SYNDROME (WARE 1992, 353)

The phrase "patient complains of . . . " in the title of this paper is taken from the language commonly used by American physicians when describing the patient's self-reporting of symptoms. In the epigraph above, the patient is describing a situation in which a physician has finally taken her complaints seriously and diagnosed her with Chronic Fatigue Syndrome, but her social cohort does not know what to make of the complaints or the diagnosis. How seriously a patient's complaints are taken by her physician or others around her will depend substantially on whether the human condition in which she finds herself has been medicalized. Medicalization is, minimally, the process by which a mental or physical condition comes to be seen as a medical condition deserving of medical attention; some medicalized conditions are granted a disease label. Once this process has begun to occur, a patient's complaints are taken more seriously by medical professionals and, later, by those members of society with whom the patient regularly interacts. This is what the sufferer of Chronic Fatigue Syndrome (CFS) might hope for. Alternatively, a person with a condition that has been medicalized who feels perfectly healthy might be diagnosed by medical professionals and treated as sick by society regardless of whether she acknowledges that there is anything at all the matter. This is what homosexuals and dissidents have had reason to fear.

In this paper, I argue that medicalization can both reinforce and disrupt existing social power structures within the clinic and outside of it, to good or ill effect, and that we would do well to attend to how this takes place locally and globally. This is particularly well illustrated by conditions that primarily affect those who lack social power because of gender, class, sexual orientation, development status, or age. I have chosen a few conditions that nicely illustrate how this can work: dyesthesia ethiopsia, autism, HIV/AIDS, depression, and CFS. Where appropriate, others—including homosexuality, dissidence, pregnancy, and race-based medical diagnostics—are used as illustration. Again, my task is to draw attention to how medicalization affects the social status and power of individuals both inside and outside of the medical setting. Without awareness of this dual nature—and potential—of medicalization, we misunderstand a process that has significant bearing on power and justice in healthcare and in society.

We begin with a brief tour of the concept of medicalization and medical humanities literature, analyzing its capacity to enforce, and thereby reinforce, social hierarchies.
The concept of medicalization and prior arguments that it reinforces social hierarchies

As a conceptual tool, interest in medicalization began in the 1950s and developed through the 1970s. During this time, according to Joseph Davis, it "referred to a specific social process—the expansion of jurisdiction of the medical profession that followed from the successful redefinition of forms of deviance, natural life processes, and problems of living as illnesses requiring medical intervention" (Davis 2006, 51). The negative critique of this process began with the use of the label medicalization in disapproval in the 1960s, as was seen in the work of medical sociologists Eliot Friedson and Irving Zola. Peter Conrad, following in Zola’s footsteps, characterized medicalization as a form of social control, an analysis he began to disseminate in his early studies on the medicalization of deviance in hyperactive children (1975; 1976). For Conrad, medicalization was explicitly the illegitimate extension of medical provenance over human conditions. Common case studies in this approach to medicalization include hyperkinesis, known more commonly as Attention Deficit and Hyperactivity Disorder, and homosexuality, a formal category of mental illness in the Diagnostic and Statistical Manual (DSM) of psychology up until the release of DSM-II in 1973 (Spitzer 1981). Conrad acknowledges that medicalization of such conditions can result in less stigma than considering these conditions to be failings of character or moral transgressions (1975, 18), but this intriguing hint at a possible benefit of medicalization that might disrupt social hierarchies is something of an aside in the context of his classic article on the medicalization of deviant behavior. Conrad’s primary concerns were fourfold.

First, Conrad was concerned with the problem of expert control: medicalization brings such human conditions under expert control, removing them “from the public realm where there can be discussion by ordinary people” and putting them “on a plane where only medical people can discuss it” (1975, 18). We see this concern in critiques of the medicalization of childbirth, which correctly note that, as pregnancy and childbirth have entered the purview of medical practice, the epistemic authority of obstetricians regarding these biological processes has in the American context displaced the epistemic authority of midwives and women almost entirely, regardless of the responsiveness or nonresponsiveness of obstetricians to empirical evidence about safety and efficacy of various medical prenatal and childbirth regimens (Cahill 2001). Nonmedicalized—by which I mean nonhospital—childbirth has thus virtually disappeared in America, occurring in less than 1 percent of births despite the claims of a report published in the Cochrane Database of Systematic Reviews that there are no reliable studies that provide empirical evidence favoring a planned hospital birth over a planned home birth for low-risk pregnant women (Olsen and Jewell 1998). Almost all such women in America now give birth in hospitals, a trend which in 2008 had 30.3 percent of births in the United States by Cesarean section (National Center for Health Statistics 2008) with preliminary data for 2007 indicating a further rise to 31.8 percent, the 11th consecutive year of increase and a record high for the nation (Hamilton, Martina, and Ventura 2009). The problem of expert control is, for Conrad, an artifact of medicalization. The same medical authority that gives rise to expert control can allow medical professionals to exert all manner of influence, of which expert control is only the first manifestation.

Second, Conrad was concerned with medical social control: “Defining deviant behavior as a medical problem allows certain things to be done that could not otherwise be considered; for example, the body may be cut open or psychoactive medications may be given. This treatment can be a form of social control” (Conrad 1975, 18–19). This is most typically illustrated by ADHD, but also by homosexuality. As in the famous case of the compulsory chemical castration of the homosexual computer pioneer Alan Turing and the use of radical surgical techniques such as testicular transplantation (Weijer 1996), the medicalization of homosexuality did indeed justify cutting the body open and giving psychoactive medications even in the face of a subject’s objections. R. L. Spitzer (1981) argues that the pathologization of homosexuality in prior iterations of the DSM ought to be analyzed not as a judgment about proper psychological health but rather as a value judgment imposed upon those who deviate from social norms. The elimination of homosexuality as a diagnostic label from the DSM-II in 1973 was not the end of value judgments in psychiatry about homosexual behavior, according to Spitzer. After all, the condition was essentially replaced by the category of Sexual Orientation Disturbance, which Spitzer claims was a compromise between the view that homosexual preferences are invariably a disorder and the view that they are a normal variation in sexuality. The value judgments were not eliminated; they were simply no longer the only assessment present. That diagnostic labels not only often incorporate value judgments but can also reinforce nonclinical value judgments has become a standard trope in assessments of—especially psychiatric—medicalization and diagnosis. Consider this statement from a 2007 Newsweek magazine article by Michael Craig Miller (M.D., as the article’s byline authoritatively remarks) titled “Diag-
nosis: Same as It Never Was”; “[D]iagnostic labels... can establish people as deviant, deprive them of rights or heap upon them a burden of shame or stigma. Even when intentions are good, diagnostic systems—like the science they are rooted in—are inevitably constrained by the intellectual, ethical and political trends of the era.” This statement nicely encapsulates this critique of medicalization as social control, whereby medicine enforces social norms on the individual.

Conrad’s third concern with medicalization was the individualization of social problems, in a sense the twin of medicalization as social control. On this critique, medicalizing a problem facilitates viewing the etiological locus in the diseased individual’s mind or body, allowing solutions to be focused on him or her via medical treatments rather than on a social system that may be causing or exacerbating the condition in question (Conrad 1975, 19). While we have already seen that medicalization can enforce social norms on the individual, here we see how problematic social factors are obscured; both serve to protect the existing social power structure. The individualization of social problems is an underlying theme in many critiques of race-based medicine, including that levied by Dorothy Roberts (2006), which propose that genetic explanations underlying modern race-based medicine can serve to distract from the possibility that it is in fact social conditions correlated with race that contribute to health disparities. As Barbara Wooton pointed out in her book Social Science and Social Pathology (1959), nicely foreshadowing Conrad’s critique, “Always it is easier to put up a clinic than to pull down a slum” (Davis 2006, 52).

The fourth problem of medicalization that concerned Conrad was depoliticization of deviant behavior, exemplified by the Soviet classification of dissenters as mentally ill, a characterization that thereby “neutralized” the meaning of political protest and dissent, rendering it the ravings of mad persons” (1975, 19–20). We see this consideration in analyses of depression which suggest that depression may be a very reasonable reaction to social structures, mores, and norms that may themselves be bad for mental health and should not be considered a dysfunction at all under such circumstances. We see it also in the work of Carl Elliott, who suggests that depression is perhaps a reaction to the “normal nihilism” of our times, the terrible rug-pulled-out-from-under-us feeling that many people have when they consider the possibility that all our cultural and moral values are the result of contingent factors such as the evolutionary history of our species, the development of our brains, the technology available to us, and the scarcity or wealth around us (Elliott 1999, 56–59). All this, and more, is true of medicalization with regard to its capacity to reinforce unjust social structures. What more? Beyond merely reinforcing unjust social structures, medicalization can also reify them.

Dyesthelia ethiopsis: Medicalization as a great reifier

The Zola and Conrad model of medicalization-as-social-control pertains to how deviance from norms is controlled by enrolling the medical establishment and the imprimatur of science in the enforcement of norms. I have been interested in how the norms thus enforced are often ones of injustice: hierarchical norms that serve to maintain power for some and to oppress others. In such cases, medicalization is contra justice in society and in healthcare, and medicine is the instrument of oppression. But the enrollment of medicalization in social hierarchies can do more, I contend, than enforce unjust norms. It can also reify them.

Reification is a process whereby the ontology of an idea shifts from mere concept to real manifestation. In Marxist and neo-Marxist thought, it is sometimes referred to as “thingification” (a literal translation from the original German Verdinglichung). A classic example given by Karl Marx is that capital is the reification of labor time. Georg Lukács notes that capitalism has gone far beyond this and has “created a form for the state and a system of law corresponding to its needs and harmonizing with its own structure” (1969, 85). Thus, an abstract idea about economic systems and its attendant values becomes instantiated in powerful social institutions. What’s more, the “reified mind,” which has come to see the reified idea as an object existing in the world, takes this objectivity as a basis for authenticity of the idea and “does not even attempt to transcend it” (ibid., 84). The reified idea thus becomes harder to overcome, or even to see as an idea rather than as a feature of the natural world. While medicine is indeed a powerful social institution (like the state and laws that reify capitalism), reification can happen in scientific explanations more generally and not just in the rules or structure of the institution of medicine. According to Peter Berger and Thomas Luckmann (1966), reification occurs when human creations are conceived of as, among other things, facts of nature or the results of cosmic laws. What I will show is that medical conditions and explanation—presented as facts of nature or the results of natural laws—can reify social and cultural values as surely as can social institutions. This does not simply enforce existing judgments of social deviance as argued by Conrad, but can authoritatively explain the reasons for and can justify unjust social hierarchies in such a way that it becomes very difficult, indeed, to see those hierarchies in action and to transcend them. The medical condition and
explanation are then—though not always—the “thingification” of the concept which had previously been all that justified oppression.

Though it has not often been analyzed qua reification, a classic example of this phenomenon is found in dysesthesia aethiopis, a diagnostic label that pathologized the black body and was devised by Samuel Cartwright, a practicing physician in the American South before and during the American Civil War. Cartwright, famous and well respected for his work in fighting yellow fever and cholera, introduced this diagnostic label for “negro physiology” in a paper delivered to the Medical Association of Louisiana in 1851. Before I describe this condition as Cartwright did, it is worth noting that in his time and place, it was common practice to pathologize the black body. Benjamin Rush—signer of the Declaration of Independence, physician, and activist for healthcare for the indigent, and later an abolitionist—medicalized the black body via a condition called “negritude,” which was said to resemble leprosy and resulted in dark skin; by definition, all “negroes” were afflicted and the cure was skin whitening. Rush’s negritude is more like Conrad’s medicalization of deviance, enforcing norms while considering whites always to be the healthy norm, and deviations taken-to-be pathological. What Cartwright did is saliently different from the medicalization of deviance, though his characterization is related: Cartwright used medicalisation to pathologize blackness in a way that both explained and justified the practice of slavery and explained away the apparent desire of blacks not to be enslaved; indeed, he reified norms.

Cartwright proposed first that all blacks suffer from an underlying condition that he called dysesthesia aethiopis. Based on the prevailing belief that health was a balance of humors in the human body, Cartwright proposed that all black folk had imbalanced humors. His evidence? Their lassitude and desire not to work as well as the deepness with which they slept, when they slept, and the fact that, “like children, they require government in all things” (Cartwright 2004, 32). In addition, there was another problem, one resulting in intellectual degradation: “It has heretofore escaped the attention of the scientific world, that the defective atmosphericization of the blood, known to occur during infancy” as the infant rebreathes its own exhalation “is the identical kind of respiration most congenial to the negro constitution, of all ages and sexes, when in repose. . . . The inevitable effect of breathing a heated air, loaded with carbonic acid and aqueous vapor, is defective hematosis and hebetude of intellect” (ibid., 31). The cure for this dysesthesia aethiopis—a disease suffered by all blacks, and only by blacks—was hard work and “governance” by a firm hand, the sort that can only be provided by a universal system of slavery. Cartwright notes that, like children, blacks needed only to fear the disapproval of their betters and the lash would be unnecessary. On this view, whites were doing a disservice to blacks by allowing them freedom. Similarly, whites ought not to have too gentle and companionable a relation with free or enslaved blacks. According to Cartwright, the black is a “slave by nature,” as proved by “anatomy, physiology, history, and the inductions drawn from philosophical observations” (ibid. 33). To attempt to transcend slavery now becomes an attempt to alter a feature of nature rather than an idea or a social power structure.

The philosophical justifications for slavery which previously existed purely as concepts, albeit very powerful ones, now had taken physiological form and been given justification by material laws of nature. What’s more, this particular form for those concepts—disease and the corresponding treatment of slavery—allowed not only an ethical justification for slavery but an ethical demand for its continuation. In dysesthesia aethiopis, we have something more than medicalization as social control, something important: we have the reification of unjust social structures through medicalization.

**Autism: Historical reification and modern disruption**

Autism serves as the turning point for my argument, for at different points in the history of this condition, the form of its medicalization has both reified some existing unjust power structures and disrupted others.

Let us begin with the topic of autism as an example of reification. Early explanations of autism did not merely enforce social hierarchies of gender relations, but reified the idea that the sole proper role of a woman who is a mother is to mother and to do so at the expense of all else. Medical anthropologist Roy Richard Grinker (2007) describes the early days of the medicalization of autism in the 1950s and 1960s, when the major theorists working in the area were psychoanalyst Bruno Bettelheim and physicians Leo Kanner and Hans Asperger. Bettelheim’s training as a psychoanalyst is deeply relevant. Psychoanalytical etiologies of mental illness tended to rely on a combination of childhood trauma and interpersonal relationships, especially with one’s parents but particularly with one’s mother. Such etiologies were, by necessity, “one of a kind” (Miller 2007). It is perhaps unsurprising that Bettelheim’s psychoanalytic background led him to attribute autism to the role of the child’s parents, an etiological explanation that became the consensus as psychoanalysts “argued that people with autism were socially impaired because they had abnormal or failed relationships
with their parents, especially their mothers" (Grinker 2007, 71; my italics). A single phrase in Leo Kanner’s 1949 description of autism as a syndrome described the parents of his first set of patients as keeping their children “neatly in a refrigerator that did not defrost” (quoted in ibid., 72). Because of the gendered nature of parenting and social power structures at the time, this analysis spawned the infamous phrase attached to the previously described mother-related etiology for autism: “refrigerator mother.” Though Kanner forever regretted this co-opting of his injudicious phrase, the consequences were more devastating for parents and autistic children, as illustrated in this anecdote:

One mother recalled the meeting when Bettelheim diagnosed her son with autism in the late 1960s. “You were in the judgment seat, and he was your judge, your prosecutor, your everything. He was going to send you to mother hell because you made this kid autistic.” (Grinker 2007, 68)

Such consequences are ill effects of medicalization, indeed, and they still persist. As recently as 1992 when Grinker and his wife took their autistic daughter Isabel for her first visit with a psychiatrist, Grinker’s physician wife was asked whether and how often she breastfed Isabel, whether she enjoyed it, and other questions indicative of the mother-related etiology. The treatment recommendation was for her to quit her job to spend more time with Isabel at home. The Grinkers sought a second opinion, and found one of the majority of psychiatricists who do not know the etiology of autism but no longer reflexively blame it on mothers.

In the case of early explanations for autism, the dominant system at the time—psychoanalysis—both combined with and embodied what we earlier saw Miller describe generically as “the intellectual, ethical and political trends of an era” (2007). Early on in autism studies, the disease construct itself—etiology, description, and treatment recommendations—realigned unjust gender relations. Thus we see, in the etiology of newly medicalized autism as in dysesthesia aethiops, how medicalization can reify existing unjust power structures in addition to merely enforcing them.

However, if we reconceive medicalization in its more modern sense—that problems come to be regarded as medical by medicine and society (Davis 2006)—medicalization as a concept can lose its inherently disapprobative normativity. We can then see that bringing conditions under the purview of medicine can also legitimize the complaints of those ill-served by norms, mores, and power structures. In this way, medicalization can disrupt unjust social structures.

Let us consider autism once again, and the role that marginalization plays in oppression as well as the one played in liberation by demarginalization. In Iris Marion Young’s work on injustice, she theorizes five “faces” of oppression: exploitation, marginalization, powerlessness, cultural imperialism, and violence. Each characterizes the structural interactions between groups of people who oppress members of one group by virtue of the latter’s membership in that group. The role of marginalization in oppression and injustice is made clear by its definition: marginalization is the process by which “a whole category of people is expelled from useful participation in life” (Young 1990, 53). A common fate of folks whose cognition or behavior is atypical or undesired is marginalization, which has both severe social consequences (isolation and restricted possibilities for relationships) and economic consequences (limited means of support or employment and thus sometimes severe material deprivation). This face of oppression, like the others, enforces unjust social hierarchies.

Demarginalization, by contrast, can disrupt unjust social hierarchies by bringing members of oppressed groups back into useful participation in life. Great social power may need to be deployed to demarginalize a group in order to counteract the great structural power that had previously maintained marginalization in numerous ways. In societies where the medical profession has sufficient authority that medicalization can be a powerful source for social control or reification of unjust social structures, the medical profession also may have the social authority—and justification—necessary to reverse marginalization. To do so, it is not enough just to get benefits for a few individuals at a time. Rather, demarginalization as a process will have to mirror marginalization as a process by reincorporating a whole category of people into society and enabling useful participation in life. Which category? Those with a particular diagnostic label.

Now let us again consider autism. Let us regard it no longer as an example of reification of unjust hierarchies but as an example of their disruption. Prior to the medicalization of autism, children in the United States who would now be diagnosed as having an autism spectrum disorder—also known as “on the spectrum”—were diagnosed with either childhood schizophrenia or a catch-all categorical diagnosis called Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). In neither case did appropriate treatment or accommodations ensue, and such children were marginalized from mainstream society, and were often poorly treated and institutionalized. But with the medicalization of autism, and the corresponding increase in medical study of and
social familiarity with the condition in the United States, such children began
to gain access to social resources, including educational accommodation, special
education settings, and extra caregiving. In the United States, laws such as the
Individuals with Disabilities Education Act (IDEA, Title 20 Chapter 33 of the
U.S. Code), which ensures that disabled students have the right to reasonable
accommodation from local public school districts, explicitly include autism. In
addition, social responses to autistic persons have changed. Grinker (2007)
describes an incident when Isabel acted out in public at the grocery store when
she was older, after autism had begun to be widely publicized as a disorder.
Whereas in her early days bystanders blamed Isabel and her parents for her
behavior, a grocery store clerk accepted Grinker’s apologetic explanation that
Isabel is autistic and made comments indicating that she viewed autism as an-
other, and sometimes admirable, form of being human. Grinker goes on to
document the struggles and changes going on globally with respect to autism,
though they are slow and incremental:

There are many other children in the world like Isabel, in every country on
every continent, and with each day–they are less strange, less foreign. Com-
munity organizations, charities, research foundations, and parent groups
are responding quickly to the new visibility of autism. The renovations to
Maureen Fanning’s group homes [for autistic adults in the United States]
have started now, and [there is a] newly built National Center for Autism
in New Delhi [in India]. Neighborhood organizations in South Korea no
longer fight to keep children with autism off their streets and out of their
schools, and under the direction of just a few tireless mothers and fathers
of children with autism, South Africa and Kenya are both renovating their
institutions and working to integrate people with autism into their schools.
(Grinker 2007, 300–301)

By virtue of such changes that have resulted from medicalization and the higher
visibility of autism qua medical condition, an entire category of people–autistic
persons and their caregivers–is no longer excluded from useful participation
in life to the same degree they once were. Note that demarginalization through
medicalization here requires that the condition still be considered a pathology–
some autistic persons believe their social standing will only truly be improved
through demedicalization of their condition—but that the social position of
those diagnosed with the condition is vastly improved.

Thus, we have a case of medicalization demarginalizing a population of
persons who had serious problems with access to social resources, including
medical and social supports, as well as training for gainful employment. In
addition, increasing social acceptance encourages integration with the larger
community rather than the continued acceptability of treating members of the
group as distinct in ways that make oppression permissible. This effectively
disrupts the social power structures that had so thoroughly disadvantaged those
persons and their families. It is worth noting that medicalization of disabilities
or other conditions lived by oppressed minorities—and used to delineate the
oppressed group—will not always be demarginalizing. Medicalization can de-

marginalize where it makes human conditions comprehensible, disrupts the
prior conceptualization of individuals which attached to their conditions and

and group membership, enables access to social resources, and otherwise reinte-
grates into the larger community individuals who would have been at its farthest
margins. Demarginalization is far more complex when we consider HIV/AIDS,
a condition that has gathered much social momentum in the last quarter cen-
tury, and which has the distinction—compared with autism—of being lethal
and communicable. HIV/AIDS thus involves fear of contagion, and is highly
value-laden because of its association with socially unacceptable behaviors.

HIV/AIDS: Destigmatization and “sufficient”
medicalization

One of the barriers standing in the way of demarginalization, or reincor-
poration of marginalized groups into society, is the social stigma often attached
to those individuals by virtue of their membership in groups. Again, my concern
is with groups defined by medical diagnoses or the way that individuals are
grouped by virtue of sharing certain human conditions. For patients infected
with HIV or diagnosed with the end result of the infection, AIDS, these
conditions are highly stigmatized. Before considering how medicalization might—but
won’t necessarily—undermine stigma and thus substantively demarginalize
groups and their members, we should first consider how stigmatization of med-
ical groups works to marginalize groups.

Stigma has long been recognized as serving to discredit those who are
stigmatized, diminishing the person or group bearing the stigma. Indeed, the
social function of stigma functions directly to demarginalize groups and sup-
port existing power structures: “[W]hile subordinating individuals or groups
in society, the stigmatizing process also reinforces hierarchical patterns of privi-
lege, where those at the top of a stratified society are pre-eminent over, and
sometimes predatory upon, others at lower levels” (Rankin et al. 2005, 0703).
Certain religious or other moral schemes that postulate punishment theories of illness causation often provide a justification for stigmatizing persons by virtue of their membership in the diagnostic group. Such theories justify casting the ill persons out of their communities, especially when combined with reductionist language identifying persons with stigmatized diseases. This happens consistently with HIV, as is seen in the language used to identify seropositive persons in some African cultures: “she is an HIV,” “he is a walking corpse,” he is a nyambazi (submarine, being stealthy, menacing, and deadly) in Tanzania (ibid.). Such persons are generally rejected from their communities, and even by their families, in order to preserve the extended family’s community membership (ibid., 0702). In India, seropositive children are commonly thrown out of schools. This also occurs to seronegative children whose parents are known to be HIV-positive (Singh 2007) in a form of stigmatization often described with terrible irony as “courtesy stigmatization,” wherein the stigma attaches to those associated with the stigmatized person (Bogart et al. 2008, 245). In all such cases, stigmatization is a mechanism for marginalization, justifying loss of social contact, educational opportunities, and employment. Rakgadi Maholohlane, program manager at Pretoria, South Africa’s Centre for the Study of AIDS, notes that “[s]tigma happens for a variety of reasons, and it’s not based in any reality—it’s based on people’s perceptions. . . . Those perceptions started from an attempt to moralize the whole HIV epidemic, and because of those perceptions some people feel—on a ‘moral ground’—that a woman who behaves a certain way deserves to have HIV, or doesn’t deserve to have a child” (PlusNews 2009).

Medicalization would not inherently disrupt stigmatization because it, too, can be moralistic. In fact, it could reinforce stigmatization of nondiagnostic social groups. Consider the history of HIV/AIDS itself. The fact that the condition first began showing up exclusively in homosexual men in the United States and with unusually high incidence of Kaposi’s sarcoma led the condition to be called first “the gay cancer” and then, with the discovery of immunosuppression, “gay-related immune deficiency” or GRID (Kher 2003). These changes in nomenclature occurred with rapid progress in characterizing the condition during 1982 until, at the end of that year, the term Acquired Immune Deficiency Syndrome (AIDS) was proposed by epidemiologists concerned with the fundamental inaccuracy of the GRID terminology (ibid.). In the case of GRID, the diagnostic category mapped onto an existing stigmatized group, namely homosexual men. It did not, however, impose additional stigma. That came later, as HIV/AIDS came to be associated with a wide range of socially unacceptable behaviors, ranging from homosexual sex to promiscuous heterosexual sex and illicit drug use.

Recall that despite Conrad’s reservations about the process of medicalization, he still acknowledged that medicalization has a powerful ability to reduce stigma. After all, stigmatization is a powerful social mechanism for reinforcing existing social hierarchies by virtue of its role in marginalization. It is all the more powerful when the condition in question is invisible. Grinker notes that people throughout the world tend to pass moral judgments on illnesses—like autism—that have few obvious physical signs. Judgments are also made about illnesses with symptoms and causes that are confusing to people or that may be incurable, such as mental illnesses, tuberculosis, and many cancers. Susan Sontag observed much the same thing in Illness as Metaphor (1978), a fact that Grinker uses to good effect:

“Nothing,” she wrote, “is more punitive than to give disease a meaning—that meaning being invariably a moralistic one. Any important disease where causality is murky and for which treatment is ineffectual, tends to be awash in significance.” Recent examples of such moral judgments include the association of HIV infection with promiscuity or criminal drug use. . . . As anthropologists Nancy Schaper-Hughes and Margaret Lock put it, the second illness, the illness double, forces the patient, “now twice victimized, further into the cage of his or her illness: shunned, silenced, and shamed in addition to being very sick.” Stigma is a branding, a way that society marks us for transgressing the bounds of what is considered normal. (Grinker 2007, 69)

In light of this analysis of stigmatization of less visible conditions such as HIV, the Tanzanian characterization of HIV-positive persons as “submarines” is particularly telling. While HIV/AIDS has been considered a disease by the medical profession for more than a quarter of a century, persons with HIV/AIDS in cultures where the condition is insufficiently medicalized have major problems accessing care—they may “receive inferior care or are denied care altogether” (Ogden and Nyblade 2005, 31)—or refuse to comply with physician recommendations about testing, treatment, or avoiding breastfeeding in order to avoid being found out by their community, so great is the persistent stigma against persons living with HIV. Such normative social judgments have not been adequately attenuated or countered by accurate medical determinations about HIV.

So how might medicalization serve the demarginalizing disruption of power structures in the case of HIV/AIDS? What do I mean by “insufficiently medicalized,” and what is the connection to marginalization and stigmatization?
Bjorn Hoffman provides us with a useful tool set for addressing such issues. Hoffman (2002) presents the Triad, developed by Andrew Twaddle early in his career (in his dissertation of 1967) and long unused. The Triad is illness, sickness, and disease. Illness is the patient’s phenomenological experience of her condition and the basis of her resulting “complaint,” sickness is society’s perception of the patient’s condition and especially the matter of whether she can fulfill expected social rules and tasks, and disease is the medical profession’s judgment of the patient’s physiological malfunction. Hoffman depicts these as overlapping spheres of influence (Hoffman 2002, 653). We might explain their relationship by reference to alcoholism, often used as a classic case of medicalization. If physicians perceive alcoholism to be a disease but society perceives it to be a vice or character flaw (akin to weakness of the will) and the patient perceives herself to be coping—just fine, thank you, only one of the three spheres (disease) is filled in; the others (the absence of sickness or illness) overpower it at that point in time. A social judgment that alcoholism is a vice or character flaw does not constitute a medicalistic sickness judgment, but rather a nonmedical normative judgment. If society perceives a patient as genuinely sick, it may demand that the person receive treatment for the condition or make allowances for his or her inability to fulfill social roles and expectations. Because of the social authority of medicine as already described in our discussion of demarginalization of autism, there is often migration (or “creep”) of concepts and judgments from the clinic to society’s and patients’ perceptions of their conditions. Recall that we are seeking to discover what I mean by “insufficiently medicalized.” Sufficiency is always relative to a particular endpoint, and my endpoint here is medicalization’s effect on power structures (for good or for ill). On the Triad scheme, and when considering the ability of medicalization to affect social structures, we might consider a disease to be sufficiently medicalized when both the disease and sickness spheres are filled in. Note that this helps to explain the power of medicalization to enforce and reify social power structures even in the absence of a person’s perception that she is ill; all that is required is that both the medical profession and society be on board. This also explains why medicalization of HIV/AIDS is “insufficient” when the social sphere of the Triad is not involved. Simply put, the conjunction of disease judgments by the medical profession and sickness judgments by society is both necessary and sufficient condition for medicalization to significantly affect relevant social power structures. However, as with GRID or the construction of homosexuality as itself a pathology, the judgment of the medical profession may be fundamen-

tally inaccurate. At this point, I am describing only the level of medicalization, accurate or inaccurate, which suffices to affect power structures in society.

The alert reader will notice that this allows for the possibility that a sufficiently medicalized condition will not involve illness. Indeed, this explains how many of the preceding examples of misuse of medicalization can still occur while patients protest that they are not ill. This should not be taken to mean that there is no value in the addition of the illness sphere. In the United States, alcoholism is not only sufficiently medicalized, but is what we might call “fully medicalized,” for all three spheres are involved. Here, alcoholism is increasingly widely considered by the medical profession to be a disease requiring treatment, by the alcoholic to be an illness from which he perceives himself to suffer, and by society as a sickness that is deserving of treatment and sometimes even compassion. How does this help us to approach HIV/AIDS?

In many places in the world, HIV/AIDS has not made the transition to full medicalization of an accurate disease conception, nor even to sufficient medicalization. Why? Consider the fact that because HIV/AIDS (like other bloodborne or sexually transmitted diseases) can be contracted through illegal drug use and illicit sexual activity, it is often considered to be a result of, if not itself the same as, vice or character flaws (Lee, Kochman, and Sikkema 2002; Ogden and Nyblade 2005; Zhang et al. 2008). In addition, there are significant misunderstandings of HIV/AIDS that perpetuate stigma and thus marginalization.

In 2000 in the United States (where persons with HIV/AIDS have reasonably good access to healthcare), a survey found that 18.7 percent of respondents in the general population nonetheless endorsed the statement, “People who get AIDS through sex or drug use have gotten what they deserve” (Lee, Kochman, and Sikkema 2002, 309). This attitude is typical of the punishment theory of illness causation and leads to an unwillingness to provide access to care. Yet this is not the case for the remaining 81.3 percent of the population who held no such judgment of just de"ects. Other studies suggest that in the United States, the “unconverted”—whom we might conceive of as unshaded spots in the sickness sphere who have not yet adopted the dominant and accurate understanding of HIV/AIDS held in the American disease sphere—still hold such stigma because they often also misunderstand how HIV/AIDS is contracted and who is most affected by it (Zhang et al. 2008, 131). This also seems to be the case in Botswana, where young people who believed that sharing a meal could transmit HIV were more likely to possess stigmatizing attitudes toward HIV-positive persons (ibid.). Compare this with modern China, where lack of knowledge about HIV also correlates with stigmatizing at-
marginalization is a powerful way to disrupt social power structures by bringing groups in from the margin to greater membership in society, and that medicalization can mediate this process. Let us now consider the epistemic dimensions of marginalization and how medicalization can counter them, thereby revealing a third facet of demarginalization by medicalization.

**Chronic Fatigue Syndrome: Demarginalization by epistemic legitimation**

Let us now consider the medicalization of chronic fatigue syndrome, or CFS. Before we can see how it represents a case of the disruption of existing power structures, much less how this occurs by altering epistemic authority, we must better understand CFS and the history of the condition.

CFS, like many syndromes, is diagnosed largely based on symptoms rather than on clinical or paraclinical signs and markers. Symptoms can be reported by the patient. When observable by an objective observer such as a medical professional, they can become signs. There are at least two classes of signs, clinical and paraclinical. Clinical signs have traditionally been observed with the clinician's own observational skills. Paraclinical signs, by contrast, are mediated by technological measurements. These include the results of chemical analysis, X-ray films, ultrasounds, as well as imaging by MRI-, CT-, and PET-scanners (Hoffman 2001, 11).

As J. N. Clarke notes of CFS, “the symptoms/signs of this disease are quite vague and variable and their observation depends, in part, on sensitivity to bodily changes” (1999, 125). Diagnosis is thus centered on the patient's illness. Recall the distinction between illness and disease, where the former is the patient's complaint and the latter is the medical profession's judgment. The dependency of the physician's determination of disease upon the patient's experience of illness is intensified when the condition in question is largely symptom-based and any paraclinical signs are inconclusive in their own right. Note that this distinction between symptoms and signs maps fairly well onto the distinction made between illness and disease in the Triad. Many new diseases begin as patient complaints that, when observed in a sufficient number of patients, come to be seen by medicine as distinct syndromes. But these are not yet diseases. Typically, the syndrome must be a malfunction in the body to be considered a medical disease (Boorse 1975), or be traceable to a distinct disease entity (Chiong 2004). CFS defies this for reasons that both fail to refute the status of a disease rather than a syndrome, and make it difficult—and perhaps frustrating—to diagnose and treat.
Perhaps because of this, those who complained of debilitating and chronic fatigue before the disease had entered mainstream nosology suffered delegitimation of their illness experience. Typically, patients were female and encountered one of two responses from physicians: your symptoms are insignificant, or the condition is psychosomatic (Ware 1992, 350). According to Norma Ware, 90 percent of persons with CFS whom she interviewed reported such delegitimizing experiences (352–53). For some, these were interpreted as implicitly or explicitly sexist (351–52). In a study comparing male and female experiences with medicalization (or lack thereof) of CFS, Clarke found that men and women were equally likely—69 percent of men and 67 percent of women—to see multiple practitioners before receiving a diagnosis (1999, 130). Yet men were considerably more likely to get information on CFS from their doctors and from support groups (ibid.). Clarke interprets this as meaning that men are significantly more likely to find doctors who take them seriously and provide information (44 percent of men vs. 22 percent of women). She also found that all of the men were sent to specialists, while not all—though still 89 percent—of the women were, and that women were somewhat more likely to have been referred to a psychiatrist upon first describing their symptoms (132). Most patients were dissatisfied with their medical encounters for CFS by comparison with prior encounters. This lends support to Ware’s analysis that “gender differences in illness can be explained as the result of medical views of the psycho-pathological nature of women and their bodies, and their proclivity to seeing women’s problems as psychogenic” (Ware 1992, 352). In Ware’s analysis of her own interviews with CFS patients, the shame that stemmed from delegitimizing treatment such as that documented by both Ware and Clarke stemmed “not from being told that they had an illness, but from being told they do not. Their shame is the shame of being wrong about the nature of reality” (1992, 354, my italics). From a philosophical perspective rather than Ware’s anthropological one, these patients—80 percent of whom were women—had been stripped of their epistemic authority. Their knowledge was given no credence in the absence of an established medical syndrome that could explain their complaints.

However, this began to change in the 1990s not long after Ware’s interviews. CFS became increasingly medicalized, as evidenced by a proliferation of medical definitions and diagnostic guidelines (Broom and Woodward 1996, 362). The condition has not yet gained firm disease status due to “an absence of any definitive biological explanations or diagnostic indicators” (ibid.). Nonetheless, a 2003 meta-analysis of research on CFS described the condition as heterogeneous in pathophysiology and stated that it has a complex and multifactorial etiology (Afari and Buchwald 2003). As this sort of language reveals, CFS is considered a fit subject for medical investigation, one at present ill-defined but now legitimated. What’s more, as of 2008, the American Centers for Disease Control and Prevention (CDC) state that CFS “is a serious illness” suffered by at least one million, and as many as four million, Americans. The CDC also provides information for clinicians on diagnosis and for patients on how to talk to healthcare providers and family members about the condition. Though debate still rages within the medical profession regarding CFS, and research is underway—some funded by the CDC—to better characterize the condition, CFS has come to be seen by powerful institutions within the disease sphere as legitimately medical. This will likely have effects on clinical practice if Clarke’s subjects were correct when they identified a lack of medicalization as part of the problem (1999, 125). Though clinical practice often takes years to catch up with research in terms of physician knowledge of medicalized conditions that were not medical during their medical education, this increasing medicalization of chronic fatigue syndrome was already shifting the social and epistemic status of those whose complaints fit the syndrome more than a decade ago (Broom and Woodward 1996).

Preliminary indications are that the medicalization of chronic fatigue syndrome has disrupted power relations in the clinic that disadvantaged these patients. I do not claim, at present, that this disruption has reached outside of the clinic. This would be a necessary step for sufficient medicalization to obviate the social delegitimation described in the epigraph to this paper. But insofar as the symptomatic testimonies of women and the epistemically disadvantaged are increasingly legitimated—albeit medicine is still the arbiter of that legitimation—we can hope for some “creep” of this legitimation into the mainstream. And it is no small matter to disrupt epistemic power relations in the clinic that have traditionally held the complaints of women to be hysteria, malingering, or psychosomia.

We have thus seen three facets of demarginalization through medicalization: access and reintegration into society as demonstrated by the case of autism, destigmatization as demonstrated by the case of HIV/AIDS, and epistemic legitimation as demonstrated by the case of CFS. However, demarginalization is by no means the only mechanism for disrupting unjust social power structures.
Depression: How individualization of social problems can disrupt unjust social hierarchies

Another way in which medicalization can disrupt social power structures is intriguingly the reverse of Conrad’s concern about the medicalization of social problems. Recall that Conrad was concerned that medicalization of problems due in part to social issues would allow society to gloss over existing problems of power and injustice in society. But it is tempting to decide that social problems can only have social solutions, a temptation to which we should not give in. What if social problems can also have medical solutions? What if relief from the suffering caused by social problems can be had now for those who suffer from unjust social structures, and be coupled with efforts to reform those social structures? Indeed, with certain kinds of suffering, the suffering itself gets in the way of reform and perpetuates social structures.

Consider the case of depression. Dan Stein and Oye Gureje, respectively of South Africa and Nigeria, write on exactly this issue in their article, “Depression and Anxiety in the Developing World: Is It Time to Medicalise the Suffering?” They acknowledge that “poverty, violence, and infectious disease, including HIV/AIDS, in the developing world, and in the lower socioeconomic strata of the developed world, lead to anguish and despair. Such responses can readily be understood as normal responses to abnormal circumstances... and therefore a phenomenon that lies on the periphery of medicine proper” (Stein and Gureje 2004, 233). Yet this may be inappropriate. After all, people do suffer from these conditions, including depression, anxiety disorders, and PTSD. What’s more, they lack access to treatment or even to serious consideration of their mental health because of the combination of development status with the marginalized mental status of psychological symptoms in such situations. In fact, these conditions themselves may interfere with attempts to break free of social structures, including the unjust social structures inherent in economic disparities between the developing and developed world. The Global Burden of Disease Study found that in 1990 and 2000, depression “caused the largest amount of non-fatal burden worldwide” (ibid.). Depression thus constitutes yet one more barrier to a better life, one that is in fact imposed in part by the very disparities a person’s society might seek to overcome. As Norah Martin puts it when discussing the depressive effects of oppression on women, medicalization of depression and thus its treatment “helps some women to reach a point where they can actually fight the conditions that oppress them. One can hardly fight oppression if one is unable to get out of bed” (2001, 435; my italics).

Thus, there seems to be a prima facie argument to be made for the merits of medicalizing depression in the developing world even in light of prior concerns about how medicalizing depression in particular, and individualizing social problems in general, can reinforce existing hierarchies. There are, however, several very reasonable concerns that must be addressed.

The first such reasonable concern about medicalizing depression would be the likely cost of therapeutic measures that rely heavily on pharmaceuticals. High-tech and high-cost therapies would be untenable in most developing countries for economic reasons; under such circumstances, medicalization would worsen the status of those who are already struggling, thereby reinforcing the global socioeconomic hierarchy. However, Stein and Gureje (2004) note a number of modest interventions that have proven superior to placebo, including generic fluoxetine for depression in India and interpersonal therapy for depression in Uganda. Medicalizing depression in these regions, combined with use of effective, low-cost therapies, could relieve disease burden that serves to perpetuate unjust power structures and is, in many cases, a result of those very power structures.

A second reasonable concern about medicalizing depression under such circumstances stems from a general concern with the amount of human activity now within medical purview. Alan Horwitz and Jerome Wakefield (2007) are concerned that defining depression as a medical issue has already gone too far. They argue that what is actually happening is the medicalization of what might be called “normal sadness.” This concern about the overextension of medicalization is reminiscent of the original disapprobative concern that medicalization is often, and perhaps always, an overextension of medical authority. However pertinent this concern is for developed countries where only the least well-off face the kind of grinding poverty and persistent violence that plague even the best well-off in many developing regions, I believe it is not pertinent in this context. I am referring not to cases of what the fourteenth-century monk Thomas Kempis referred to as “the proper sorrows of the soul”—the sort of thing Horwitz and Wakefield perhaps rightly wish to keep unpathologized—but rather to large numbers of cases of burdensome disease that actually compound the injustice already suffered. While it may be difficult to distinguish between the two when we are talking about depressive responses to sorrowful conditions, as we are here, nonetheless the burdens of depression are in addition to those of oppression and can counter the likelihood of relief from oppression. In such a situation, medicalization would be less likely to impose new wrongs and more likely to allow people to go on in terrible circumstances and to improve them.
Thus, we see at least one case in which the individualization of social problems may be a way not only that medicalization reinforces existing unjust hierarchies, but may also contribute to their disruption. At the least, it will minimize the burdens imposed in part by unjust economic hierarchies.

Conclusion

My goal has been to draw attention to the complexity of medicalization as a mediator of social power and justice both within the clinic and outside it, for ill and for good. The classic critique of medicalization as social control has focused on reinforcement of unjust social power structures. I have argued that, in some cases, medicalization can in fact reify unjust social power structures. This adds to the existing understanding of medicalization as a social process of which we should be most wary whenever it would serve existing power structures.

However, if my argument so far holds water, it would clearly be inappropriate to leave an analysis of medicalization at the level of wariness or even unreflective rejection exemplified by conceiving of medicalization as inherently a misuse of “the power of doctors, who, in the guise of treatment, were doing things that were bad for people,” as Jonathon Metzl summarizes the position (quoted in Edelson 2007). On the contrary, I have argued that a full understanding of medicalization’s role in mediating power and justice requires acknowledging not only that it can support but also that it can disrupt social power structures that are most certainly “bad for people.” Such disruption can be accomplished in at least four ways as evidenced by particular conditions: demarginalization by virtue of access to services and reintegration into the community (autism), demarginalization by destigmatization (HIV/AIDS), demarginalization by epistemic legitimation (CSF), and the flip-side of the individualization of social problems whereby medicalization might relieve conditions caused by injustice and standing in the way of remedy for injustice (depression in the developing world).

I have also argued that medicalization is at its most powerful, for good or for ill, when a condition is sufficiently medicalized by mobilization of both the disease and sickness spheres or fully medicalized by mobilization of the disease, sickness, and illness spheres. What determines whether this is for good or for ill is in large part the accuracy of the medical conceptualization of the condition in question, as well as whether it reinforces or disrupts existing unjust power structures.

My hope is that this framework will allow us to practically assess instances of medicalization. For instance, we might be able to distinguish between pernicious “disease mongering” by pharmaceutical companies and the promotional introduction of new and beneficial medications for conditions only recently introduced to the nosology. We might be able to better determine whether the medicalization of menopause is in service of the needs of women or the power of others, whether the medicalization of aging is an attempt to relieve the age-related suffering of the elderly or another instance of ageism run amok, whether increased attention to malaria vaccination on the part of researchers is likely to disrupt power structures that benefit the developed world at the expense of the developing world or not, whether new terminology renaming the family of intersex conditions as Disorders of Sex Development is good for the already marginalized persons belonging to this group or in service of rigid and oppressive social norms, whether the medicalization of pregnancy and childbirth is in excess in some locations such as the United States and deficient in others such as Sierra Leone.

Clearly, medicalization is a powerful process and an ongoing one, both in the inclusion of new conditions and in patterns of interaction between medical professionals, patients, and society. It is not only the welfare of individuals that is affected by the progress of medicine, but also the basic structures of society. Only by upgrading our understanding of medicalization can we responsibly oversee it.

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Notes

1. By calling homosexuality a condition, I do not mean to imply that it is inherently pathological or to imply that homosexuals are “suffering” from their homosexuality. Rather, I use the term condition throughout to refer to a human condition, a state of being that may be temporary or part of one’s self and is not intrinsically either normal or pathological, admirable or worthy of condemnation. It is in this neutral sense of human condition that critiques of the medicalization of human conditions such as “normal sadness” or grief—see my discussion of depression—take place.
2. It was, after all, the mother who was the most present parent in households where women either did not work outside of the home or took their children to work with them as domestics.

3. Relevance, autistic children and other children with cognitive disorders who are dealt with in the public schools are contrasted with their "neurotypical" peers. When separated from neurotypical children, autistic children may get the services they need but are physically marginalized. When mainstreamed into classrooms with neurotypical children and provided with personal aides, many autistic children also do well (this is the case for Grinker's daughter Isabel) and are no longer physically marginalized. Severely autistic children may not be capable of mainstreaming and may require physical marginalization in order to get needed and appropriate services.

4. This differs from country to country. In South Korea, children with what we call autism are still largely diagnosed with Reactive Attachment Disorder, a condition that contains elements of blame for parents or other caregivers. In France, autism only became a diagnostic category in 2000; prior to that, children now diagnosed as autistic would have been diagnosed with a form of psychosis.

References

THE HPV VACCINE CONTROVERSY:
WHERE ARE THE WOMEN? WHERE ARE THE MEN?
WHERE IS THE MONEY?

JENNIFER CASELDFNE-BRACHT

Abstract
Should the HPV vaccine be mandatory for young women? Many proponents of mandatory vaccinations argue that it is good for women. Yet feminists have reason to be concerned. A partial list of reasons that are cause for skepticism include the following: (1) the fact that there are large expenses associated with the vaccination, which could lead to some serious conflicts of interest; (2) the fact that men carry this virus, yet there is no push to vaccinate them; and (3) the fact that it is not clear that the vaccine has been sufficiently tested to ensure women's safety. This paper will examine legislation to make the HPV vaccine mandatory and will discuss the implications that surround it.

In November 2006, Merck pharmaceuticals started a massive advertising and lobbying campaign aimed at promoting Gardasil, a vaccine that prevents cervical cancer from two of the thirty strains of the human papillomavirus (HPV) that can cause cervical cancer. Their advertising campaign, titled "One