

## The art of medicine

### Naming the problem: disorders and their meanings

It has been 30 years since Susan Sontag so powerfully brought to light the metaphorical meanings of illness and the consequences of these meanings for the ways that illness is understood, treated, and most importantly, experienced and lived. Our increasingly complex scientific explanations of illnesses in the past few decades can nevertheless make it easy to overlook how illnesses carry with them equally complex yet underexamined social meanings—including moral judgments—that affect not simply the medical treatment of illness, but the experience of it. This more expansive view of illness points to something beyond clinical pathology; it includes the way in which individuals, family members, and society perceive and thus respond to medical conditions. We are accustomed to thinking about the suffering wrought by illness as a matter of its physical aspects and its treatment. There are cases, however, in which the medical naming of illness and its attendant social meaning can have equally harmful effects.

If the meaning of an illness derives from what are taken to be its salient features—ie, its aetiology and symptoms, how it is contracted or transmitted, the vulnerability of specific individuals or groups to it—this understanding is also bound inextricably to its name, which can convey subtle and not so subtle ideas about normal and abnormal, good and bad. The ways we identify medical conditions—together with their permutations in labels, identities, or diagnoses attributed to (and sometimes embraced by) individuals thereafter—are freighted with meaning that is tied to a sense of self. Particularly when diagnoses come to denote “kinds” of people, disease, once named, may constrain the lives of those so labelled who must live intimately with its meaning. Sociologist Arthur Frank writes eloquently of “becoming a victim of medicine”. This victimisation, he argues, stems from the individual experience of medicine’s colonisation of the body, whereby medicine casts the body in the narrow terms of the disorder it must treat, and thus reduces an individual’s suffering to its general view.

Perhaps nowhere today are the connections between the naming of medical conditions and the social and medical implications of this naming more obvious than in debates over the recent change in medical nomenclature describing intersex conditions as disorders of sex development. Whereas some view the new term as a way to circumvent the stigmatising effects of the older terms hermaphrodite and intersex, resistance to the language of disorder has come most forcefully from those who have experienced the introduction of disorders of sex development as still another instance of medical “pathologisation” of their bodies and their selves—a view powerfully captured in one activist’s declaration that “I am a person, not a disorder”. At first glance

this controversy over naming might seem to be an esoteric debate of limited interest to those outside the field, but the conflict concerning the stigma associated with the term “intersex” and now “disorder” has much greater implications with respect to the meanings attached to medical conditions and the contribution of these meanings to a patient’s suffering. It is a lesson we all too often fail to remember.

The problem with how intersex has been medically managed is tied to its meaning. Intersex (and the older term hermaphrodite) was not limited to a condition incidental to one’s person. Rather, it referred to something one essentially was, and the term conjured images of people who were either both male and female, or else neither male nor female. Locating the problem in individuals rather than in societal conceptions of sex, medicine construed atypical somatic sex difference as the primary problem associated with these conditions. An individual’s wellbeing thus lay in eliminating this difference and in concealing the condition responsible for it. Rather than demystifying the medical conditions associated with atypical sex anatomy, medical nomenclature served instead to reinforce the notion that intersex conditions were shameful.

An unfortunate consequence of using the term intersex (and earlier hermaphrodite) to identify kinds of people who violate cultural rules of gender has been medicine’s preoccupation with “fixing sex” over, and sometimes against, attending to the health sequelae or consequences of such conditions. The nomenclature thus contributed to the portrayal of intersex conditions as problems that can be fixed—through correct gender assignment, cosmetic genital surgery, and hormone replacement—and helped shape unethical aspects of treatment since at least the 1950s.

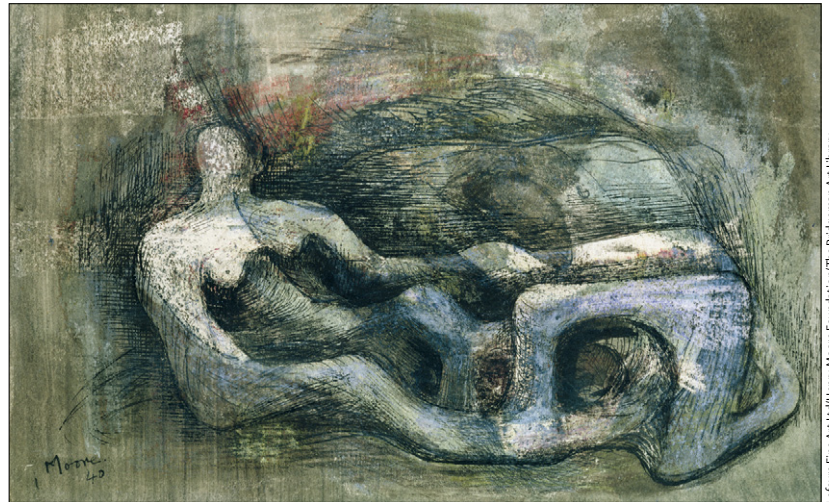
Because it is impossible to change what they are at their core—ie, combinations of somatic traits that defy commonly and deeply held understandings of the differences between male and female—some advocates, in partnership with sympathetic physicians, sought to rename these conditions. Their hope was that in so doing, clinical attention would shift towards the diseases associated with atypical sex anatomies. Indeed, medical attention to those with atypical anatomies, they argued, should be recast from a preoccupation with “normal appearance” to the concern with human flourishing and wellbeing that should be the focus of medical practice. For those advocates in favour of the change in nomenclature, the term disorders of sex development marks an understanding that theirs is a medical condition rather than an identity. For those who have embraced intersex as an identity, the shift to disorders of sex development reinforces a harmful pathologisation of their very selves. Because atypical sex anatomy remains

the distinguishing feature by which such diverse conditions are grouped together, the use of the term “disorder” strikes some as no better than hermaphrodite. The name is furthermore objectionable to many beyond the English-speaking world because it is not possible in some languages to make a distinction between sex development as a biological process, and sexual development as an affective process involving matters such as gender identity and sexual orientation, leaving the impression that an intersex condition renders “disordered” a person’s sexual development in its entirety. But whether one sees the change in nomenclature as an advance for its focus on conditions rather than individuals, or sees the change in nomenclature as perpetuating the same pathologisation as earlier terms, the central issue is an ethical one: granting humanity to those whose bodies defy deeply held assumptions about what is “normal”.

Intersex conditions are by no means unique in the social meanings conveyed by their names. An early example is consumption, later known as tuberculosis, a disease whose “truth”, as philosopher Ian Hacking put it, was transformed by the late 19th-century discovery of the “brute fact” that it is a disease transmitted by microbes. This discovery changed, but did not immediately displace, the earlier belief that consumption was “a moral failing, caused by defects of character”. If tuberculosis, unlike consumption, was understood at last to be a contagious disease, it was in the USA nevertheless considered a disease of only some and not all people: essentially immigrants and the poor.

In its early years, HIV/AIDS was thought to be a disease that chiefly affected gay men and nomenclature reflected that understanding. Some people referred to it as gay-related immune deficiency (GRID), whereas others called it “gay compromise syndrome” and “gay cancer”. What to call this new disease was controversial. The shift to HIV/AIDS was prompted by clinicians and public-health professionals who were rightly concerned that these terms focused attention on types of people. These names would not only inaccurately describe those affected, but would, as history would confirm, prove a barrier to securing the education, support, and research necessary to contain the pandemic.

Invoking the historical cases of tuberculosis and AIDS suggests that there is room both for robust criticism of the stigma attached to the bodies of those who contract the disease (or those understood to be “at risk”), and for appreciating the importance of attending to the medical treatment of the condition. If at least for some period, social stigma and medical “truth” could coexist in the cases of tuberculosis and AIDS, we may similarly regard intersex treatment to be in a state of transition. Focusing on the genuine medical conditions that attended consumption and GRID led to the distinguishing of “properly medical” issues from social issues of class, immigration, or ethnicity (in the case of tuberculosis) and sexual orientation (in the case of AIDS). The issue of intersex conditions may be



Henry Moore, *Study for Reclining Figure in Wood* (1940)  
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similarly understood; that is to say, the difference between the genuine medical problems that attend these conditions and the social problems presented by so-called ambiguous sex is now being parsed.

Sontag noted that “the most truthful way of regarding illness—and the healthiest way of being ill—is one most purified of, most resistant to, metaphoric thinking”. What the change in nomenclature can promise, although obviously not guarantee, is the possibility that disorders of sex development will refocus our attention away from interventions aimed at providing a coherent gender to those that improve health and wellbeing.

What it would mean to do justice to Sontag’s point in the case of intersex conditions will nevertheless require a development beyond the new nomenclature. What motivates this collective grouping is not a common aetiology or clinical features, but the social meaning attached to atypical sex anatomy. Such meaning, as the lessons of tuberculosis and AIDS teach us, is a function of culture and history; it is our hope that as these conditions come to be treated as disorders like many others, the individual diagnoses will be regarded alongside conditions that genuinely share clinical features. Recasting diverse diagnoses in this way would have dramatic effects on those with disorders of sex development. Rather than be regarded as “types” of people whose care is directed at correcting sexual difference, affected individuals should receive the attention to their health and wellbeing that all should take to be their right.

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**Further reading**

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