

STATE OF THE ART AND SCIENCE

What Should Clinicians and Patients Know About the Clinical Gaze, Disability, and Iatrogenic Harm When Making Decisions?

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Abstract

While clinicians, ethicists, and policymakers are increasingly aware that race, ethnicity, sexuality, gender, and class biases interfere with care provision, disability is not always considered as a confounding factor. This article explores the way embodiment affects personal and professional values. When patients who live with bodies others might not fully comprehend or embrace refuse or challenge clinical interventions, they offer real opportunities for clinicians to grasp the central role that embodied experience plays in how patients make health decisions and thereby avoid harming patients or undermining their relationships with patients.

Disabled lives are as valid as nondisabled lives, but they are not the same.

Andrew Solomon¹

Creating space is difficult. The world does its best to resist.

Jan Grue²

Clinical Gaze

Diagnostic and treatment paradigms in medicine have historically presumed a standard human body: one that is White and male.^{3,4} While clinicians, ethicists, and policymakers have become increasingly aware that race, ethnicity, sexuality, gender, and class biases can interfere with care provision, disability has not always been considered as a confounding factor in health care. Here, we argue that differences in perceptions of embodiment—specifically, the gap between how persons with disabilities are seen by an ableist society (and by medicine) and the way in which disability is experienced as a component (but not a singular defining element) of a lived life—can result in dissonance in the patient-physician relationship. Furthermore, medical science and technology often buttress social beliefs that pathologize bodies that perform outside the typical range. As such, patients living in a disabling context can challenge medical treatment as a rejection of the many narratives that both society and medicine construct about their apparently “incapacitated” lives. We believe that patients with disabilities offer real opportunities for able-bodied health care professionals and ethicists to grasp the central role that embodied experience plays in making reasoned health care decisions.

Disability confronts cultural norms about physical, psychological, and cognitive human experience and, in doing so, poignantly highlights the fact that all of our autonomies are mediated by imperfect bodies interacting with the world.

Embodiment

A principlist approach to bioethics suggests the value of principles of nonmaleficence and beneficence alongside justice and respect for patient autonomy.^{5,6} Within this framework, autonomy speaks to the Kantian right or condition of a person to rational self-governance—that is, to the right of the individual to freely choose for and by themselves.⁷ In bioethics, autonomy requires health care professionals to respect patient choice (as long as the patient is competent) and imparts a duty to provide sufficient information, as well as the physical and temporal space, for the patient to make an informed, uncoerced decision.

It is critical, however, to note that principlism is not neutral, but rather reflects intrinsic biases held by medicine and medical practitioners. In *The Birth of the Clinic*, Michel Foucault draws attention to the objectification of the human body through the rise of the postmortem and the reification of both the body and disease in the dissected corpse beginning in the late 18th century.⁸ Peter Conrad further argues that Foucault's conception of the clinical, objectifying gaze has become a form of medicalization in which a human condition or state becomes defined as a problem and requires medical intervention.⁹ As critically, Foucault argues that society internalizes this **medical gaze**, accepting it as the objective articulation of the embodied self in modernity.⁸ Foucault's point is that even as the medical sciences emerged within a social and political environment that espoused liberty and equality, clinical knowledge used an objectifying gaze that sought authority over the patient's body and over illness. Clinical assessment and treatment were rooted in a clinical gaze that assumed a normative body and sought to coerce patients to see themselves as ill, thereby (hopefully) creating the opportunity for treatment and cure. The power of medicine is thus embedded in the objectification of the patient body by the medical professional and by medical knowledge,⁸ a process that intrinsically harbors the assumptions and biases of both.

What is left unsaid is that the medical gaze—with its assumptions and biases—defines what is normative. Historically, diagnostic models have presumed a standard human body. While race, ethnicity, sexuality, gender, and class have been identified as complicating this assumption in medicine, less consideration has been given to disability.^{10,11,12} The classification of “dis-ease” presumes a norm from which the patient deviates: when an individual lives a life with a chronic dis-ease, they always already deviate from a clinical norm. The unconventional lived identity of an individual living with a facial or limb deformity or a sensory impairment challenges and destabilizes the health-disease binary within which medicine typically functions. As such, health professionals may be limited in their work of fully encountering a patient living in a disabling context, as this encounter is mediated and defined by the inherently reductive nature of the medical gaze. Rosemarie Garland-Thomson summarizes this difficulty as “[t]he medical-scientific aim to make us ‘better’ clumsily balances the conflict between the charge of medicine to ‘do good’ and the caution to ‘do no harm.’”¹

One of physicians' duties within the patient-physician relationship is to delineate their patients' goals and preferences. Many patients identify a tension between their personal understanding and experience of their illness and the medicalized articulation of their disease. In other words, a distinction exists between patient and clinical narratives of

shared events. People with disabilities **live full lives** even though these lives may be seen through an ableist lens as constrained and incomplete.^{13,14,15} For individuals with a disability, the lacunae between the identity constructed for them by the medical gaze (which Foucault argues simultaneously objectively sees and speaks what it observes) and their self-conception can be substantial. The risks for patients with disabilities in entering the patient-physician relationship are thus more pronounced and potentially more impactful. A physician's ability to withhold or insist upon a specific treatment, remedy, or even disease classification (in the case of insurance) can utterly upset the unique balance and approach with which a person with disability leads their life.

Disabled Embodiment

Evidence-based medicine, which relies on statistically significant findings from aggregate data, can fail patients with disabilities. Characteristics or responses of people with disabilities and chronic illnesses often lie outside "normalizing" averages. Their bodies react and perform differently from the "norm." Moreover, how they value their bodies and the ways they perform and function—the manner, in other words, in which they embody themselves—may be and often is substantially different from the way in which the average person does. We live in an ableist world, in which able bodies are the social and medical standard. Medicine's scientific and technological feats depend on data on human bodies—data that are aggregated and described by a statistically normal distribution. This approach enables clinicians to recommend the most efficacious treatment for the greatest number of people. However, this practice inevitably privileges physical uniformity over variation—at the cost of those bodies that figuratively lie at the ends of the distribution. This oversight means that individuals with disabilities (just like members of other minority ethnicities and races) must remain circumspect about medical guidance that often fails, culturally and statistically, to "see" them. Furthermore, as Jan Grue, who has spinal muscular atrophy, adroitly points out, one person with an amputation or arthritis experiences their disease trajectory in quite a different manner than another person with the same "ailment."² Generalized disease descriptions are just that—general—and do not capture the specificity of the adaptive and innovative life that a person with disabilities lives.

This tendency to mask individual differences makes grappling with the lived experiences of persons with disabilities critical. Grue writes of the weight of social perception of the disabled body on the disabled individual: "To be stared at, gawked at, is to develop an external sense of one's self, a sense that is always premodulated to the expectations of the surroundings. It is also to be situated in a narrative that has already been written, and that is told by others."² This act of depersonalization is compounded by the medical gaze. For example, consider the information provided to expectant couples when they inquire about amniocentesis and prenatal genetic testing. Seldom, if ever, do these materials include descriptions or testimonies of people who live with the disorder being selected against. Prenatal testing claims to be objective, scientific, and technocratic, presuming that all disabled lives are unwanted and that fulfilling disabled lives are impossible.¹⁶ Some scholars and activists with disabilities see prenatal testing as medicine's **attempt to erase disability** or to stigmatize it.¹⁷ It is important to remember that the presence of cytogenetic testing does not eradicate disability—disability is an inevitable aspect of the human condition and occurs throughout the range of life expectancy. And, given medicine's increasing ability to secure greater longevity for people with cancers and chronic illnesses, it would seem that the profession and bioethics need to more consciously address how disability impacts and shapes people's lives. The Centers for Disease Control and Prevention estimated in 2020 that 26% of

American adults have a disability,¹⁸ making them a large, if not the largest, minority seeking health care. Yet, when we listen to authors with disabilities, it's clear that **ableist tendencies** permeate medical contacts and that patients with disabilities feel as though their experiences and their self-expression and autonomy are overlooked.^{19,20,21,22} Everything—from the fact that clinic exam tables are largely inaccessible to the fact that the clinical frailty scale²³ does not account for a person who normally functions “differently”—puts patients with disabilities in suboptimal positions in terms of determining their care. In this context, it is not surprising that patients with disabilities often challenge or refuse medical treatment.

The work of embodiment—the work of deciding who and what we are, of identifying what is important to us, of determining our own goals and ends—is critical to the achievement of autonomy. In his memoir, Grue describes the nightly battle in his family over the use of leg braces when he was a child. The orthotics were supposed to prolong his walking, but they caused such pain and discomfort that he seldom slept. He eventually abandoned their use—their prescription was ill-conceived and destructive.² Grue identifies a dissonance between how the disabled subject is cast by the medical gaze and how the actual individual with the disease or impairment constructs their own self: “No pathological picture resembles another one perfectly. Diagnosis is not fate. But it's easy to believe that it is. It's easier not to look too closely. What is this gaze, which is so sharp and penetrating, but simultaneously dull and disinterested, that separates things that should not be separated and at the same time mistakes one thing for something very different?”²

Critical race theorists and activists and writers with disabilities have long known that their embodied experience of the world is vastly different than that codified in textbooks, social codes, and laws.^{24,25,26} Understanding the centrality of the interchange between any person's body, mind, and autonomous expression, on the one hand, and their environment, on the other, is critical, particularly when physicians and patients negotiate the terms of the care contract.

Conclusion

Clinicians and bioethicists need to address the ableism that is inherent in medicine and medical ethics. Given medicine's capacity to rescue individuals from illnesses and trauma that were lethal a mere generation ago, we need to become aware that the lives that emerge from our greater medical capacities are ones that may be seen as disabled but are fully human even in their difference. It is medical knowledge and power that often create disability. Patients with disabilities challenge our conceptions of human possibility. We should pay attention.

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