

## **D4. Negotiating Norms: Biomedicine in 20th century**

**D4:1** Caroline Wechsler, *Standardizing syndromes: Clinical scoring systems in genetic connective tissue disorders*

Despite the proliferation of genetic sequencing and molecular techniques, clinical observation and bodily measurement remain key diagnostic tools for medical geneticists. Using internationally standardized clinical checklists, many genetic conditions are primarily screened and diagnosed not through sequencing but through observed bodily features (e.g. facial structure, stature, skin texture) and clinical maneuvers (e.g. thumb-wrist sign, joint hyperextension). In this talk, I trace the history of diagnostic tools for two genetic disorders, the Beighton score for Ehlers-Danlos syndrome (EDS) and the Marfan systemic score for Marfan Syndrome, arguing that these clinical scoring systems represent attempts to standardize two unwieldy diagnoses, revealing tensions and anxieties around expertise and bodily norms. When and why did these clinical scoring tools emerge, and what do they reveal about medical geneticists' practices, anxieties, and limitations? How did geneticists draw the line between "normal" mobility and habitus and "disordered"? I show how both tools emerged out of late 20th century concerns around "overdiagnosis" of genetic disease and blurry diagnostic categories. I argue that these tools demonstrate medical geneticists' attempts to standardize their clinical practice in a medical world increasingly driven by "objective" testing, yet preserve and codify their own clinical expertise. I attend to the role of race and gender in constructing both scoring tools, showing how both embed assumptions about racial and gendered difference in body and mobility. I also argue that clinical scoring tools represent longstanding practices of visibility and bodily measurement in genetics, and interrogate the effects of this emphasis on uncovering diagnosis "hidden" in visible facial and bodily features on geneticists' perceptions of disability and their own expertise. As medical genetics has increasingly come to rely on genetic sequencing, I show how these clinical scoring tools have come into tension with new genetic diagnostic techniques in the first decades of the 21st century; moreover, I show how these tools have taken on new dimensions of complexity as information about them circulates online and patients begin to use them to self-diagnose. Ultimately, I demonstrate how the development of these clinical tools reflect tensions around expertise and identity in genetic diagnosis, for patients and providers.

### Learning Outcomes

- Develop the capacity for critical thinking about the nature, ends and limits of genetic medicine
- Understand the dynamic history of medical ideas and practices, their implications for patients and health care
- Contribute to the improvement of patient care by critically appraising clinical diagnosis from a historical perspective

**D4:2** Sofia Grant, *Blocked Impulses: Myasthenia Gravis, the Prostigmin Test, and the Making of a Clinical Diagnosis in Midcentury America*

The standardization and rationalization of clinical disease entities on the basis of specific biological mechanisms has provided an important method of organizing biomedical practice in the late nineteenth, twentieth, and twenty-first centuries. Synthesizing historical perspectives on the specific disease entity with the work of feminist science studies scholars, this paper demonstrates how the standardization and rationalization of biomedical disease identities can (re)produce forms of exclusion for patients with symptoms that do not easily conform to standardized diagnostic categories.

In the interwar and postwar United States, myasthenia gravis, a disease causing muscular weakness and fatigue, was increasingly understood as a disorder of neuromuscular transmission treatable with the anticholinesterase drug Prostigmin. This paper examines the history of Massachusetts General Hospital's Myasthenia Gravis Clinic, as its boundaries came to be configured around the Prostigmin test, a quantitative diagnostic tool that purported to distinguish between myasthenia gravis and psychoneurosis on a rational basis. The Prostigmin test promised to establish myasthenia gravis as a disorder of the neuromuscular junction while solving the Clinic's practical and financial problems by limiting the number of patients who would receive long-term Prostigmin treatment from the hospital's pharmacy.

Through analysis of clinic records and correspondence with patients who claimed to benefit from Prostigmin, I locate the Prostigmin test within a network of powerful scientific, corporate, and institutional interests. By arguing that the Clinic's emphasis on the Prostigmin test as a defining criterion for myasthenia gravis diverted some patients away from the Clinic and from access to biomedical validation, this paper demonstrates the limits of standardization and specificity in the diagnosis and care of nonspecific illnesses.

Learning Outcomes

- Understand the role of institutional and economic factors in shaping the identities of diseases, patients, and clinical spaces.
- Critically evaluate the relationship of diagnostic tests to patient experience and the patient's voice, including the role of diagnosis in producing forms of validation and exclusion.
- Recognize the limitations of standardized diagnostic instruments, forms of specialization, and models of disease for addressing the needs of patients with chronic or nonspecific illnesses.

**D4:3** Adrien Gau, *Of Monolids and Medicine: On the racialization of upper-eyelid blepharoplasty*

Cosmetic surgery procedures have faced increased scrutiny in recent years for promoting a highly racialized ideal of beauty and normativity. Perhaps one of the most visible examples is blepharoplasty in patients of East Asian descent, specifically to transform a "monolid" to a "double-lid" or a creased upper eyelid. Alongside the meteoric rise of contemporary East Asian pop culture, overshadowing but not erasing the twentieth-century history of yellow peril and US-East Asian Cold War tensions, double eyelid surgery has come to stand in for the tension between westernization and racialized bodily differences.

Historians of plastic surgery have highlighted other racialized cosmetic surgery procedures such as rhinoplasty; historians of East Asia have spoken to the rise of plastic surgery in Korea and Japan in the broader context of US-Cold War politics, and American medical sociologists and anthropologists have attempted to tackle the "Asian eyelid" phenomenon from the viewpoint of westernization and psychological complexes. As practicing physicians have pointed out, however, double-eyelid surgery has been practiced in Asia long before the Cold War and cultural globalization.

This paper synthesizes these perspectives and approaches the racialization of blepharoplasty through the questions: when did double-eyelid surgery become racialized? What kinds of measurements and standards were involved in determining not only the "necessity" of such a procedure, but the original definition and prevalence of "monolids" in the first place? How did plastic surgeons and patients determine what a "successful" outcome for double-eyelid surgery looked like?

Learning Outcomes

- Apply the lenses of race, geopolitics, and Orientalism to understanding the history of plastic surgery
- Demonstrate an interdisciplinary approach to contextualizing a particular procedure in cosmetic surgery
- Highlight continuities and ruptures between societal views of cosmetic surgery over time

**D4:4** Melody Slavnik-Xu, *In the Eye of the Beholder: the Use of Film and Video in the Mackworth Eye-Tracking Devices (1945-1975)*

Film and video technologies served a range of purposes for 20th century psychologists. Many historical studies have analyzed the use of visual devices for scientific and medical communication, education, and training. My presentation departs from this tradition by emphasizing the subtle ways in which video technologies have constructed and shaped researchers' understanding of bodies and minds.

I trace the development, use, and reception of a series of eye-tracking devices developed by Norman H. Mackworth (1917-2005) in the 1950s-70s. His devices, which relied on the use of film in combination with the use of corneal reflection techniques, allowed researchers to create a visual record of where someone was looking. Used by dozens of laboratories, hospitals, and research centers across the United States and Canada over this period, they became a means of discovering and establishing physiobiological dichotomies between bodies which were normal or abnormal and average or extraordinary. Through the analysis of research publications, patent records, archival materials, I show that these devices also show an underlying consistency in the use of research methods and technologies rooted in behaviorism during a time period traditionally associated with the field's shift to the "cognitive revolution."

Despite the initial excitement from the scientific community regarding the potential for a technology that promised to let them see through someone else's eyes, Mackworth's eye trackers were ultimately met with both professional and public criticism. Researchers challenged his device and the material and methodological constraints of his devices, revealing the fluid and sometimes even contradictory conceptualization of objectivity, accuracy, and precision. Finally, by situating these technologies within the historical backdrop of Cold-War era America, this work reveals the ways in which these eye-trackers embodied and reflected broader anxieties and fears regarding surveillance and secrecy.

Learning Outcomes

- Recognize the active role technologies have in shaping our understanding of bodies and bodily processes.
- Discuss the limitations of a paradigmatic understanding of 20th century psychological sciences.
- Identify different means of incorporating film and video into scientific practices