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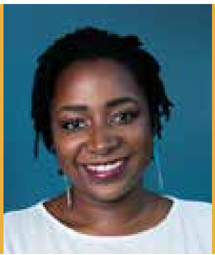

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# "Neurotech Justice" in the Clinic:

## Key Takeaways from the Harvard Medical School Center for Bioethics Neurotech Justice Summit

### Introduction

Neurotechnologies, including neuroimaging, wearable, and implantable neuro-stimulatory devices, are rapidly evolving, spurring ethical questions about their potential to create more harm than good in society.[1–3] As part of the Dana Foundation Center for Neuroscience and Society planning grant, an interdisciplinary team of lawyers, clinicians, ethicists, and "Dana Planning Grant Next Generation Leaders"[4] held the inaugural Neurotech Justice Summit on January 24, 2023, sponsored by the Dana Foundation and the Harvard Medical School (HMS) Center for Bioethics. The application of ethics to neurotechnology, which we term "neurotech justice," is important to define and pursue in clinical settings. Here, we share discussions from sessions and present strategies for how neurosurgeons can pursue neurotech justice.

### How Do We Define "Neurotech Justice"?

Next Generation Leaders identified and presented four essential elements of neurotech justice: socio-ecological, distributive, transformative, and restorative.

### Socio-ecological Justice

Socio-ecological models analyze health-outcomes at individual, interpersonal, community, and socioeconomic levels.[5,6] We adapt these models to neurotechnology applications. On individual levels, these frameworks prioritize notions inspired by neurorights, which encompasses mental privacy, agency, and personal identity.[3] Interpersonal considerations include building trust within the intertwined relationships of patients, caregivers, surgeons, and industry representatives.[7] Inclusion of demographically diverse patient populations perspectives on neurotechnologies will create nuanced community perspectives.[6] Systemically, policies must price neurotechnologies affordably.[7]

### Distributive Justice

Neurotechnology use is limited by varied insurance coverage decisions that generate inequitable treatment options.[8,9] Research highlights higher rates of Medicaid-use among African-American patients with Parkinson's Disease as a potential mediator for their lower access to deep brain stimulation.[10] Burdensome out-of-pocket costs and insurance gaps unfairly allocate neurotechnologies.[11] Just distributions of neurotechnologies will meet increasing device demands, in financially inclusive ways, as diagnoses of neurologic and psychiatric conditions rise.[12]

Clinical access to neurotechnologies is influenced by federal and state governments, insurance companies, and physician-specialty groups that create guidelines on their uses for diagnosis, prognosis, treatment, insurance coverage and reimbursement.[8–10] Guidelines must account for drivers of health inequities--racism, sexism, classism, ableism, xenophobia, and homophobia--to enforce practices that consciously and proactively meet all patients' needs.

### Transformative & Restorative Justice

Transformative and restorative practices are community-based efforts to prioritize healing and accountability for harms.[13,14] Indigenous, Black and Brown, immigrant, poor, disabled, queer, transgender, and sex-work communities pioneered these to build safe spaces within structurally-violent systems.[15,16] In health care, approaches should respond to current and historical medical injustices to improve neurotechnology development and distribution."

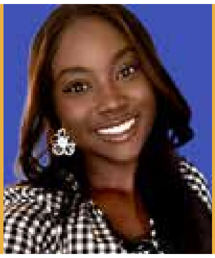
Patients' realities of pain, decreased functions, and diminished consciousness are compounded by harms that occur when their identity intersects multiple marginalized groups. Restoration requires acknowledgement and care about the structural and interpersonal harms patients experience and tangible efforts to repair harms.[17] Transformative approaches require thoughtful broadscale interventions for the needs of patients, families, and communities harmed by unjust development, distribution, and applications of neurotechnologies.[17]

### Neurotech Justice In the Clinic

Later in the Neurotech Justice Summit, panelists discussed a case study presented by an HMS bioethicist and neurosurgeon:

An adult patient with severe traumatic brain injury (sTBI) caused by a subdural hematoma showed cognitive-motor dissociation (CMD) on an fMRI, eliciting a guarded but positive prognosis from the surgeon. Post-rehabilitation, the patient exhibits the cognitive functionality of a child, which the family remains disappointed with.

The clinical case study introduced ethical questions regarding uses of neuroimaging to enhance prognostic capabilities, potential outcomes, and protection of patient



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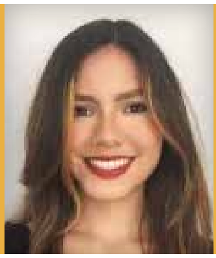

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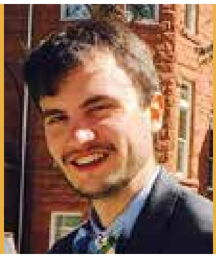

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neurorights. We discussed the meanings of "minimally acceptable outcomes" versus "favorable outcomes."[18] Because TBI recovery can take many years, transparent communication between surgeons, patients, and caregivers is necessary to evaluate how "minimally acceptable outcomes" change throughout recovery.[18] Further, we considered neuroimaging uses for more comprehensive prognostication of disorders of consciousness, and how access to such technologies supports accurate prognoses and timely decision-making.[19] The panelists characterized neurotechnology as a potential instrument of justice, and highlighted using fMRI as a communication tool among patients in minimally conscious states.[20,21] This productive session scratches the surface of expansive ethical considerations regarding patient-physician communication, technology access, and the protection of mental integrity with neurotechnologies.

## How Can Neurosurgeons Advance Neurotech Justice?

### In the Clinic

Research shows that neurotechnologies (e.g., EEG, fNIRS, cerebral oximetry) perpetuate phenotypic, racial, ethnic, and cultural biases, because they are not developed with diverse populations, limiting their usability and efficacy in marginalized groups.[22] Neurosurgeons must recognize these biases and restructure clinical trials to ensure developing neurotechnologies are widely applicable. Furthermore, neurosurgery teams must build trust with vulnerable patient populations to ensure every patient is respected and has agency to join fair clinical trials.

Neurosurgeons must acknowledge their underlying biases that could prevent prompt recommendations of potentially beneficial neurotechnological interventions to patients. Neurosurgeons often face difficult decisions in suboptimal conditions, e.g., urgency, emotional distress, and fatigue.[23] Time constraints and information gaps can cloud surgeons' ability to make comprehensive judgements about patient values and clinical circumstances to prevent patient harm.

To address these biases, surgeons need diverse and effective teams and should consider implementing innovative care delivery models to fill information gaps. Establishing a diverse work environment where everyone safely shares opinions about patient-care decisions ensures patients' needs are prioritized, and options are explored for the patient's benefit. Neurosurgeons should solicit team members' opinions, rectify non-inclusive team dynamics, and implement relevant aids (e.g. predictive analytics, surgical risk calculators,[24] ethics consultations, and relevant models of care delivery,[25–27] like integrated care pathways[28]) to make comprehensive decisions

### Communication

Neurosurgery teams face numerous barriers to effectively communicate with patients and caregivers and to understand patient values and outcomes.[29,30] Improving communication with patients/caregivers amidst complex and urgent circumstances requires teams to embrace radical transparency: prioritize sharing emerging patient information and ensure an understanding of all recommended treatment options. Additionally, language/cultural discordance and physicians' individual judgements prevent necessary discussions of diagnoses, prognosis, and treatment options in timely and culturally sensitive manners.[31] Neurosurgeons must be trained to engage with patients from different backgrounds and to integrate medical/cultural interpreters into patient-care.[32–34]

Neurosurgeons are situated to engage with insurance representatives, neurotechnology companies, and medical administration and should similarly lead with radical transparency during meetings. Discussion must be continually held regarding insurance barriers, device pricing, insurance reimbursement, and administrative workloads that prevent neurosurgery teams from providing quality care to all patients.[35–39]

Open conversation on neurotech justice should extend beyond academia to interpersonal engagement to understand the perspectives of patients, families, and communities on neurotechnologies. Recommended works for discussion include the memoir All That Moves Us by pediatric neurosurgeon Jay Wellons, MD, MSPH,[40] Healing by psychiatrist Thomas Insel, MD,[41] The Battle For Your Brain by legal ethicist Nita Farahany, JD, PhD,[42] and the mini-documentary centering patient experiences with implantable neurotechnology, Seizing Hope: High Tech Journeys in Pediatric Epilepsy.[43]

### Advocacy

Advocacy can begin with interdisciplinary discourse at professional gatherings and journals, like the Summit and this Congress Quarterly's theme. This may require collaborative large-group meetings, small-group negotiations, research to measure harms, and long-term efforts devoting funding, personnel, and time to rectify distribution and outcome disparities. Such clinical conversations and policy developments must involve patients and caregivers.

### Conclusion

Ensuring all patients can comfortably access necessary neurotechnological interventions pushes society towards achieving neurotech justice. These are long-term commitments to minimize biased development and distribution of neurotechnologies. Nevertheless, engaging now reduces the potential for future harm to patients and communities. ◂

### References

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