

# DISORDERS OF CONSCIOUSNESS, DISTRIBUTIVE EPISTEMIC JUSTICE, AND THE DUTIES OF PRIVILEGED EPISTEMIC AGENTS

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## MORE THAN DISTRIBUTIVE JUSTICE

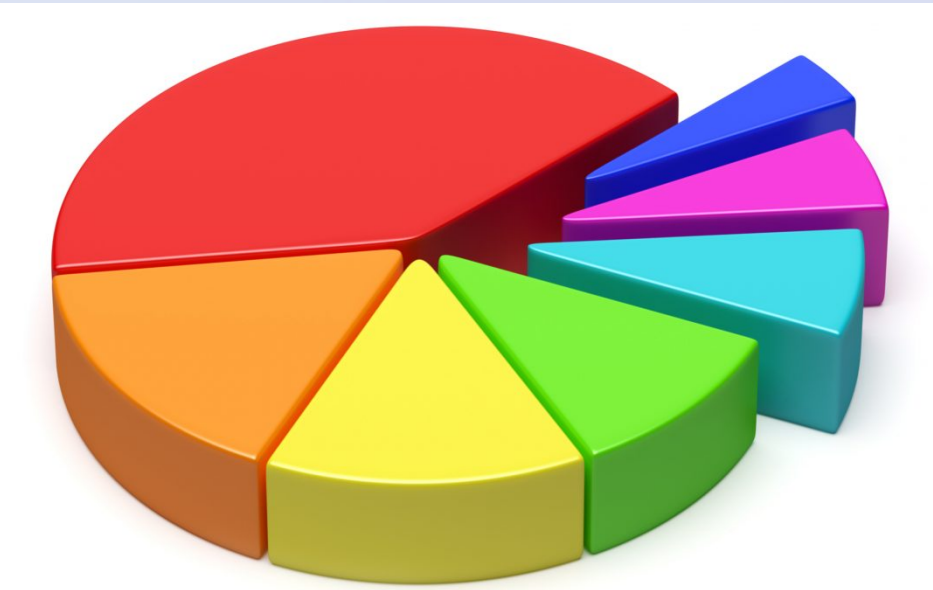
Justice as a bio/neuroethical principle is frequently and narrowly concerned with the allocation and use of limited medical resources. In the context of disorders of consciousness (DoCs), it is sometimes argued that it is unjust to use medical resources to keep DoC patients alive, and that healthcare monies ought to be used in a way that is more beneficial to society. Viewed more expansively, justice in healthcare demands that the **vulnerable and marginalized** not be targeted for rationing or cost-cutting,

not be excluded from the benefits of medical treatment, just because they are easy targets, voiceless, or without societal support, or because they are not valued. Using healthcare as a **distributive scalpel** to

excise the unwanted, the disordered, the different is incompatible with viewing healthcare as an instrument of justice, equity, freedom, opportunity, and right treatment [1].

## REIMAGINING DISTRIBUTIVE JUSTICE

Obligations of justice within healthcare require us to think about how healthcare can make society more just, more equitable, more fair, rather than how healthcare can be allocated (or denied) within already **unjust societal structures** [1].



## EPISTEMIC UNCERTAINTY IN DOCS

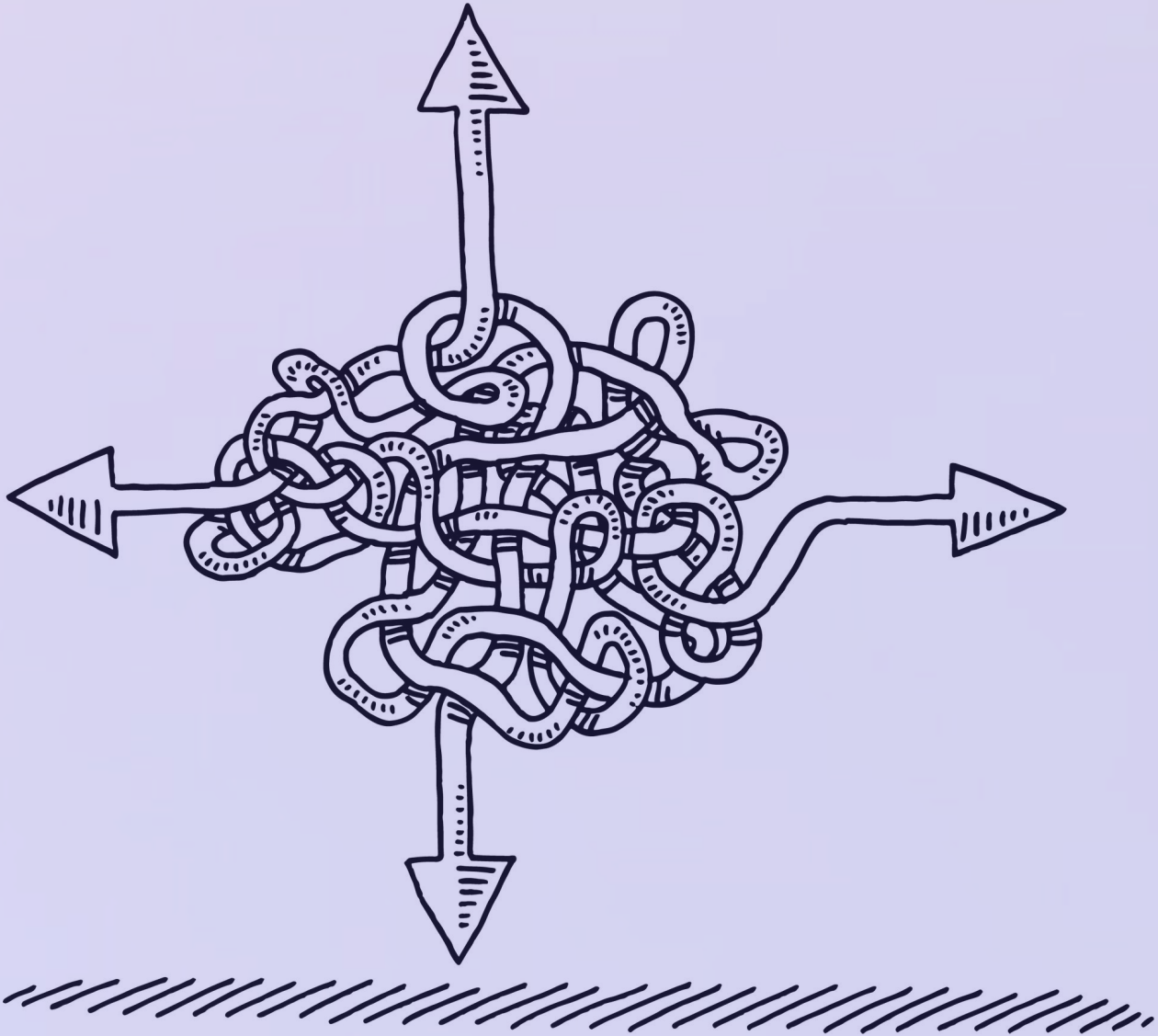
Surrogates for DoC patients face epistemic and ethical uncertainty due to the high rate of **misdiagnosis** in DoCs; about 40% of patients diagnosed as unconscious are conscious. Surrogates face uncertainty about prognosis for survival, recovery, disability, and patient experience. Surrogates are at an **epistemic disadvantage**, dependent on medical staff to provide, interpret, and contextualize complex clinical information in an accurate, trustworthy manner [2]. The epistemic asymmetry makes them vulnerable to **distributive epistemic injustice**, “the unfair distribution of epistemic goods such as education or information” [3].

## EPISTEMIC ASYMMETRY, EPISTEMIC DUTIES

Medical staff have access to epistemic resources that surrogates lack. In particular, they possess knowledge about the uncertainties concerning DoCs. Medical staff are **privileged epistemic agents** who have a duty to share knowledge of uncertainty as a matter of justice. Sharing epistemic resources contributes to shared epistemic goals in decision making for DoC patients. Withholding those resources impairs the surrogate’s ability to act as an epistemic agent, and is therefore distributive epistemic injustice.

## DUTY TO INFORM AS DISTRIBUTIVE EPISTEMIC JUSTICE

Medical staff are privileged epistemic agents who have a **duty to share** needed information as a matter of justice. As epistemic agents with access to **knowledge of uncertainty** regarding DoCs, medical staff have a **duty to inform** surrogates-as-epistemic-agents of that uncertainty. Their failure to do so maintains epistemic asymmetries and ignorance, and impedes disadvantaged epistemic agents as they try to make informed, ethical decisions that align with the patient’s wishes, values, and interests.



### References

- [1] Johnson LSM. The Ethics of Uncertainty: Entangled Ethical and Epistemic Risks in Disorders of Consciousness. New York: Oxford University Press, 2022.
- [2] Buchman DZ, Ho A and Goldberg DS. Investigating trust, expertise, and epistemic injustice in chronic pain. Journal of Bioethical Inquiry 2017; 14: 31-42
- [3] Fricker M. Epistemic justice as a condition of political freedom? Synthese 2013; 190: 1317-1332

DECLARATIONS: None