

Mosaic Decisionmaking and Severe Brain Injury: Adding Another Piece to the Argument

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Of Possibility and Faint Voices

Reading Andrew Peterson's critique of my proposal for mosaic decisionmaking following severe brain injury,^{1,2} I recalled a comment attributed to Nelson Mandela. Mandela observed that: *It always seems impossible until it is done.* Systematic oppression had always seemed a permanent fixture of South African life, impossible to remove. But after the banishment of apartheid, that impossibility joined the realm of the possible. Mandela, a witness and molder of history, reminded us that change is possible even when it first appears not. So when Peterson characterized mosaic decisionmaking as "untenable," I took solace from Mandela's observations. Over the arc of history, normative conventions, big and small, can be changed.

I have great respect for Professor Peterson and admit that he may be correct in his critique. Time will tell. But I would contend that he is viewing what I proposed through the shackles of history and a view of surrogate decisionmaking that was designed for a moment in time, and for a particular purpose. That moment was the rise of the right-to-die movement and that purpose was the ethical salience of a patient's previously expressed preferences when capacity was lost.^{3,4}

The question addressed in my paper is a different one: patients with severe

brain injury who were regaining their moral agency as they recovered but still had not reached the legal threshold of competence.^{5,6,7} I sought to argue that their reemergent agency was morally relevant and that their views need to be heard, albeit in a manner that would balance their wishes against their ability to express them, and have them prudently acted upon. It was a question of voice versus safety. To achieve that balance, I offered the model of mosaic decisionmaking, which while it requires the role of a surrogate decisionmaker, was not traditional surrogate decisionmaking.

It is important to not reify—or worse yet misunderstand or misrepresent—the bioethical constructs of the past especially as the emerging science of brain injury^{8,9} suggests that a simple dichotomization of either the patient or surrogate's voice would suffice to accommodate the needs of an emerging population that has a reemergent agency. The unique challenges of reemergent agency must be normatively accommodated. It can neither be adequately addressed by simplicity nor with timidity.

That there are practical and procedural questions, there is no doubt. Indeed, I devoted a whole "Caveats" section in my paper to their articulation. I explicitly state that, "As instrumental as this mosaic process of decisionmaking might be, I do not suggest it

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without reservations ... my appeal for a mosaic approach for decisionmaking is more a heuristic than a practice guideline."¹⁰ But that does not mean that procedural concerns or challenges invalidate the quest, or that as Peterson suggests that they make its achievement untenable. Instead my paper—and this exchange with a colleague—needs to be understood as a dialectical one. Professor Peterson's critique and my response is only valuable if it leads to further refinement of an argument made for patients whose time has come and whose voices must be heard, however faint and distant they may be.

Limits of Principlism

One of the limitations of Peterson's argument is that he casts his objections—under the guise of principlism. By formulaically invoking principlism, he loses nuance of description. For example he maintains that I am seeking to "balance the competing ethical principles of autonomy and beneficence in health care deliberations with brain-injured patients."¹¹ I did not cast the challenge that way. Autonomy and beneficence in this context are ill-fitting to the problem at hand. Instead of a deductive approach to moral reasoning, which lays at the heart of principlism, an inductive one is called for that pragmatically addresses particulars, as I have described previously.^{12,13,14,15}

For example, invoking the standard approach to decisionmaking, Peterson argues that "harmonizing the principle of autonomy and beneficence during consent is the assessment of a patient's decision-making capacity."¹⁶ He continues to present the conventional argument that if a patient has capacity, the patient's autonomy must be respected by the clinician. If not, there is a duty to protect the patient from harm.

This is indeed the standard view. But what of the situation when the patient does not have capacity, but still voices preferences? It was for this reason that I moved beyond the usual formulation of autonomy versus beneficence. As we all appreciate, autonomy means self-governance from the Greek *autos* (self) and *nomos* (law). Patients who are the object of the mosaic model I have proposed have a reemergent self that can not yet, and may never, self-govern. Indeed, if a patient had autonomy, there would be no need for either surrogate or mosaic decisionmaking. Instead, the operative question was one of reemergent agency, a complex concept that autonomy itself can not circumscribe. Similarly, the question was not one of achieving beneficence. Instead it was the prevention of harm by ascribing agency prematurely, or too fully, to individuals who could not adequately represent themselves.

I sought to overcome this binary approach by introducing the mosaic metaphor, with its many pieces. Peterson objects to its use, but the metaphor was motivated by a need to operate in the space between patient and surrogate where neither has dominion over decisionmaking. When there is reemerging agency, the clinical transaction can not be reduced to a simple dyad. Neither the doctor-patient, nor doctor-surrogate dyad contains the requisite elements for decisional authority. The point was to envision, and motivate a deliberative process, where benefits and burdens could be assessed by all the stakeholders in order to yield a consensus.

By proposing a mosaic, my goal was to depict the many elements that go into a decision. Like a discursive consensus,¹⁷ a mosaic is made of discrete stones that visually coalesce into a discernible pattern. When one of the stones is missing, it becomes clear that the image is incomplete, much like when

the absence of a stakeholder makes the achievement of consensus elusive.

Paternalism Paradox

Although the mosaic model fosters consensus, Peterson worries that it could instead lead to paternalism. As a remedy he paradoxically places his faith in the fiduciary relationship. He writes:

Clinicians, by virtue of their knowledge, expertise, and authority to prescribe, have power over sick and vulnerable patients. Patients therefore place their trust in clinicians to treat them competently. Violation of trust, whether through neglect, negligence, or infidelity, undermines the fiduciary relationship.¹⁸

While Peterson properly notes the “structural inequality” in the doctor patient relationship, it defies logic that he would seek its remedy in that very power asymmetry. Asking patients to trust physicians to “treat them competently” becomes problematic because it begs the question of what is meant by competence. Are we to understand it as narrowly defined clinical competence, or a willingness to hear the patient’s emerging voice? This is left undefined and underspecified.

To support his contention that mosaic decisionmaking could lead to paternalism, Peterson offers a hypothetical case. He asks us to imagine a patient recovering from brain injury who has hematuria and is being considered for a cystoscopy. The patient evinces an objection at some level of dissent, and not outright refusal as he lacks decisionmaking capacity. All the members of the mosaic think that cystoscopy is indicated and they collectively agree to proceed. Peterson believes this is a breach of the patient’s autonomy and “... a mosaic decision would be made in spite of the patient’s preferences, not in support of them.”¹⁹

In my view, he misses the point. A patient’s preference deserves deference but is not necessarily dispositive, especially if there is decisional incapacity and one’s expressed preferences are disproportionate. The purpose of the mosaic is not to achieve unfettered autonomy. Rather it is to improve the quality of decisionmaking, *mitigate* paternalism and prevent a rush to judgment. By opening up the conversation beyond the usual doctor-surrogate dyad, the mosaic helps to ensure that the patient’s emerging voice is heard, aided and abetted by the perspective of the advocate. In the cystoscopy example, the mosaic process might lead to a better appreciation of the patient’s past experiences and help ensure the provision of adequate analgesia and/or anxiolytic medication, to patients whose pain has been tragically unrecognized²⁰ and thus untreated.²¹ Absent mosaic deliberations, the neuro-palliative care obligation to provide requisite pain and symptom management might go unappreciated.^{22,23}

Literalism and the Law

Professor Peterson also asks whether a legal framework for mosaic decisionmaking is appropriate. Here, I fear he has taken what I have proposed too literally. My proposal is more a normative one than a purely legal one. To that end, the careful reader will observe that I have written about reemergent agency and not about the return of capacity or competence. This was intentional so as to avoid the strict dichotomization that the law requires. My purpose was to invoke agency to offer a normative frame that *did justice* to intermediate cases not easily categorized by the bright line distinctions of the law.

More to the point, both the New York State Commission on Quality of Care for the Mentally Ill²⁴ and the mosaic model are extra-judicial. The Commission

approach works *in lieu of guardianship* as a means to work toward a collaborative versus adversarial court-based proceeding. The goal is for an ensemble to collaborate—or co-labor together²⁵—in order to achieve a normative consensus. The same can be said for the mosaic model.

While I draw a parallel to the collaborative process of the New York State Commission, it is offered as a starting point, not an endpoint. There are obvious disanalogies between the Commission and the mosaic model, and Peterson is quite right to point them out. The Commission is used for decisionally-incapacitated patients who do not have surrogates. Patients in the mosaic are represented by surrogates. So why draw the parallel?

The response is that both the isolated incapacitated patient and those with reemergent agency share a similar vulnerability. Each is susceptible to representational risk. The former because there is no surrogate and the later paradoxically because there is one. Lacking a surrogate can make the unrepresented patient vulnerable to both over and under treatment, because consent can not be obtained. Patients with reemergent agency may be *overrepresented* by surrogates who operate in isolation without any deference to their preferences.

In both cases, group dynamics mitigate these risks by providing a balance of perspectives and expertise. For the patient without a surrogate, the Commission helps to provide timely care decisions and avoid idiosyncratic decisions by a guardian. For the patient with reemergent agency, the mosaic tempers the tendency to fall back into the familiar patterns of surrogate representation. This default occurs at the expense of the patient's reemergent voice and violates a tenet central to disability rights: *Nothing about us without us*.²⁶

Aesthetics and Consensus

Finally, Peterson invokes the neurobiology of visual processing to critique the metaphorical use of the mosaic. Speaking of the mosaic, we do not disagree that, "the individual color points or tiles are not the visual representation," and that "visual representation emerges from their collective color, shape, and organization." He is quite right that "...when presented with a mosaic our brains tend to blend the tiles into a unified image."²⁷ But that is a wonderful thing, and not a limitation.

The cortical and integrative visual processing which turns a collection of stones, or pixels as it were, into art is a marvel and no less remarkable than how a normative consensus emerges from the deliberative process which mosaic decisionmaking is meant to represent. The aesthetic value of a mosaic is far more than simply a collection of percepts but rather their integration. What the eye perceives and the mind understands is not the color of each stone or dab of the pointillist brush, but rather something deeper and richer. This integrative cognitive function seems the perfect metaphor to capture the synthesis that occurs as a group comes together to reach a consensus.

Beyond the constitution of its participants, the utility of a mosaic can also be seen in its ability to be dynamic. It can respond to different questions and to the evolving brain states characteristic of patients with disorders of consciousness.²⁸ Again, the metaphor serves us well. With individual stones that can refract light depending on angle and intensity, the mosaic can represent *different* decisions even as they involve the same individuals. In this way, the mosaic captures a richly multidimensional process and a dynamic response. To view these decisions otherwise is to abridge

the reemergent agency of those recovering from severe brain injury.

In his recent book, *Reductionism in Art and Brain Science*, Eric Kandel has eloquently written of how materiality becomes art.²⁹ The Nobel Laureate argues that reductionism can help us understand how artists create art, and how the brain perceives and processes it. Instead of viewing the science of vision and the aesthetics of the humanities as antithetical, Kandel is optimistic that we might have a convergence of what C.P. Snow famously described as the two cultures divide.^{30,31} Kandel writes:

Since 1959, when Snow first talked about the two cultures, we have found that science and art (including abstract art) can interact and enrich each other. Each brings its particular perspectives to bear on essential questions about the human condition, and each uses reductionism as a means of doing so. Moreover, the new science of mind seems on the verge of bringing about a dialogue between brain science and art that could open up new dimensions in intellectual and cultural history.³²

I would argue that this hoped-for convergence of neuroscience and humanities—into what Snow subsequently described as a *third culture*^{33,34}—might be embodied in the use of the mosaic metaphor to depict the ethics and science of reemergent agency following brain injury. By turning to art, and the beauty of the mosaic, we can envision the deliberative process that gives voice to agency, which is a product of neurobiological resilience.

Silent World Revisited

It is curious, and perhaps even comforting, that someone a couple of decades my junior would be the conservative

holding on to the norms of surrogate decisionmaking. Peterson's conservatism upends how disciplinary paradigms should shift, at least as Thomas Kuhn understood things.³⁵ In Kuhn's formulation, the next generation should be the innovators. Mine should hold on to the status quo. But the roles are reversed here, at least with respect to this modest proposal.

This is curious too, given the origins of bioethics, which was (and hopefully still is) an interdisciplinary project constructed to question traditional norms and hierarchies in medicine, to interrogate what Jay Katz famously described as the silent world that existed between doctors and patients.³⁶ Recently, Alan Weisbard, not coincidentally one of Katz's students at Yale Law School, posted an instructive comment on the Medical College of Wisconsin (MCW) bioethics blog—about the deliberations of the President's Commission whose *oeuvre* has been a foundational document for our conceptualization of surrogate decisionmaking, capacity, and competence.

Responding to a conversation about the scope of capacity determinations, Weisbard, who served as staff for the Commission reminds us that, "...the President's Commission argued for a variable, decision-specific notion of decision-making capacity, and against a unitary, global concept of capacity or competence, at least insofar as health care decisions are involved."³⁷ While admitting practical challenges reminiscent of those encountered in mosaic decisionmaking, Weisbard called for overcoming procedural barriers in lieu of compromising more fundamental concerns:

While recognizing the practical difficulties involved with this outlook, and the challenge of relating it to earlier binary legal standards of competence or incompetence, I

continue to adhere to the decision specific approach.³⁸

And then most importantly for our considerations here, Weisbard voices concern about how global assessments of capacity might obscure the interests of those with liminal capacities. He calls for a more nuanced approach that is more “capacious,” even at the risk of added complexity. Given Weisbard’s standing in our field, and his presence at the inception, I quote at length:

I am disappointed by the several recent comments that seem to adhere to a global conception of competence in relation to nursing and custodial care in institutional settings. Patients with much diminished cognitive capacity may still have an interest, arguably an autonomy interest although it is not only that, in being treated with respect and dignity in those settings. Our concepts should be sufficiently capacious, and sufficiently compassionate, to deal with that. We still have work to do.³⁹

Now as we begin to hear the faint voices of patients recovering from severe brain injury, we need to do this work. We need to be as attentive to their yearnings and as receptive to their legitimacy as Jay Katz was, decades ago, to the silent world he chronicled. His work, and others of the founding generation, were quietly revolutionary in attacking the status quo in the quest for justice.

We should be no less bold.

Notes

1. Fins JJ. Mosaic decisionmaking and reemergent agency following severe brain injury. *Cambridge Quarterly of Health Care Ethics* 2018;27(1):163–74.
2. Peterson A. A critical analysis of Fins’s mosaic decisionmaking. *Cambridge Quarterly of Healthcare Ethics* 28(4). <https://doi.org/10.1017/S0963180119000665>.
3. Jonsen AR. *The Birth of Bioethics*. New York: Oxford University Press; 1998.
4. Fins JJ. *A Palliative Ethic of Care: Clinical Wisdom at Life’s End*. Sudbury, MA: Jones and Bartlett; 2006.
5. Fins JJ. *Rights Come to Mind: Brain Injury, Ethics and the Struggle for Consciousness*. New York: Cambridge University Press; 2015.
6. Wright MS, Ulrich MR and Fins JJ. Participating in research while under guardianship? Implications of current law and policy for research on persons with brain injuries and disorders of consciousness. *Kennedy Institute of Ethics Journal* 2017;27(1):43–70.
7. Wright MS, Kraft C, Ulrich MR, Fins JJ. Capacity, competence, and the minimally conscious state: Lessons from a developmental model. *American Journal of Bioethics-Neuroscience* 2018;9:56–64.
8. Giacino JT, Fins JJ, Laureys S, Schiff ND. Disorders of consciousness after acquired brain injury: The state of the science. *Nature Reviews Neurology* 2014;10:99–114.
9. Giacino JT, Katz DI, Schiff ND, Whyte J, Ashman EJ, Ashwal S, Barbano R, Hammond FM, Laureys S, Ling GSF, Nakase-Richardson R, Seel RT, Yablon S, Getchius TSD, Gronseth GS, Armstrong MJ. Practice guideline update recommendations summary: Disorders of consciousness: Report of the Guideline Development, Dissemination, and Implementation Subcommittee of the American Academy of Neurology; the American Congress of Rehabilitation Medicine; and the National Institute on Disability, Independent Living, and Rehabilitation Research. *Neurology* 2018;91(10):450–60. Simultaneously published in: *Archives of Physical Medicine and Rehabilitation* 2018;99(9):1699–709.
10. See note 1, Fins 2018.
11. See note 2, Peterson 2019.
12. Miller FG, Fins JJ, Bacchetta MD. Clinical pragmatism: John Dewey and clinical ethics. *The Journal of Contemporary Health Law and Policy* 1996;13(27):27–51.
13. Fins JJ, Bacchetta MD, Miller FG. Clinical pragmatism: A method of moral problem solving. *Kennedy Institute of Ethics Journal* 1997;7(2):129–45.
14. Fins JJ. Clinical pragmatism and the care of brain injured patients: Towards a palliative neuroethics for disorders of consciousness. *Progress in Brain Research* 2005;150:565–82.
15. Fins JJ, Illes J. Pragmatic convergence and the epistemology of an adolescent neuroethics. Introduction to a collection entitled, *Competing Identities of Neuroethics*. *Cambridge Quarterly of Healthcare Ethics* 2018;27(4):554–7.

Responses and Dialogue

16. See note 2, Peterson 2019.
17. Moreno JD. *Deciding Together: Bioethics and Moral Consensus*. New York: Oxford University Press; 1995.
18. See note 2, Peterson 2019.
19. See note 2, Peterson 2019.
20. Chatelle C, Thibaut A, Whyte J, De Val MD, Laureys S, Schnakers C. Pain issues in disorders of consciousness. *Brain Injury* 2014;28(9):1202–8.
21. Fins JJ, Bernat JL. Ethical, palliative, and policy considerations in disorders of consciousness. *Neurology* 2018;91:471–5. Simultaneously published in: *Archives of Physical Medicine and Rehabilitation* 2018;99(9):1927–31.
22. Fins JJ. Neuroethics and disorders of consciousness: A pragmatic approach to neuro-palliative care. In, *The Neurology of Consciousness, Cognitive Neuroscience and Neuropathology*, 2nd ed. Laureys S, Osseries O, Tononi G, eds. Amsterdam: Elsevier; 2015, at 241–55.
23. Fins JJ, Pohl BR. Neuro-palliative care and disorders of consciousness. In, *Oxford Textbook of Palliative Medicine*, 5th ed. Hanks G, Cherny NI, Christakis NA, Fallon M, Kassa S, Portenoy RK, eds. Oxford: Oxford University Press; 2015, at 285–91.
24. New York State Justice Center for the Protection of People with Special Needs. Surrogate Decision-Making Committee Program: Volunteer Panel Member Handbook. Surrogate Decision-making Committee, January 2019; available at https://www.justicecenter.ny.gov/sites/default/files/documents/SDMC%20VPM%20Handbook%201.4.19_2.pdf (last accessed 14 May 2019).
25. Groopman L, Miller FG, Fins JJ. The Patient's Work. *Cambridge Quarterly of Healthcare Ethics* 2007;14:44–52.
26. Charlton JI. *Nothing About Us Without Us*. Berkeley: University of California Press; 2000.
27. See note 2, Peterson 2019.
28. Fins JJ, Schiff ND. Differences that make a difference in disorders of consciousness. *American Journal of Bioethics-Neuroethics* 2017;8(3):131–4.
29. Kandel E. *Reductionism in Art and Brain Science: Bridging the Two Cultures*. New York: Columbia University Press; 2016.
30. Snow CP. *The Two Cultures and The Scientific Revolution*. New York: Cambridge University Press; 1959.
31. Fins JJ, de Melo Martin I. C.P. Snow's Two Cultures fifty years later: An enduring problem with an elusive solution. *Technology in Society* 2010;32(1):1–4.
32. See note 29, Kandel 2016.
33. Snow CP. *The Two Cultures and a Second Look*. New York: Mentor; 1964.
34. Fins JJ. C.P. Snow at Wesleyan: Liberal learning and the origins of the "Third Culture." *Technology in Society* 2010;32(1):10–7.
35. Kuhn TS. *The Structure of Scientific Revolutions*, 2nd ed. Chicago: University of Chicago Press; 1970.
36. Katz J. *The Silent World of Doctor and Patient*. New York: The Free Press; 1984.
37. Weisbard AJ. MCW Bioethics Discussion Forum. 9/19/18. Quoted with permission of Professor Weisbard.
38. See note 37, Weisbard 2018.
39. See note 37, Weisbard 2018.