

Neuroimaging, impaired states of consciousness, and public outreach

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One of the greatest challenges in science and medicine is negotiating public responses to the dissemination of research results that have potential clinical implications. This challenge has been particularly acute for clinical researchers who are involved in the development of novel applications of functional brain imaging for the assessment of patients with disorders of consciousness.^{1–6} In our experience, scientific publication of experimental findings in this area is often followed closely by media inquiries regarding the clinical and societal relevance of the results reported and, shortly thereafter, by inquiries from patient caregivers and family members. While many areas of research are susceptible to similar public curiosity, neuroimaging procedures and disorders of consciousness have especially captured the imagination of the media and public alike.^{7,8} Subsequent to publication of newspaper and magazine articles—*What if There is Something Going on in There; Twilight Zone; Mental Activity Seen in a Brain Gravely Injured; For the First Time, Doctors Communicate with Patient in Persistent Vegetative State; and Silent Minds*^{9–13}—we received numerous inquiries at JFK Medical Center and Stanford University both from family members of patients in our institutions and from individuals in geographically remote regions. Some requests were made simply in order to acquire additional information, while others were pleas to obtain a brain scan that might enable a patient's level of consciousness to finally be discerned. Some requests followed accurate and well-balanced media reports; others followed reports with sensationalized findings and unrealistic appraisals of the diagnostic and prognostic capabilities of functional brain imaging.

Expressions of belief and hope that functional neuroimaging may provide signals about a patient's state of consciousness, offer prospects for recovery and assist with health-care decision-making are as profound as the accompanying ethical issues. Indeed, the complex problem of 'consciousness' after brain injury is unlikely to be resolved by neuroimaging studies

alone. Human consciousness encompasses unique capacities such as perception, subjectivity, sentience and self-awareness that exist within a distributed neural network of circuits including the posterior and anterior attentional brain networks,¹⁴ the ascending reticular formation¹⁵ and frontoparietal associative cortical systems.¹⁶ Detection of conscious awareness via functional neuroimaging is further complicated by procedural challenges. Functional activation studies with healthy control individuals that are designed to engage cognitive processes assume adequate comprehension of instructions, attentional focus and maintenance of mental set across tasks. In the population of people with brain injury, however, these prerequisite functions represent core deficits that interfere with task demands, changing both the manner in which tasks are performed and the neural structures activated during the task. The type of information that can be expected to be gleaned from functional neuroimaging studies, and the strength of the evidence acquired are, therefore, also contingent upon the paradigmatic features of study, such as choice of stimuli, modality of stimuli (e.g. aural, visual or haptic)¹⁷ and timing. The latest generation of studies provides more-convincing data than ever before on the temporal contiguity between task instructions, the onset of specific cognitive activities, and the activation of corresponding neural structures that are believed to mediate these activities, but the sources of variance attributable to patients and paradigms remain poorly understood.

The use of functional neuroimaging for the evaluation of consciousness is further complicated by the lack of data on the inter-rater reliability of neuroimaging findings. By contrast, standardized bedside examinations such as the Glasgow Coma Scale or JFK Coma Recovery Scale are available for the behavioral assessment of consciousness. For example, if two different examiners administer the JFK Coma Recovery Scale to the same patient in proximate time, one can expect, with a reasonable degree of confidence,

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that the findings will be similar across examiners; however, the same cannot be said of neuroimaging examinations. Neuroimaging centers have their own unique scanning paradigms and data analysis strategies. Published evidence of findings replicated between one center and another is not yet available and, even within centers, disagreement about the interpretation of a particular activation map is not uncommon. Given all these factors, multicenter studies that enroll substantial patient numbers and incorporate multimodal assessment (i.e. behavioral testing, electrophysiological studies, and structural and functional neuroimaging) are much needed to further evaluate the diagnostic usefulness of neuroimaging studies in this setting.

Until the clinical benefit of imaging in patients who are in a state of impaired consciousness is ultimately validated or refuted, what is a reasoned approach to the challenges of increasing public understanding? We believe that beyond providing cautious, well-informed answers to questions about emerging research—a task that clinicians are accustomed to handling in their practices—clinicians would benefit from the availability of outreach information, particularly on high-visibility and potentially high-impact studies, prepared by researchers themselves, that can be readily shared with patients and families. In response to this need for better dissemination of information, we have developed an information sheet of ‘Frequently Asked Questions’ (FAQ) that describes in simple language some of the basics of neuroimaging and the knowledge obtained from state-of-the-art functional neuroimaging of brain injury today (see Supplementary Material Online). The FAQ also addresses ethical issues surrounding neuroimaging research in this context; it includes a clear statement of the limited therapeutic and decision-making benefits of participation in research, and it provides guidance to surrogate decision makers in deciding whether to enroll a person in a neuroimaging study by prompting consideration of whether the patient might have autonomously enrolled in such a study under conditions of unimpaired capacity. The FAQ hand-out is one example of outreach that can directly bridge cutting-edge innovation, science journalism and expectations

by stakeholder communities and policy makers. When aligned closely with the fast pace of research common to neurological sciences and medicine that clinical practice has to keep up with, this type of outreach can be a vital first step in opening a dialogue that promotes understanding and trust.

Supplementary information in the form of a checklist is available on the *Nature Clinical Practice Neurology* website.

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