

Who Are You? Identity and Dementia

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Phineas Gage is arguably the most famous case study in the history of neuroscience. Gage was a railroad worker who in the autumn of 1848 was helping to prepare a new roadbed near Cavendish, Vermont, when an accidental explosion sent a three-foot tamping iron through his head. The missile entered the left side of his face, passed behind his left eye, and exited through the top of his skull. Gage, remarkably, lived to tell about the mishap.

But friends said he had changed—that he was “no longer Gage”—and this is what has intrigued psychological scientists. Formerly industrious and conscientious and amiable, he became irreverent and profane, incapable of returning to his former job. It appeared that the brain damage—primarily to his left frontal lobe—had dramatically altered his behavior and personality, the very essence of who he was.

Much is in dispute about the facts in the case of Phineas Gage, but what endures is scientific interest in the brain as the seat of identity. There is a widespread public perception that dementia can lead to a loss of a sense of self, but this notion has not been rigorously investigated—at least not from the perspective of close friends and family. One way to study this is to look at actual cases of brain degeneration, and see if the damage is linked to identity changes perceived by others. Do people with specific kinds of brain damage become no longer themselves, just as Gage became no longer Gage?

This is the basic question that Duke University psychological scientist Nina Strohminger has been exploring in her laboratory. She and philosopher Shaun Nichols of the University of Arizona wanted to see not only what brain damage does to others’ perceptions of identity, but also the role of memory and morality to an enduring sense of selfhood.

To do this, Strohminger and Nichols recruited patients with three kinds of brain damage—Alzheimer’s disease, frontotemporal dementia, or FTD, and amyotrophic lateral sclerosis, or ALS. FTD is the most common form of dementia after Alzheimer’s, and one in which prefrontal dysfunction leads to moral impairment—dishonesty, disregard for social norms, loss of empathy. ALS was included as a control condition, since its psychological effects are much milder than in the two forms of dementia.

The study was unique in focusing on family members’ perceptions of the patients. Most of the family members were spouses or partners of patients, while a smaller number were children, and all had frequent contact with the patients. These relatives filled out an online questionnaire about the patients’ symptoms, including various kinds of memory loss. They also answered questions about the patients’ personality traits and moral character—and changes in these measures since onset of disease—and about the quality of their relationship with the patient. Finally, they answered questions about their perceptions of patients’ identity: “Do you feel like you still know who the patient is?” “How much do you sense that the patient is still the same person underneath?” “Does the patient seem like a stranger to you?”

When they crunched all the data, the main finding was very clear: Identity disintegrates primarily when

the moral system is impaired. Indeed, the primacy of morality, as a determinant of identity, held true even when moral impairment was not the dominant feature of the disease. Other cognitive deficits—including amnesia—showed no measurable impact on the persistence of identity. These results, reported in a forthcoming issue of the journal *Psychological Science*, speak to longstanding philosophical questions about the nature of identity, suggesting that moral capacity is more important than memory or emotional make-up the preservation of selfhood.

The researchers' findings also show that relatives' perceptions of identity change—the sense that a dear one is disappearing, or gone—is the main cause of deteriorating family relations in cases of dementia. An estimated 36 million people are living with degenerative brain disease today, and the devastation of these diseases extends far beyond the patients themselves. Strohminger and Nichols envision future therapies that aim to preserve moral capacity—a largely unappreciated factor in patient and family well-being.

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