

ETHICAL PERSPECTIVES IN NEUROLOGY

Eran Klein

The practice of neurology presents a series of ethical challenges for the clinician. These rarely have simple or straightforward solutions, but require careful consideration by the neurologist. This section of *CONTINUUM* provides a case vignette that raises one or more ethical questions related to the subject area of this issue. The discussion that follows, written by colleague(s) with particular interest in bioethics, should help the reader understand and resolve the ethical dilemma.

NOTE: This is a hypothetical case.

A 56-year-old insurance salesman with a history of heavy alcohol use and liver failure is admitted to the hospital with altered mental status. According to his wife, the patient's comorbid conditions (alcoholic neuropathy, mild but progressive dementia, and TIAs) have disqualified him from the liver transplant list, and he has been in and out of hospitals for the past year with periodic worsening of his mental status. On this admission, the patient is visited by his estranged son who happens to relay to you his own recent history of stroke and memory difficulties and the attendant emotional and financial burden this has caused him given his lack of health insurance. During the patient's evaluation, an MRI of the brain is obtained and shows evidence of previous strokes in a pattern highly suggestive of cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy (CADASIL). Given the imaging findings and the patient's personal and family history of young-onset dementia and stroke, you suspect CADASIL and offer the patient's wife the option to test for the *NOTCH3* gene. The patient's wife refuses to consent for the test (and the patient, it appears, is unlikely to regain decision-making capacity). She cites the cost of the test (the patient and his wife are uninsured), her feeling that the result of the test will not affect the patient's quality of life or outcome, and her belief that the patient would not have wanted such information about him to be known. The patient's wife is unmoved by the potential benefit that this knowledge could have to her son and specifically instructs you not to discuss any details of the patient's condition, imaging, or history with him or other family members.

COMMENT

► The present and future of neurology is intertwined with the rapidly developing field of neuroimaging. Each new modality or refinement in technique brings promise of better

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diagnostic or prognostic power. Neuroimaging has the potential to fundamentally transform the practice of neurology. This has not been lost on those with an eye toward the social and ethical challenges that will accompany such a transformation. Neuroimaging has been a central focus of what some have called a new field of “neuroethics” (Illes, 2003). The expanding role of imaging in (and perhaps outside of) neurology raises old as well as new ethical challenges. The case above highlights some of the challenges that neuroimaging raises for neurology.

Progress in functional neuroimaging has accelerated in recent years, and in its wake the promise of illuminating largely hidden brain processes has not been undersold. PET, SPECT, and fMRI are now being used to investigate a wide spectrum of human behavior. Although largely confined to a research context, work in functional imaging has generated significant interest (and controversy). Can functional imaging be used as a sophisticated lie detector (Farah, 2002)? Are there imaging correlates to types of moral reasoning (Greene et al, 2001)? Prejudices (Phelps et al, 2000)? Personality traits (Canli, 2004)? Political preferences (Kaplan et al, 2007)? Conclusions drawn from this work, even if preliminary, have the potential to reshape how we view ourselves and our interactions with others in profound ways. It is no wonder that functional imaging has been a hotbed of interest. The ultimate role and importance of functional neuroimaging in patient care will not be known for some time. It would be surprising if functional imaging does not make its way increasingly into at least selected clinical areas (eg, diagnosing minimally conscious state, assessing depression and response to therapy, evaluating dementia variants) and, as it does, raise unique ethical concerns.

Advances in nonfunctional, structural neuroimaging technique and interpretation are more likely, at least in the near future, to generate the kind of ethical dilemmas that the neurologist faces. What should be done with incidental findings (eg, small caudate volume in a patient being evaluated for a condition unrelated to Huntington disease (Aylward et al, 2004)? What are the costs and benefits (to the patient or to society) of frequent, high-resolution imaging (eg, in patients after a first demyelinating event (Pestalozza et al, 2005)? When is taking time to obtain better imaging worth delaying emergent therapy (eg, in acute stroke (Fisher and Albers, 1999)? Advances in structural neuroimaging bring new or sharper focus to existing ethical concerns in neurologic practice. The clinical case above raises some of these concerns:

1. How does the increased role of neuroimaging affect the patient-clinician relationship in neurology?
2. Does imaging challenge the current practice of surrogate decision making?
3. How does neuroimaging fit into the neurologist’s commitment to confidentiality?

CLINICIAN-PATIENT RELATIONSHIP

► The doctor-patient relationship (or more broadly, the patient-clinician relationship) is central to the practice of neurology (Zaner, 1988). The relationship defines the respective roles of the neurologist and the patient and gives a structure and a sense of purpose to everyday activities. In an era in which neuroimaging has taken on greater and greater importance, there might be a tendency to downplay the role of this relationship in neurology. The imaging “tells” the diagnosis; it “shows” that the therapy is not working; it “gives” the answer. The neurologist might seem merely to be a conduit for information in this regard. The case above highlights why this cannot be the case, why the rise of neuroimaging, if anything, makes the doctor-patient relationship even *more* important. The neurologist serves a role as an interpreter of the *meaning* of

neuroimaging. A number of different models or metaphors inform the doctor-patient relationship (Childress and Siegler, 1984). The relationship has been analogized to that of relationships between parent and child, equal partners, rational contractors, friends, or technician and client. All of these relationships have some affinity to the relationship between doctor and patient—and have through history held more or less sway—but none of them fully captures the inherently moral character of the relationship. The word *patient* comes from the middle English word *pacyent*, which means “one who suffers”; and the word *physician*, which derives from the Latin *physic*, means to practice the “art of healing” (Oxford English Dictionary, 1933). There is something unique about the fact of illness and the call for help that grounds a set of duties and responsibilities not captured by analogy to everyday relationships (Pellegrino and Thomasma, 1981). Recognition of the moral structure of the relationship helps us make sense of why the neurologist who comes to care for a patient for the first time, as in the case above, already is bound by a set of deep moral commitments to the patient’s best interest.

The ethics of the doctor-patient relationship have not historically been a primary focus of the specialty of neuroradiology, but this may be changing as the field changes. Traditionally, ethical concerns in radiology and neuroradiology have centered on areas that bear only indirectly on the primary doctor-patient relationship—reporting questionable behavior of referring physicians or fellow radiologists, not prematurely communicating results to patients, disclosing and avoiding financial conflicts of interest (Armstrong, 1999). In important ways, the field of neuroradiology is moving toward more patient interaction and hence a need for a more robust understanding of the doctor-patient relationship. Interventional radiologists and neurologists trained in radiology have significant contact with patients, as do those who subspecialize in radiology fields with whom neurologists closely interact, such as radiation oncology and nuclear medicine.

SURROGACY

▶ Neurologists often have to work with surrogates when patients are temporarily or permanently unable to participate in medical decision making. In practice, routine medical decision making typically falls to the family member who is most involved with the patient (eg, a son taking care of a mother with Alzheimer disease or sister taking care of a brother with advanced multiple sclerosis). When disagreements arise (for instance, between family members or between a surrogate and the treating physician) or when decisions of greater magnitude need to be made (eg, do-not-resuscitate orders), more formal surrogacy is established. Surrogates can be designated by the patient in an advanced directive. Or a surrogate can be established by a court, either on an *ad hoc* individual basis or through a formal line of succession (eg, spouse, parents, adult children, and so on) (Trial, 2007). It is important to note, however, that even a court-sanctioned surrogate can be challenged if a decision being made for a patient appears not to be in that patient’s best interest. While the wife’s decision to decline genetic testing may nor may not be an admirable one, there is little indication that it is contrary to the patient’s own medical (or other) interests. The wife’s preference not to have the patient’s medical condition and test results shared with others, including her son, should be respected.

Several models exist as guides for surrogate decision making (Beauchamp and Childress, 2001). The “instructive” model of informed consent encourages surrogates to use the patient’s own past spoken or written words as a guide. If the patient once made

comments about not wanting to have artificial nutrition, this could inform a refusal of a feeding tube (eg, Cruzan (497 U.S. 261 [1990])). Unfortunately, past preferences are rarely of a sort to clearly guide surrogates in complex decisions. The “best interest” model is an alternative that directs surrogates to make decisions that would be in the best interest of the average person were he or she to be in the patient’s particular situation. This model, while providing welcome flexibility to the surrogate, raises serious questions about the meaningfulness of the “average person” or there being a single “best interest.” A third model is that of “substituted judgment.” In a model of substituted judgment, the surrogate is asked to step into the history and value system of the patient and best approximate the decision the patient would make. While surrogates can have difficulty keeping the values of the patient and their own values separate, this is probably the model that best keeps faith with the patient as a distinct, once-autonomous individual, and appears to be the one appropriately used in the case above.

CONFIDENTIALITY

- ▶ Confidentiality is central to the integrity of the clinician-patient relationship. As far back as Hippocrates, confidentiality was recognized as necessary for providing a sphere in which patients can safely share information, often of a most intimate sort, without fear of misuse or dissemination (Temkin and Temkin, 1967). The earnest belief on the part of both patient and clinician that shared information will only be used for the patient’s benefit is an inimitable part of this fiduciary relationship.

The physician has a *prima facie* obligation to confidentiality, but this can at times be trumped by overriding concerns. The most obvious of these exceptions is when public health and confidentiality conflict, as can sometimes be the case with mandatory reporting of certain communicable infectious diseases (eg, HIV, syphilis, botulism, West Nile). Reporting of genetic information can also override confidentiality (eg, neonatal testing for sickle cell disease or phenylketonuria). In neurology, the need to break confidentiality arises with respect to reporting conditions (eg, epilepsy, advanced dementia) that impair automobile driving (Bacon et al, 2007).

The subject of confidentiality has not traditionally been a major area of concern within neuroimaging, but this may be changing. In the research arena, this question has arisen with respect to incidental findings (Illes et al, 2006). When a subject “shares” her brain imaging with researchers and they note an unexpected and potentially dangerous finding, are there obligations of confidentiality (eg, with respect to family? insurance? employers?)? Worries about imaging and confidentiality creep into clinical practice as well. Imaging provides diagnostic and prognostic information that many people besides the patient may find valuable (as in the case above). Imaging “findings” should be treated like other medical information and be kept in trust between the ordering physician (and, by extension, the interpreting physician) and the patient or the patient’s surrogate. Although others (eg, family) might significantly benefit from this information, and may even make a claim to it, this claim almost never outweighs the clinician’s fiduciary obligation to the patient or surrogate.

CONCLUSION

- ▶ Neuroimaging brings into sharper focus many of the ethical challenges faced in neurologic practice. The use of imaging demands strict safeguards for privacy and confidentiality. The more that medical decision making relies on imaging, the more it

must fall in line with established standards for surrogacy and capacity. The role of the neurologist with respect to neuroimaging is to be more than just someone who orders and relays information. Imaging carries meaning, and it is the role of the neurologist within the clinician-patient relationship to help the patient interpret this meaning and to fit it into the patient's overall goals of care.

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