

Virtual Mentor

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CLINICAL CASE

Decision Making in a Case of Personality Change

Commentary by Kristi L. Kirschner, MD

As a second-year neurology resident, Dr. Johnson has been fascinated by the case of Mr. Thompson, a construction worker who was nailing shingles to a roof when his co-worker's gun slipped, lodging a nail deep into Mr. Thompson's frontal lobe. Although comatose at first, Mr. Thompson regained consciousness and function under Dr. Johnson's care.

Despite his physical improvements after this accident, everyone in Mr. Thompson's life agreed that he was "not himself." Previously a gregarious, sunny man, according to his family and friends, "the kind of guy who always had a good word for everyone," "a joker," he had now become surly, withdrawn, and disinhibited. Before the accident Mr. Thompson loved having his friends and family around; now he threw everyone out of the room at the slightest provocation, all the while cursing and screaming. Happily married to his wife for 27 years, Mr. Thompson had three children and no prior history of medical or psychiatric disorders. After his accident, however, he disparaged and insulted his wife when she visited and refused to see his children. He had a living will in the chart in which his wife was named as his health care proxy. During his recovery from the accident she had made decisions for him.

When Mr. Thompson had made good progress in his physical recovery, the neurosurgery team brought up the topic of removing the nail lodged in his skull, presenting the risks and benefits of the surgery to Mrs. Thompson. Even though the operation would be tricky, the surgeons firmly believed that the benefits outweighed the risks. Mrs. Thompson opposed the surgery, but Mr. Thompson was adamant about going ahead with it.

Dr. Johnson was called to Mr. Thompson's room. The nursing staff reported that he was particularly agitated after a visit from his wife, during which they had discussed the possibility of surgery. "I'm tired of my family telling me what to do, those jerks," Mr. Thompson grouched. "I don't know why I married Laverne in the first place, and I don't even think the kids are mine. I want to change that living will and get her off of there. Nobody makes decisions for me but me."

Dutifully, Dr. Johnson assessed his patient's capacity. Mr. Thompson was alert and oriented to person, place, and time; he passed the cognitive exam with flying colors. He verbalized understanding of his situation, stated clearly his treatment options and the risks and benefits of his surgery. He appeared to meet all the clinical benchmarks

for decision-making capacity, and he was adamant that he no longer wished for his wife to be his health care proxy.

Dr. Johnson asked his team what they thought. The junior resident said, “the guy has a traumatic brain injury. He’s literally not himself—he’s a different person. He’s impaired. That’s the bottom line.”

“I disagree,” the senior resident said. “He’s clearly oriented and capable of abstract reasoning. Personality changes don’t mean you can trample on his autonomy.”

Commentary

Mr. Thompson reminds me of a famous patient, Phineas Gage. Mr. Gage was a railroad foreman who suffered a devastating injury in 1848 when a tamping iron shot through his left cheek, traversed the frontal lobes of his brain and exited through the top of his skull [1]. His notoriety stemmed not only from his survival in the pre-antibiotic era, but from observations of the dramatic sequelae of the injury. Though initially perceived to be remarkably intact neurologically, this previously respected and successful man experienced a sad denouement in the years that followed. In short, Mr. Gage became a living laboratory for the study of the brain (specifically the frontal lobes) and behavior.

Like Mr. Thompson, Mr. Gage retained the ability to walk, talk, see, hear, remember, and express wishes and preferences. What he lost, though, were the very qualities of behavior, e.g., many of his personality “traits”—his comportment, his judgment—by which people had identified him as Mr. Gage. Prior to the accident he was described by others as having a “well-balanced mind;” he was “shrewd,” a “smart business man,” and “persistent in executing all his plans of action” [2]. After the injury, Mr. Gage was unable to maintain steady employment, his language became profane and his behavior erratic, with one observer writing that he was “at times capricious and vacillating, devising many plans of future operation, which are no sooner arranged than they are abandoned” [2].

Frontal lobe injuries such as the kind sustained by Mr. Thompson and Phineas Gage both frustrate and fascinate not only physicians but also the individual’s intimates and acquaintances. Despite great strides in understanding the neurobiology of the brain and how it affects behavior through the pioneering work of behavioral neurologists such as Norman Geschwind, Antonio Damasio, and Marsel Mesulam [3], the diagnosis and appreciation of the full consequence of frontal lobe injuries often remains elusive, particularly in the immediate aftermath of injury. Bedside neurological examinations and even routine neuropsychological tests such as intellectual quotients and memory tests, can appear surprisingly normal, yet patients like Mr. Thompson and Mr. Gage often experience devastating downturns in their social functioning and personal fortunes.

Friends and families describe such persons as “not themselves” (as happened in both our examples) after such injuries. Research on frontal lobe injuries by Antonio

Damasio and his colleagues has demonstrated that subtle but devastating deficits in social awareness and affective valence can disrupt judgment, reasoning, and ultimately the ability to make wise choices and exercise adaptive judgments [4]. Unfortunately such deficits may only become apparent when the patient's behavior is observed in actual, rather than imagined or laboratory, situations.

Mr. Thompson's Decision-Making Capacity

With this background in mind, how then should the health care team consider Mr. Thompson? Is he now somehow a different "person"? His current conduct reflects impulsivity, thought disorder, and inappropriate social choices, as demonstrated by his wish no longer to see his children whose parentage he now questions, his disparaging comments regarding his wife, and his lack of inhibition. Whether we consider him a "different person" or not depends on the definition we choose when we discuss "person." The definition of personhood as used by the junior resident (and the one often chosen by the lay public) is more akin to the concept of personality—"the unique self; the organized system of attitudes and behavioral predispositions by which one feels, thinks, acts, and impresses and establishes relationships with others" [5]—than to legal, philosophical, or theological definitions of personhood. Indeed, an individual's *social*, or relational, identity arguably hinges more on personality than on physical appearance or even intellectual capacities.

Unfortunately, discussing personhood without establishing and defining the framework—social, legal, philosophical, spiritual, etc.—for the discussion can be frustrating, as demonstrated by the experience of Mr. Thompson's health care team. A vitalist, for example, might argue for a human species definition of personhood (i.e., simply being alive and human means one is a person), whereas others such as John Locke, Immanuel Kant, or Peter Singer might argue that personhood requires self-consciousness, rationality, and a sense of the future [6]. Mr. Thompson is clearly sentient (not comatose or vegetative), a unique human being, with one-of-a-kind DNA and a personal history. He also has some marked emotional, cognitive, and behavioral changes. The question now is how to put all of this information together in understanding Mr. Thompson's capacity to make decisions. To answer this question we need to use information from the above narrative, our tools for assessing decision-making capacity (DMC), and our knowledge of Mr. Thompson's brain injury.

Grisso and Applebaum have written extensively about the criteria for assessing DMC and suggest that a patient must be able to: (1) communicate a choice, (2) understand relevant information, (3) appreciate the situation and its consequences, and (4) rationally manipulate information [7, 8]. When assessing decision-making capacity it is important to remember that it is situation-specific, and the assessment must evaluate the congruence, or the "match or mismatch between the patient's abilities and the decision-making demands of the situation the patient faces" [9]. The more significant the consequences of a decision, the greater the evidence of DMC required. It is the process of evaluating DMC that is critical [10].

So what do we know about the assessment of Mr. Thompson's DMC? We are told he is alert and oriented to person, place, and time and easily passes the cognitive exam. Though this is helpful information, it provides only limited support for criterion 3—i.e., that he has some appreciation of his situation and knows that he is in the hospital [9]. Further, we are told that he can verbalize his situation and the options presented to him including the risks and benefits of the various choices—very important information for assessing criteria 2 and 3. Mr. Thompson is also expressing a preference to go ahead with surgery and to “fire” his wife as his proxy—demonstrating his ability to communicate choices (criterion 1). But is this enough to say he has met all the clinical benchmarks for DMC? I think not. We have at best a superficial, and *verbally mediated*, understanding of his decision-making capacity with strong evidence that his abilities to manipulate information rationally and anticipate consequences are impaired—skills that are critical components of DMC.

Assuming that the information we have about his prior relationships is accurate (and I would look for independent confirmation of this information), his paranoia and beliefs concerning his wife and children are grossly irrational (apropos criterion 4) and incongruent with his history and relationships prior to the brain injury. I also question how much insight he has into his condition. Does he have awareness of the dramatic changes in his personality and behavior, and does he seem to feel appropriately distressed by them? His sexual disinhibition also argues against self-awareness.

Based upon the above analysis, I conclude that Mr. Thompson currently does not have the capacity to make a decision regarding surgery. I believe the critical skills required to weigh decisions of such consequence, to manipulate information rationally, and to choose wisely are the skills most impaired by Mr. Thompson's frontal lobe injury. Efforts should therefore be directed to mitigate the permanency of his brain injury and to maximize his recovery. If there is a chance that removing the nail could help Mr. Thompson recover his decisional abilities and prevent further deterioration (from a complication such as an abscess), then this decision has great future consequence. Indeed, his long term well-being and future autonomy are at stake. At least for the time being, Mr. Thompson needs the protection of a surrogate to help make decisions of major importance. We also must recognize the limitations of this evaluation. This is neither a global nor definitive determination, and frequent reassessments will be needed as Mr. Thompson's condition changes and evolves. Rather, this is only a recommendation for the specific question at hand.

Whether his wife should continue in the role as his proxy, though, is a separate question. For this particular decision an argument could be made to partially honor Mr. Thompson's wishes. Given the conflict that now exists between Mr. Thompson and his wife, a guardian ad litem would be a reasonable alternate decision maker and could serve as a neutral third party to weigh information (from Mr. Thompson, the health care team, and family) and facilitate a decision about surgery. In general, although one must be competent to execute an advance directive, there is a bias in

favor of allowing a person to negate such a document in the future—whether or not he or she is fully competent [11].

The interesting twist here, and one we don't have adequate time or space to address, is Mr. Thompson's preference for surgery (the decision recommended by the neurosurgeons) and his wife's refusal. Though it's tempting to say that Mr. Thompson has DMC because he is making the decision recommended by his health care team (i.e., if he agrees with us we are less likely to question his capacity), it is the soundness of his process of deciding that is important. I believe, as described earlier, that Mr. Thompson's process is flawed and that he does not have DMC.

The wife's decision to refuse surgery because she believes it is "too risky" also raises questions. Surrogates are instructed to make decisions either by using substituted judgment (in which they make the decision they believe the patient would make for him- or herself based upon the patient's prior statements or expressed wishes), or, in the absence of such information, by basing the decision upon the subject's best interests, weighing the expected benefits and burdens of the treatment. Recognizing that we have limited information to understand Mrs. Thompson's rationale, I am hard pressed to understand how her decision meets either criterion. At a minimum, further discussion with Mrs. Thompson is warranted.

In summary, I believe Mr. Thompson has had a brain injury which affects not only his personality but also his insight and reasoning abilities. I do not think he has adequate DMC to make a decision regarding surgery, and the protection of a surrogate is required. I would also emphasize that this determination is for this point in time only, and for this particular decision. His DMC will need to be reevaluated as his condition changes and as new treatment questions arise. Given the current conflict with his wife and the complexities of the situation, I would consider bringing in a guardian ad litem to assist with the decision-making process.

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