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## *At the Bedside*

# Slowing Down Fast Thinking to Enhance Understanding

*Edmund G. Howe*

### ABSTRACT

Stress can make the comprehension of complex information more difficult, yet patients and their family members often must receive, process, and make decisions based on new, complex information presented in unfamiliar and stressful clinical environments such as the intensive care unit. Families may be asked to make decisions regarding the donation of organs and genetic tissue soon after the death of a loved one, based on new, complex information, under tight time limits. How can we assist patients and families to better process complex information while under stress, and make better decisions for themselves or a loved one?

In this issue of *The Journal of Clinical Ethics*, in "Impact of Cognitive Load on Family Decision Makers' Recall and Understanding of Genotype-Tissue Expression (GTEx) Project Donation Requests," Laura A. Siminoff, Heather M. Traino, Maghboeba Mosavel, Howard M. Nathan, Richard D. Hasz, Jennifer Trgina, K. Laura Barker, Maureen Wilson Genderson, and Gary Walters discuss how clinicians can help patients and families better understand requests for donations of genetic tissue. The authors

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recommend strategies to help clinicians and researchers provide complex information to any person who is under stress, as, for example, patients and family members who struggle to make decisions in an intensive care unit (ICU).<sup>1</sup>

But even when information is shared in the best possible way, patients, families, and most anyone who is in a stressful situation may not understand as well as they might when they are calmer. Emotions such as fear can decrease our capacity to think carefully. Due to fear or another strong emotion, we may have a fight-or-flight-like response or feel emotionally paralyzed on receiving new information. Other emotions such as hate and even love may also cloud our capacity to accurately understand. When we hate, we may automatically and immediately dismiss what another says, and, when we love, see all that our loved one says as rose-colored. Our emotional responses may be all-important and adaptive. But when we must think more carefully, the intuitive, automatic, and unreasoned responses that feelings can engender may "hijack" our capacity to reflect more deeply. Thus, when this occurs, it may leave us wholly dependent on what our feelings "tell us." Daniel Kahneman describes this hijacking in detail in his recent book on what he calls "fast and slow thinking." Our faster, intuitive thinking system is, he says, more influential than our slower reasoning. This faster system he says, is not readily educable.<sup>2</sup> Thus, this may be a *second* obstacle to patients' and family members' understanding.

Therefore, in this article, I will discuss several ways that we can help to reduce patients' and fam-

ily members' fast thinking, so that they can make decisions that better reflect their genuine needs, over the long run.<sup>3</sup> I will do this in three sections. In the first, I discuss fast and slow thinking more generally. A critically important aspect of the concept is that when we engage in fast thinking, we may not know that we seem to be locked into that state. As Kahneman says, we may search for plausible reasons for what we feel, and then believe the stories we may "make up" as a result.<sup>4</sup> But immediate intuitions may seem miraculous and even lifesaving, for example, a fireman who senses hidden, imminent danger and saves himself and his crew, or a physician who makes a complex diagnosis after a glance at a patient. Kahneman points out that these seemingly magical insights may be nothing more than subtle cues that trigger associated memories.

When intuition or fast thinking determines our response without our knowing it, it can leave us exceptionally vulnerable to making suboptimal decisions without realizing it. We may later deeply regret what we decided. In this first section I will give three case examples in which patients who knew about fast thinking became less vulnerable to such hijacking. The cases illustrate the risks of fast thinking and the possible gains of alerting patients and family members to this concept before we discuss with them the treatment choices they have to make.

In the second section, I will discuss how we may be able to assist patients and families when they confront ethical decisions involving genetics. Our capacity to see patients' fast thinking may itself be impaired by our own fast thinking. The two issues I will principally address are how we might help patients decide whether they want to be screened for genetic disease, and whether they want to give information about their genes to biologically related relatives who could benefit from it. I will address some policy questions that involve genetics, parents, and children to illustrate how fast thinking may influence determinations of policy.

In the third section I will consider several ways that we can help reduce families' fast thinking in the ICU, so they can better understand new information when we use the approaches Siminoff and colleagues recommend. The ICU is one of the more stressful settings these authors mention. If we can help to reduce family members' fast thinking in this setting, they should do better and may make better ethical decisions regarding their loved one.

It may seem, from this description of what I will address, that I am downplaying the importance of what patients *feel* and the importance of the fast thinking that their emotions may evoke. Emotions may be critically important in helping patients to

discern what they need and want, and their emotions may do this by helping them narrow and frame their options. Then, using slow thinking—our reasoning—we may attend to what our patients have discerned. Fast thinking may be markedly adaptive and further better solutions in countless situations.

### FAST AND SLOW THINKING

Fast thinking is likely to occur immediately in response to a stressful event, although it may provide immediate insights, as exemplified by the example of the physician who saw at once a patient's complex diagnosis. But when fast thinking is emotionally driven, fast thoughts may replace logic. Fast thinking and logic may become mutually exclusive thought processes, and may function as parallel lines or brain circuits that never meet. Decisions we make when we are affected by fast thinking, in response to a stressful situation, may, though, *feel* right. As Kahneman writes (citing the psychologist Jonathan Haidt): "The emotional tail wags the rational dog."<sup>5</sup> This suggests that what patients and family members *do* may not be at all what they really most *want*. What they want may lie outside their awareness and not be able to be known to them. What their feelings suggest may be tragically misleading, and they may come to bitterly regret their choice. As Quist wrote, "individual defense mechanisms and habits of thought" may be ". . . least accessible to introspection or self-reflection as participants struggle to keep the external world consistent with their internal world. . . ." People "get themselves wrong, what they want and lack . . . we *all* get it wrong."<sup>6</sup>

#### Triggers of Fast Thinking: Cues and Risks

An important aspect of fast thinking is how it may occur in response to a visual cue. For example, if we see something we find shocking, that strong emotion may create a memory that *stays with us*. That it may stay with us has enormous implications, because a visual event may greatly skew what we decide in the moment, and it may continue to determine what we decide over time—and perhaps for the rest of our life. An example of such a visual cue is when a surgeon deliberately set out to shock a parent to save a child's life. The boy's leg had become terribly infected, and he would die unless it was amputated. The boy's mother, however, refused to consent. The surgeon took her to the boy's bedside, removed his bandages, and showed her the open wound. After he did this, the mother consented, and her son survived. This is not to recommend that clinicians do this routinely; instead I mean it to show how visual cues may trigger fast

thinking and how powerful that can be, even overthrowing strongly held prior concerns, as in this case. There are many cues that can trigger fast thinking; visual cues are only one.<sup>7</sup>

Our visual system may, however, “trick us,” as when we are duped by a visual illusion. Kahneman refers to this phenomenon metaphorically when he posits how we might best respond to such treachery, using a well-known Müller-Lyer visual illusion as an example. Viewers of the illusion are asked to mark the middle of a horizontal arrow on a page, but invariably draw a mark toward closer to the arrow’s tail. Kahneman suggests that we should not trust our impression of the arrow’s length in this exercise, and we should do likewise when we encounter possible products of our own fast thinking.

A cue that triggers fast thinking may be, for example, no more than the memory of what a loved one said about an illness and treatment she or he had. Or it may be no more than a report by a stranger on the internet. As Kahneman notes, we may feel optimistic, but not know why, because something reminds us of a beloved sister, or we may dislike a person because he or she looks vaguely like our dentist.<sup>8</sup> We may have no idea why we want what we want. Visual cues trigger fast thinking, but the cue that is most likely to negatively affect us is an exaggerated fear of, and thus reluctance to take, actions with possibly adverse results. This fear is common. As Kahneman puts it, “if a potential outcome is framed as a *loss*, it may have more impact than if it is presented as a gain.”<sup>9</sup>

How an exaggerated aversion to risk may begin is illustrated by an example using percentages of gain and loss. For instance, if a procedure to treat back pain is presented as having a 50 percent chance of success, we are more likely to agree to it than if it is presented as having a 50 percent chance of failure. An orthopedic surgeon recently suggested that all clinicians who perform the same procedure should use the same words when they inform patients about it, and convey potential gains and losses as percentages. This would reduce, he proposes, the risk of triggering the above, irrational result.<sup>10</sup> Doing this may well help reduce patients’ confusion regarding relative and absolute risks. In the next section I will present three clinical examples that illustrate another way we may be able to help reduce this possible source of irrational thinking for patients. The approach can have surprisingly rapid results.

### Clinical Examples

We can inform patients about fast and slow thinking and that fast thinking may adversely affect them, as it does to everyone. With this knowledge,

they may be better able to decide what they want for themselves. The following two examples involve patients I have seen. I will refer to them by well-known characters in our Western culture. This may help readers capture and remember them.

*King Lear.* The first patient I will refer to as King Lear. Lear is the main character in the Shakespearean play of the same name. He had two daughters whom he believed had greatly wronged him. The patient I saw felt greatly wronged by his daughter. For this reason, he thought that he possibly or probably wanted to disinherit her. Yet he also felt ambivalence. “After all,” he said, “she *is* my daughter.” He felt miserable and, in his own words, “*stuck*.” I explained to him about fast and slow thinking, and I suggested that, based on what he’d said, it might be that he was stuck between fast and slow thinking. His daughter’s wrongdoing may have triggered his anger, and the resulting fast thinking—although it was triggered decades earlier—may have remained; whereas his *not* wanting to disinherit his daughter might represent his present slow thinking.

My interest, I said, was not to influence him to decide one way or the other, but solely to try to help him free himself from the painful ambivalence in which he reported himself stuck. I hoped, I said, that this new knowledge of fast and slow thinking might help him better decide what he now really most wanted. It seems this is what then occurred: he suddenly, he said, *knew* what he wanted. He wanted to include his daughter in his will, although she had wronged him decades before. She was, he said, after all, his only child, his only daughter.

*The Prodigal Son.* A second example also involves a father. He had given his son an inheritance early. I will refer to the son as the Prodigal Son, since, like the character in the Bible, he had squandered the wealth that his father gave him, and then returned feeling great remorse.<sup>11</sup> Like the patient I called King Lear, this father was wracked with ambivalence. He was furious at his son for having squandered his early inheritance, but, at the same time, had positive feelings for him. He felt that morally, though, he had no choice but to “disown” him.

I explained to the man how fast and slow thinking work. When saying this, I acknowledged that these two types of thinking take place in all of us. I said this to try to be surer that he knew I was speaking about people in general, and not only about him. This additional statement is an approach I use often and believe that clinicians and ethics consultants should apply more widely. I anticipate the possible ways that what I say may be ambiguous and may be misinterpreted by patients and families. Anticipating this, I can say what I *won’t* mean first.

In the above case, I clarified that my explanation was not a comment about this patient, more than any other person, but rather, that fast thinking is a tendency that is universal, and information about fast thinking was something that he, at that time, might find particularly helpful. The patient reported that after I had described fast and slow thinking, his anger at his son abruptly vanished. In its place he had, he said, a “sudden flash of insight.” He realized at that moment, he said, that his son’s remorse was an expression of the *person* his son was, and that squandering his inheritance was a “human” mistake. This father said that, “deeper down,” he most loved his son for his remorse: “People make big mistakes,” he said. “I have.”

One might wonder how it could be that these two patients, just learning about fast and slow thinking, could change their views and emotions so fast. The answer is that just as emotions can hijack slow thinking, a capacity for one part of the brain to influence another goes both ways. A new awareness can change what we feel, and quickly.

To illustrate to patients that this is possible, I may share with them, prior to doing therapy that may alter their thinking, the following exercise. I ask them to imagine that they are the last person to enter an elevator and they enter backwards, and the elevator door closes close to the tip of their nose. I ask them to imagine next that they feel a hard, round object pressing against them, into their lower back. I suggest that they feel irritated that the person behind them doesn’t notice this, and doesn’t stop it. I suggest that as the elevator opens at the next floor, they turn and see the person behind them. They see that the person behind them is blind, and the hard, round object pressed against them is the halter of a seeing-eye dog. Patients say they immediately lose the feeling of being annoyed, and may even feel a tad ashamed. I share with patients how, likewise, having a new thought may change their emotions, and how this, in turn, may help them feel better.

These examples may be misleading; I have “cherry-picked” successes. It may be that with the two above patients, explaining fast and slow thinking had little or no effect, but may have occurred due to other factors. In other parts of their brain, functions bent on the underlying agenda of finding some way to reconcile the past wrongs of their child may have played a primary role.

In any case, this approach can be included in ethics consultation. That is, we can say *why* we will do something before we do it. In the last section of this article, I suggest that, in the ICU, we can tell patients’ family members why they are being asked to gather for a special meeting, before we ask to have

a meeting. As I will relate, doing this may do much to relieve a family’s possible stress. Telling patients and families beforehand why we do what we will do may not only help them to see the underlying rationale, it may help them to understand more clearly what is going on. Then they may be more likely to respond in a way that helps the medical team and themselves. Sharing our rationale with patients and families helps us to work more as co-equal partners, which may reduce their possible perception that they are at the lower end of a top-down relationship, which may add to their fear. For example, I shared with King Lear and the father of the Prodigal Son why I told them about fast and slow thinking—it might help them slow down their thinking—and that explanation may have allowed them to use this new awareness more effectively.

*A Colleague Who Had this Awareness Already.* A colleague shared with me what she had done on her own. She knew about fast and slow thinking and used this awareness to change what her fast thinking initially had “decided.” She told me not only that I could share her story with others, but urged me to do so, because she believed that what she did for herself might be helpful to others. She had breast cancer. Upon learning this, she knew exactly what she would do. She would do just what her mother had done. Her mother too had breast cancer, and she survived it. She had both breasts removed and later had no breast reconstruction. Then my colleague tried to make herself “slow think.” “What do I want for *myself*?” she asked. She decided to have only one breast removed. She decided she wanted to retain her other breast so she would be able to sexually respond in this area. She also chose to have the breast that was removed reconstructed. An additional aspect of her experience warrants mention: throughout this experience she visited many different doctors. None raised the question of whether she would value retaining her sexual responsivity. This clearly is a need or want that clinicians might mention.<sup>12</sup> She now lives—and lives well—although she knows that her cancer could recur at any time.

She told me about an approach she uses that helps to reduce her fear that the cancer will return that is worth reporting. She draws a horizontal line across a piece of paper, and then writes above the line the factors in her life that she can’t control. Below the line, she writes out the factors that she can control. Seeing in print what she can’t control—for example, whether her cancer will recur—helps her, she says, accept that this risk is beyond her control. It helps her to reduce her fear and even, one might say, to deny it. The positive effect of being able to deny such a risk I will discuss shortly in consider-

ing how to explore with patients whether they think they can deny a risk of having dementia.

My colleague's use of drawing a horizontal line illustrates again how a visual cue can trigger fast thinking. In this instance, a visual cue is put to positive use, rather than spurring biased thinking. Another positive use of a visual cue, as mentioned above, is the surgeon who intentionally showed a woman her son's wound, to try to save the boy's life. Kahneman notes that it is easier to see the problems that fast thinking can bring about than to solve the problems. He asks, "What can be done about these biases?" and answers, "The short answer is . . . little . . . without a considerable investment of effort."<sup>13</sup> Kahneman says, more generally, that "The way to block errors . . . is simple in principle: recognize the signs that you are in a cognitive minefield, slow down, and ask for reinforcement from your [slow thinking]." As my colleague's personal experience suggests, the task of not just seeing, but resolving, these problems with the use of a visual cue may trigger positive gains from fast thinking. Clinicians are now encouraged to write down recommendations that are not ones we would normally write out, as a prescription. For example, recommending that our patients exercise several times a week, or write down each morning three things they are grateful for, may be more effective in moving patients to do these beneficial acts than just saying to do them. The visual effect of writing, it is believed, may have more therapeutic clout than just saying something.

It may be that urging such a self-practice would not affect patients significantly, and telling our patients about fast thinking wouldn't affect them significantly either. But input from just one other person may pierce others' defenses and move them to change. We may bolster patients and family members as they resolve their problems, such as reducing their fear, by offering our strong, felt support. With the support of just one other person, they may be able to resist making a decision that is driven by fast thinking, and can choose instead what, over the longer run, they want more. This may be what occurred with King Lear and the father of the Prodigal Son.

When patients and family members say they feel compelled to make a fast decision, we may alert them to other approaches that may help. Should they have a recurrent worry created by a visual cue, we can suggest they distance themselves from it by quantifying an aspect of it, for example by grading the intensity of the recurrent worry on a scale of one to 10. Patients and family members who continue to experience painful intrusive thoughts created by fast thinking may gain some relief by writing about their

deepest feelings.<sup>14</sup> Trying to directly suppress unwanted thoughts is unlikely to provide relief.<sup>15</sup>

My colleague who draws a line on a piece of paper in response to her fear that her breast cancer will return has an excellent capacity to use the psychological defense of denial. In the next section I will consider how helpful denial may be to patients deciding whether to undergo genetic screening. If they have a strong capacity for denial, they may fare better without genetic knowledge that may be troubling, such as whether or not they have early signs of a disorder such as dementia. Using denial, they may be more able to continue to enjoy their life.

Whether or not patients have a capacity to use denial in this way may be the most critical question we can explore with them, to decide *together* whether they should undergo genetic screening or preliminary memory testing. While this testing can be conducted in minutes in an outpatient office, it may profoundly change and negatively alter their life—even though, in most cases, the testing and the results may have no apparent effect.

#### HELPING PATIENTS MAKE GENETIC CHOICES

In their article in this issue of *JCE*, Siminoff and colleagues highlight ways to best share genetic information with patients. But even if it were possible to be flawless in our communication with patients and families, emotions such as fear may cause fast thinking that hijacks their capacity to understand the information they receive. The delivery of genetic information may evoke the same kind of fear. And, as I have said, once evoked, a strong emotion may remain. Then, even much later, patients and family members may not want to share their genetic information with relatives for this reason. In the next two sections of this article, I will discuss patients' deciding whether they want to be genetically screened, and patients' deciding whether they want to give their genetic information to others.

#### Helping Patients to Decide What They Want to Know

We can screen people now to see if they will develop Huntington's disease. Many who know that they are at risk of having this disease (50 percent if they have a parent so affected) choose not to be tested.<sup>16</sup> This is—or should be—instructive. It suggests that some prefer not to know about their genetic risks. This awareness raises, in turn, the question of how we should proceed with all patients, since there is a complete gradient of risks of having an illness and the magnitude of those illnesses. Perhaps the chief question we might want to consider is patients' capacity to effectively use denial. When

a danger faces us, our use of denial as a defense may help save us from feelings of unremitting despair. Denial may be consciously willed and created, or it may occur unconsciously, wholly outside our control. Or it may not occur at all. It takes place in almost all of us; for example, we all know we will die, but most of us can live and focus on our daily life.

My colleague with breast cancer believes that her capacity to use denial serves her well, although she may have been able to contain her fear and enjoy her life for other reasons, such as having an optimistic outlook. Some patients may be able to use denial more effectively than others.<sup>17</sup> This may help them cope better when under stress, but at the same time this may have a price, as they then lack some awareness of reality. As one physician said, after she experienced devastating hardship and recognized the denial she experienced as a doctor, “Denial has its place. But when life shatters the protective walls of denial and frees the energy required to maintain them, it proves strangely liberating.”<sup>18</sup>

Therapists seek generally to gradually help patients reduce their denial over time. Given the difference in the degree to which different people can successfully use denial, I will now pose a hypothetical case regarding what we should do when we encounter a patient who is considering whether to be screened for the earliest signs of a serious disease such as dementia. (These same concerns may arise regarding genetic screening, although to a more limited extent, and we shall consider similar ethical concerns that arise in this context subsequently.) Our hypothetical case is that of an aged patient who comes to his clinician for a routine annual check up. The patient reports he is doing fine, but has noticed some difficulties with his memory, although it hasn't affected his life. The patient may have early Alzheimer's dementia (AD) or symptoms that precede AD, or he may just have the changes that go with normal aging. The ethical question this poses is whether his clinician should do any immediate outpatient memory testing. On the one hand, the clinician may believe he or she is obligated, absolutely, as a medical professional, to test, based on the widely held first principle of “diagnose first.” On the other hand, the patient's memory deficits presently don't negatively affect his life. Thus, if the clinician tests him and finds memory deficits that suggest he has early AD, it may place a dark cloud over the rest of his life, *from that moment onward*,

In this situation, the clinician may ask the patient what he would want to do. Or, better yet, the clinician may brief the patient on the question at stake, and ask, before the patient makes a decision about testing, whether he would like to discuss the

pros and cons of the decision. The clinician can suggest that the patient not make a decision immediately, but think it over, ideally with his family. While the clinician may have “opened a Pandora's box” by mentioning that the patient's memory loss could be a first sign of dementia, that possibility has not been tested, and the patient could be experiencing no more than normal aging. His choice not to be tested may make it more possible for him to go on with his life, and deny it could be dementia.

Genetic testing for AD presents similar questions, even though having an AD gene contributes only slightly to later developing AD.<sup>19</sup> Yet, regardless of the extent of patients' risk of having an AD gene, patients may believe that they are the one person out of many who will be affected by having it, and just knowing that they have an AD gene may cause them to be significantly negatively affected. Because AD begins earlier in life than previously thought, and preventive treatments must begin early to be effective, genetic testing for AD is being done at an increasingly earlier age.<sup>20</sup> Genetic testing for AD is now common when much younger people volunteer to participate in research. Researchers who work with younger study participants should take into account these considerations. The fear evoked in even preliminary discussions of genetic testing could trigger fast thinking, and study participants might become less able to decide what they want.<sup>21</sup> Even older study participants who face making decisions about genetic testing may benefit when researchers inform them about the risks of fast thinking, and as a result be better able to make decisions.

A third example that involves making possibly difficult decisions about genetic testing—in addition to identifying an increased risk of AD in the clinic and in research—is the unearthing of so-called incidental findings.<sup>22</sup> These are test results that are not sought, but which nonetheless appear. When it is not clear that sharing an incidental finding will have any beneficial effect for a patient, sharing such findings is presently controversial. It is feared, on the one hand, that disclosing incidental findings may scare patients, research participants, or their family members. On the other hand, to inform them respects them maximally, even though the knowledge they receive may not be helpful to them.

An optimal approach that gives priority to respecting patients' autonomy is to ask them, when possible, what they want to do regarding incidental findings. When it is possible to ask, and patients want to discuss the findings, the discussion should not be short and ideally should be spread out over time. We might ask patients how they were able to deal with uncertain fears in the past, if they had any,

and ask them to imagine how they would feel in the future with or without the incidental findings. When patients consider how they responded to fears in the past, or how they may respond in the future, it may trigger fast thinking. We can inform patients about this risk, as it may help them to less readily accept their first, fast conclusions.

### **Patients Who Won't Share Genetic Information**

Another difficult ethical question posed by genetic testing is how to respond when patients won't share genetic information that may be important to their biological relatives.<sup>23</sup> Their relatives may, for example, be at higher risk of having a disease or of being a carrier. Even if they are a carrier, they may not want to risk passing on the gene to their offspring. Generally we are precluded from informing relatives when patients don't want us to do so; usually we must respect patients' confidentiality. However, we can inform patients that even simply discussing sharing test results may evoke fast thinking. We can say that knowing about fast thinking may be beneficial to them, as it was to King Lear and the father of the Prodigal Son. If patients decide to share genetic information, who should deliver the information? There are concerns for patients who provide information and for those who receive it. We might offer to be present when patients share information and/or seek out clinicians who are knowledgeable about genetics and skilled in sharing bad news, and invite them to join the patient.

We might ask patients if it would be acceptable to tell them about some other patients we have seen. We might clarify the reason for asking, much as I did with King Lear: we are not trying to change the patients' mind, but we want to give them information that may be important to them. We can share how many patients near the end of life—or when they know they have early AD—see value in contacting a relative they once loved, even if they have lost or severed all contact for decades. These initiatives address the reality that people may value meeting and interacting with loved ones with whom they have severed ties previously, although they may not foresee this. Taking initiative to inform patients that this may be the case may prove most beneficial to them. Patients may talk about a relative they once loved, like a sibling or cousin with whom they enjoyed fishing. If this is the case, we can ask if they have any interest in our trying, on their behalf, to see if we can help them reunite—to say hello once again, while they still can. We can say that the results sometimes are close to miraculous—because they are. Patients often are able to reunite and are glad that they did.

We can share this with patients who are trying to decide whether to give relatives genetic information. We might first explain the likely effect of their having such a discussion with us—namely, that it may trigger fast thinking. It might also stir up a resentment they felt long ago. If we say this, it may become a cue for fast thinking. This is called the “bandwagon effect”: presenting information about what others do can increase pressure on us to do likewise, and this pressure can trigger fast thinking. Doing this, then, is mildly coercive. To offset this effect, we can explicitly acknowledge its coercive effect. We can inform patients that this is an additional cue that may trigger fast thinking, and it, too, may decrease their capacity to soundly reason in regard to whether they are willing to share with relatives important information about their genes.

### **Fast Thinking Can Influence Policy Makers**

In regard to genetics, many policies are open to question—at the least. A policy considered above is whether to respect a patient's confidentiality when, as a result, another may be harmed. Some particularly contested policies regarding genetics were designed primarily to protect children. One such policy is parents shouldn't have access to genetic information about their child unless the child would benefit medically, during childhood.<sup>24</sup> A second is that children should not have access to information about their own genes until they can decide whether they want the information as an adult.<sup>25</sup> A third is that parents should not receive genetic information regarding a child's paternity.<sup>26</sup>

Policies intended to protect children may be the result of value priorities that were influenced by fast thinking, or slow thinking that was mistaken. This may be especially likely because we have such strong feelings about children and about protecting them. As Kahneman says, “Anyone can understand and sympathize with the reluctance of parents to trade even a minute increase of risk to their child for money.”<sup>27</sup> These three policies may be the best possible, but each may have been affected by fast thinking. Some policies enacted in the past to protect children prevented the conduct of research needed now to treat them. We shall look at three policies briefly. Since the policies were intended to protect children, these examples particularly exemplify decisions that may reflect fast thinking. The following are some brief thoughts and questions.

*Not Being Able to Know about a Child's Genes.* When parents know about a genetic illness that their child may or will experience as an adult, they may be better able to help their child be prepared.<sup>28</sup> This is possible because parents may be able to love the

child just as he or she is, and the child may internalize this love and become maximally resilient. When parents unconditionally love their child, the child may adopt the same highest regard for him- or herself and so become “immunized” to stresses caused by to genetic illness as an adult.

Here is an example of the kind of unconditional regard I mean. Some of my patients feel depressed because they lack an ability others have. If the patient is a parent, I ask how the patient would feel if their child was the worst player on a sports team. I ask the parent, would he or she be more proud of the child if the child was the best player on the team than if the child was the worst player? The patients uniformly and instantly respond, “No! I would be prouder if my child was the *worst* player, because then my child would have the courage to keep playing under those circumstances.” I then ask, “Why is it that you can’t apply this same critical insight to yourself?” Sometimes this seems like an epiphany. Parents do not value the child for what the child can *do*, but rather who the child *is*. This exemplifies the unconditional regard that helps children become resilient. Many of us were fortunate to have parents who could greatly soothe us. As we go on and age, that memory may be a source of resilience. We know that we can be soothed, and we know we can do this for ourselves.

*Giving a Child Genetic Information.* Another policy is to not give children information about a genetic condition that may not affect them until they grow up. It could be argued that parents can handle this information, but children cannot. This argument may reflect unrecognized biased, fast thinking, because actually, parents and children might gain a great deal from having and sharing this knowledge together. I think particularly of families who have a child with cystic fibrosis (CF).<sup>29</sup> These parents may care so greatly for their child that they provide a quality of life equal to or surpasses that of many children. These parents and children may have such joy in their lives that parents who have one child with CF may choose to risk having another. These parents may see themselves as their child’s ally. This exceptional commitment may be necessary should the child decide the time has come to die. Only with the parents’ pressure may the child’s clinician allow it.<sup>30</sup> Further, parents who know their child may have a genetic illness when the child grows up, and who talk with their child about it, may help the child prepare for this possible later experience.<sup>31</sup>

*Disclosing Nonpaternity.* What of the present policy to not give parents information that “may indicate” nonpaternity? I place “may indicate” in quotes because this is what some clinicians say, in

an effort to allow parents to believe, in spite of genetic testing, that the father is his child’s biological parent. This is always possible, and may be most critical to some. It is all-important that we, in every way possible, seek to convey to parents that they can parent as fully and richly as possible whether they are or are not a child’s biological parent.

Would a change in our nonpaternity policy affect this approach? Probably not. Yet this is a change we surely should try to promote in other ways. Here, fast thinking may further two opposite ends. We know how nonpaternity revelations may affect some families. It may destroy them. This may move us—as our desire to protect children does—to keep the policy we have. A second response is more instructive. Some people believe strongly that we should divulge nonpaternity because, as they may put it, the mother has “made her own bed.” This “fast belief” smacks of contempt and exemplifies the worst kind of outcome that fast thinking can bring about. These policies may be as they should be, but, regardless, whether they reflect fast thinking is a question we should ask. When making policy, fast thinking outside our awareness may skew our options and lead to suboptimal decisions we may later regret.

## FAMILIES IN THE ICU

In their article, Siminoff and colleagues suggest the approaches they share will be useful to those who experience stress, for example, in an ICU. I will expand on this. I will address ways in which we might best reduce the stress that family members feel, and the fast thinking that may result from it, that may impair the decisions they make in an ICU.<sup>32</sup>

### What Is Most Important to Families?

An ideal way to help to reduce family members’ fast thinking is to ask them what they fear most. This has been studied. One study reports families’ three main concerns: clinicians will abandon the patient, and them; clinicians will allow the patient to suffer; and clinicians will go against what the family wants. The last is the hardest to consistently address. I will suggest several approaches that may reduce the risks of fast thinking in the ICU. I will discuss them in order, from the time a patient enters the ICU until he or she may be near death. I will focus on less-common steps to help families that may reduce their primary fears to the greatest extent possible.

### Approaches to Reduce Families’ Fast Thinking

*Indicate Why “We” Are Meeting.* When we first convene any special kind of meeting, family members may fear bad news, and this may trigger their

fast thinking. Family members may fear, for example, that we are about to tell them that the patient has taken a turn for the worse—or, worse still, we are about to tell them we will do something they don't want. This apprehension is particularly likely if, in the past, clinicians have always talked with them only informally and when they were "on the run."

Consequently, our first task when we call for a special meeting is to try to reduce family members' fast thinking by saying why we will be meeting, before anything else. We should reassure the family, if we can, and if it is true, that we will meet because, in the ICU, such meetings are routine, and this is so because the illnesses of patients in the ICU are more serious. (If this is never the case, because there are no routine meetings, staff might want to consider instituting routine meetings, so that someone on staff meets with each patient's family members on a regular basis.) In one neonatal ICU, for instance, a nurse makes herself seen and available on an ongoing basis. She does this so that parents can get to know her, and thus and more easily approach her if they feel the need. A profound gain from doing this, in spite of the greater expense, is that parents may seek out this nurse when they merely *feel* they have the need, whether or not it turns out that their need was, on whatever scale used, justified or valid.<sup>33</sup>

#### *When We Will Not Do What the Family Wants.*

The greatest fear of family members is that we will go against what they want.<sup>34</sup> We can inform them that we will do our best to make choices *together*. We can further say we will do our best to tell them when that is not possible, and make every effort to explain why and talk it through with them. For example, a hospital may have a futility policy that allows staff to not give a patient a treatment that they believe is futile. By pointing out this policy early on, before any such condition arises, we can be crystal clear that we are sharing this with the family to maximally inform them, not because we are in an instance of such futility. Paradoxically, doing this may increase the family's feelings of trust, and possibly help them later, should these circumstances arise. When we provide this information ahead of time, we can say *why* we are saying it when we are. We can say we are aware that, for many families, this is their chief fear and concern. We can hopefully offset any likely ill-effect by telling the family that we want to reassure them by sharing the criteria we will use when we work with them. This may seem too radical an approach, but it is worth considering the situation from the family's "shoes."

An optimal way to help patients and families may be to urge them to imagine there are three persons who are always at the bedside: one is a clini-

an, expert on the patient's medical condition; one is an ethicist, able to see whether any values are being missed; one is a lawyer, who can ensure that patients and families are able to pursue all of the options to which they are legally entitled. These three persons can help patients and families accomplish two important goals: to give patients every treatment to which they are entitled, and to ensure that patients are treated equally and have good treatment, whether they are rich or poor.

We may wish to explicitly tell families that these goals are most important to us. We can add that we say this because, if they believe for a moment that the patient is receiving suboptimal medical care, suboptimal ethical care, or not having some option to which they believe the patient is legally entitled, they should tell us. We can say that we will seek out experts to address their doubts as best we can.

*Give Families 24/7 Access to Knowledge.* To address families' fears that we may abandon their loved one, and them, we can say that we will not abandon them, using other words, and act to exemplify this.<sup>35</sup> Perhaps the best way is to arrange for someone *who knows specifics about the patient* to be available around the clock. This requires adequate and additional briefing. Its cost should be more than offset by the practical and humane gains it confers. We may go beyond this. Families' fears of being abandoned may be fueled by the increased isolation they feel as a result of having lost contact with prior clinicians.<sup>36</sup> Thus, in the ICU we can, and should, find a way to offer to contact previous clinicians, and fill them in on the patients' condition, so that families can discuss their decisions with prior clinicians, if this is what they want. And there is an attitude that we may seek to have that may be even more important.<sup>37</sup> We may have to have this attitude if families are not to feel abandoned: rather than feel we must fight death during our shift, we could feel that, if death occurs, we *want* it to happen on our shift. Why? Because then we could be *with* patients and families when this occurs, with them emotionally, as patients pass on from this life. This attitude is manifested by hospice workers, who hope, rather than fear, that their patients will die on their shift so that they can have what they see is the greatest privilege, of being with patients and families at this time. An easier way to reduce families' fear of abandonment is to acquire the habit of listening more than we speak. Research indicates that families are much more satisfied when they can talk about what they feel and think than when they only listen. We tend not to see this. There is evidence that even when clinicians talk much more than families do, and families report they felt that clinicians cut them off,

many clinicians rate their interactions with families as the best that could possibly be achieved.<sup>38</sup>

*Share Clinical Uncertainty.* We should soothe families even when we feel uncertain. We may feel it is best to hide differing views and conflicts among staff because it is necessary to reduce family members' fears. But it is much more likely that we can reduce their fears by sharing our own feelings of uncertainty, and, as we strive to be "with" patients as they die, to bear our fears about uncertainty together. At the last annual meeting of the American Society for Bioethics and Humanities (ASBH), there was a pre-meeting course to help clinicians become more at ease with uncertainty. This approach had been carried out with clinicians at Harvard, and follow-up studies indicate the participants in the program changed: they became more at ease with uncertainty. The program involved looking at art, in groups.<sup>39</sup> The different interpretations of art that clinicians experienced helped them to newly tolerate differences in viewpoints that could not be resolved. Clinicians who are comfortable with uncertainty may be able to convey this to patients and families by what they say and how they conduct themselves.

*Share Frightening Prognoses.* We can reduce family members' fast thinking, even when telling them bad news about the patient's likely demise.<sup>40</sup> Some patients have a medical condition that makes it particularly likely, under certain circumstances, that they will die. Their family should know this. And we should tell them. Examples are congestive heart failure and chronic obstructive pulmonary disease. When patients have one of these conditions, their course typically waxes and wanes. If this happens many times, and each time patients recover, family members may be lulled into believing that when this occurs in the future, the patients will again recover. We should tell these families, however, this may well not be the case. The family may be much more afraid, but will be more prepared. In addition to this gain, families may see how far we will go to show the greatest care for them. Thus, in the short run, this may hurt them, but in the longer run it may increase their trust and reduce their fear.

*Ask Families if Patients Are Suffering.* Perhaps the best way we can help to assure that family members know that we will not let patients suffer is to encourage them to come to us whenever they fear patients are experiencing physical or emotional pain. All too often the opposite is the case. We are busy. We can give families a reason we want them to do this: they are likely to be with patients much more and so will be much more likely to see signs of distress. We can do even more: relieve what families may see as distress when it does not harm the pa-

tient. Some clinicians, for example, give medications to reduce a patient's fluid load when there are gurgling sounds coming from the patient's throat that the family sees as evidence the patient feels air hunger, as if the patient is suffocating. Some clinicians may, at the other extreme, give a patient intravenous fluids when the patient's skin is dry, and family members believe the patient is parched and thirsty.

What is remarkable about these examples is that they represent the extent to which some clinicians will depart from the often-voiced principle that only the patient's good should always, absolutely prevail and never be compromised by others' interests, including those of their family. At the most recent meeting of the ASBH, two presentations especially carved out conditions when families' interests should be assigned moral weight.<sup>41</sup> Increased commitment to families' interests, when what patients want or need is little affected, is supported by this underlying rationale: it may be what the vast majority of patients would want if they were asked.

#### **Help Families Decide What to Say at the End of Life**

As the death of a loved one comes near, we may reduce the stress and fast thinking experienced by family members by taking the initiative to give them guidance in what they may say to the patient. Four thoughts are well known and have been shared over time: "I love you." "Thank you." "Please forgive me." "I forgive you." A fifth thought we could suggest is less well known: family members may tell their loved one that although they will feel extreme sadness at the loved one's death, they know for sure that they will be able to carry on well, afterward. Family members may want to say this, we can add—speaking once again to the "why"—because many patients, as they die, may, more than anything, fear that their family will not be able to carry on well after their death. We can discuss this with family members. We can say that they may worry that saying they will be okay may risk communicating to the patient, wrongly, that they don't really care. Anticipating this concern, we can address it. If family members remain concerned, we can say what we ourselves do with our patients, and why. We can give them, as I've said before, our *reasons*.

With this information, family members will be able, as they talk with their dying loved one, to say that they fear the patient may take what they are about to say the wrong way, but they do not know how to say what they want to say in a way that avoids this. This should reassure the patient, and may relieve the patient of what may be his or her greatest fear—that family members may not be able to get along well after the patient dies. The patient may

not know whether family members will be able to get along well, but may gain some faith from the fact that family members say they can. Family members have had the courage to say this, even though they know that the patient could take it the wrong way. We can also tell family members about *this*.

When family members communicate their concerns with their loved one, they may feel great apprehension they might “get it wrong.” We may, accordingly, reassure them that if they take the risk of sharing this important information with their loved one, they should take special care later to not feel regret. At all costs, they should feel good they did the best they could. What they said, we can remind them, no matter how they said it, will have gone an extremely long way.

### CONCLUSION

In this issue of *JCE*, Siminoff and colleagues describe how clinicians can help patients better understand the donation of genetic tissue and the information they receive in stressful settings such as the ICU. I presented other factors that may rob families of their capacity to understand, even when we communicate optimally. I used Kahneman’s concepts of fast and slow thinking and focussed particularly on how fast thinking may bias our reasoning when we are under stress. I discussed this generally and in regard to genetic testing and policies regarding genetic testing, and in regard to the families in the ICU. There is, though, an implicit distortion noted at the beginning of this article: in concentrating on the harms of emotionally driven fast thinking, I have ignored the immense gains that emotions and fast thinking can make possible.<sup>42</sup>

### NOTES

1. L.A. Siminoff et al., “Impact of Cognitive Load on Family Decision Maker Recall and Understanding of Genotype-Tissue Expression (GTEx) Project Donation Requests,” in this issue of *The Journal of Clinical Ethics* 29, number 1 (Spring 2018).

2. D. Kahneman, *Thinking Fast and Slow* (New York: Farrar, Straus, and Giroux, 2011).

3. B. Alsoufi, “Thinking, Fast and Slow,” *Journal of Thoracic and Cardiovascular Surgery* 153, no. 3 (March 2017): 646-64, 646.

4. Kahneman, *Thinking Fast and Slow*, see note 2 above, p. 415.

5. *Ibid.*, 139.

6. N. Quist, “Hope, Uncertainty, and Lacking Mechanisms,” *The Journal of Clinical Ethics* 18, no. 4 (Win 2007): 357-61, 358, 361. Emphasis added.

I would like to thank Norman Quist for his careful

reading and insightful suggestions and contributions in reading this article.

7. R.H. Thaler and C.R. Sunstein, *Nudge: Improving Decisions about Health, Wealth, and Happiness* (New Haven, Conn.: Yale University Press, 2008).

8. Kahneman, *Thinking Fast and Slow*, see note 2 above, pp. 139-140.

9. Emphasis added. *Ibid.*, 414.

10. J. Bernstein, E. Kupperman, L.A. Kandel, and J. Ahn, “Shared Decision Making, Fast and Slow: Implications for Informed Consent, Resource Utilization, and Patient Satisfaction in Orthopaedic Surgery,” *Journal of the American Academy of Orthopedic Surgery* 24, no. 7 (July 2016): 495-502.

11. Luke 15: 11-32.

12. S. Faghani and F. Ghaffari, “Effects of Sexual Rehabilitation Using the PLISSIT Model on Quality of Sexual Life and Sexual Functioning in Post-Mastectomy Breast Cancer Survivors,” *Asian Pacific Journal of Cancer Prevention* 17, no. 11 (November 2016): 4845-51.

13. Kahneman, *Thinking Fast and Slow*, see note 2 above, p. 417.

14. Q. Lu et al., “Expressive Writing among Chinese American Breast Cancer Survivors: A Randomized Controlled Trial,” *Health Psychology* 36, no. 4 (April 2017): 370-9.

15. S. Najmi, B.C. Riemann, and D.M. Wegner, “Managing Unwanted Intrusive Thoughts in Obsessive-Compulsive Disorder: Relative Effectiveness of Suppression, Focused Distraction, and Acceptance,” *Behavior Research Methods* 47, no. 6 (June 2009): 494-503.

16. Less than 20 percent of individuals at risk of having Huntington’s disease choose to have predictive testing. S.S. Baig et al., “22 Years of Predictive Testing for Huntington’s Disease: The Experience of the UK Huntington’s Prediction Consortium,” *European Journal of Human Genetics* 24, no. 10 (October 2016): 1396-1402, 1401.

17. C. Church et al., “Childhood Trauma and Minimalization/Denial in People with and without a Mental Disorder,” *Frontiers in Psychology* 8, no. 1276 (August 2017): 1-7.

18. J.S. Saxe, “Denial,” *Annals of Internal Medicine* 167, no. 11 (December 2017): 828-9, 829.

19. S.A. Bemelmans et al., “Psychological, Behavioral and Social Effects of Disclosing Alzheimer’s Disease Biomarkers to Research Participants: A Systematic Review,” *Alzheimers Research & Therapy* 8, no. 46 (2016).

20. D.S. Davis, “Ethical Issues in Alzheimer’s Disease Research Involving Human Subjects,” *Journal of Medical Ethics* 43, no. 12 (December 2017): 852-6.

21. M.L. Baum, “Patient Requests for Off-Label Bioprediction of Dementia,” *Cambridge Quarterly of Healthcare Ethics* 25, no. 4 (October 2016): 686-90; H.L. Hietaranta-Luoma, H.T. Luomala, H. Puolijoki, and A. Hopia, “Using Apo-E Genotyping to Promote Healthy Lifestyles in Finland—Psychological Impacts: Randomized Controlled Trials,” *Journal of Genetic Counseling* 24, no. 6 (December 2015): 908-21; C.A. Beard, D.J. Amor, L. Di Pietro, and A.D. Archibald, “‘I’m Healthy, It’s Not Going To Be Me’: Exploring Experiences of Carriers Identified Through a Population Reproductive Genetic Carrier

Screening Panel in Australia," *American Journal of Medical Genetics* 170, no. 8 (August 2016): 2052-9; C. Lerman et al., "What You Don't Know Can Hurt You: Adverse Psychologic Effects in Members of BRCA1-linked and BRCA2-linked Families Who Decline Genetic Testing," *Journal of Clinical Oncology* 16, no. 5 (May 1998): 1650-4.

22. S.M. Wolf et al., "Managing Incidental Findings in Human Subjects Research: Analysis and Recommendations," *Journal of Law, Medicine & Ethics* 36, no. 2 (Summer 2008): 219-48; L. Eckstein, J.R. Garrett, and B.E. Berkman, "A Framework for Analyzing the Ethics of Disclosing Genetic Research Findings," *Journal of Law, Medicine & Ethics* 42, no. 2 (Summer 2014): 190-207.

23. M.E. Wiens, B.L. Wilson, C. Honeywell, and H. Etchegary, "A Family Genetic Risk Communication Framework: Guiding Tool Development in Genetics Health Services," *Journal of Community Genetics* 4, no. 2 (April 2013): 233-42; S. Dheensa, A. Fenwick, and A. Lucassen, "Approaching Confidentiality at a Familial Level in Genomic Medicine: a Focus Group Study with Healthcare Professionals," *BMJ Open* 7, no. 2 (3 February 2017); E.S. Dove et al., "Beyond Individualism: Is There a Place for Relational Autonomy in Clinical Practice and Research?" *Clinical Ethics* 12, no. 3 (September 2017): 150-65.

24. A.K. Rahm et al., "Parental Attitudes and Expectations Towards Receiving Genomic Test Results in Healthy Children," *Translational Behavioral Medicine* 8, no. 1 (29 January 2018): 44-53; O.W. Quarrell et al., "Predictive Testing of Minors for Huntington's Disease: The UK and Netherland Experiences," *American Journal of Medical Genetics Part B, Neuropsychiatric Genetics* 177, no. 1 (January 2018): 35-9;

25. A. Werner-Lin, S.L. Merrill, and A.C. Brandt, "Talking with Children About Adult-Onset Hereditary Cancer Risk: A Developmental Approach for Parents," *Journal of Genetic Counseling* (30 January 2018); D.F. Vears, S.A. Metcalfe, "Carrier Testing in Children and Adolescents," *European Journal of Medical Genetics* 58, no. 12 (December 2015): 659-67.

26. J.R. Garrett, "Beyond Harms and Benefits: Rethinking Duties to Disclose Misattributed Parentage," *Hastings Center Report* 45, no. 1 (July-August 2015): 37-8; A. Mandava, J. Millum, and B.E. Berkman, "When Should Genome Researchers Disclose Misattributed Parentage?" *Hastings Center Report* 45, no. 4 (July-August 2015): 28-36.

In this instance, Kahneman was thinking about parents and children in a different context. Kahneman, *Thinking Fast and Slow*, see note 2 above, p. 350.

28. S. Madigan, M. Wade, A. Plamondon, and D. Browne, "Birth Weight Variability and Language Development: Risk, Resilience, and Responsive Parenting," *Journal of Pediatric Psychology* 40, no. 9 (October 2015): 869-77.

29. N. Jamieson et al., "Children's Experiences of Cystic Fibrosis: A Systematic Review of Qualitative Studies," *Pediatrics* 133, no. 6 (June 2014): e1683-97.

30. For a poignant depiction of this, see B. Lo, *Resolving Ethical Dilemmas*, 5th ed. (Philadelphia: Wolters

Kluwer/Lippincott Williams & Wilkins, 2013), vii.

31. T.H. Lee, Y. Qu, and E.H. Telzer, "Love Flows Downstream: Mothers' and Children's Neural Representation Similarity in Perceiving Distress of Self and Family," *Social Cognitive and Affective Neuroscience* 12, no. 12 (1 December 2017): 1916-27.

32. R.D. Stapleton et al., "Clinician Statements and Family Satisfaction with Family Conferences in the Intensive Care Unit," *Critical Care Medicine* 34, no. 6 (June 2006): 1679-85. See also, A. Lautrette et al., "A Communication Strategy and Brochure for Relatives of Patients Dying in the ICU," *New England Journal of Medicine* 356, no. 5 (2007): 469-78; J.R. Curtis and D.B. White, "Practical Guidance for Evidence-Based ICU Family Conferences," *Chest* 134, no. 4 (October 2008): 835-43; J.E. Davidson, C. Jones, and O.J. Bienvenu, "Family Response to Critical Illness: Postintensive Care Syndrome-Family," *Critical Care Medicine* 40, no. 2 (February 2012): 618-24; X. Cai et al., "Patient Preferences and Surrogate Decision Making in Neuroscience Intensive Care Units," *Neurocritical Care* 23, no. 1 (August 2015): 131-41.

33. S. Trowbridge, "Changing the Ethics Culture in the PICU/ PICU Nurse Ethics Liaison Model," presentation at the 19th Annual Meeting of the ASBH, Kansas City, Mo., 19 October 2017; J.R. Curtis et al., "The Family Conference as a Focus to Improve Communication about End-of-Life Care in the Intensive Care Unit: Opportunities for Improvement," *Critical Care Medicine* 29, no. 2 (February 2001): N26-33, N29.

34. *Ibid.*

35. Stapleton et al., "Clinician Statements," see note 32 above, p. 1685.

36. Curtis et al. "The Family Conference," see note 33 above, p. N29.

37. F. Wright, "Personal Reflections on Hugh Mullan: Existential Group Therapist," *Internal Journal of Group Psychotherapy* 62, no. 1 (2012): 23-42.

38. Stapleton et al., "Clinician Statements," see note 32 above, p. 1680; Curtis et al., "The Family Conference," see note 33 above, p. N26.

39. A. Miller, "Safe Dilemmas: Visual Art and the Cultivation of the Medical Mind," presentation at the 19th Annual ASBH Meeting, Kansas City, Mo., 20 October 2017.

40. A.R. Derse, "The Brutal but Utile Truth of 'Futile,'" *Perspectives in Biology and Medicine* 60, no. 3 (2018): 340-4; "Selective Paternalism," *AMA Journal of Ethics/Virtual Mentor* 14, no. 4 (July 2012): 582-8.

41. K. Miller and M.P. Aulisio, "The Heart of the Matter: Reframing the Best-Interest Standard in Choosing Technology-Dependent Life for Neurologically Devastated Children," presentation at the 19th Annual ASBH Meeting, 19 October 2018; E.K. Salter, "Conflating Capacity and Authority: Why We're Asking the Wrong Question in the Mature Minor Debate," presentation at the 19th Annual ASBH Meeting, 19 October 2018.

42. H. Hermann, M. Trachsel, B.S. Elger, and N. Biller-Andorno, "Emotion and Value in the Evaluation of Medical Decision-Making Capacity: A Narrative Review of Arguments," *Frontiers of Psychology* 26, no. 7 (May 2016): 765.